10/3/2022 - *Submitted via email to:*[redacted]

NSTC SUBCOMMITTEE ON EQUITABLE DATA
OFFICE OF SCIENCE AND TECHNOLOGY POLICY
EISENHOWER EXECUTIVE OFFICE BUILDING
[redacted]
WASHINGTON, DC 20504

Thank you for the opportunity to submit comments in response to the request for information on the White House Office of Science and Technology Policy (OSTP), RFI on Advancing Equity with Community Partnerships.

As one of the first Independent Practice Associations (IPA) in the country exclusively focused on social determinants of health (SDoH), Healthy Alliance has forged a new path toward successfully building and optimizing an integrated social care network spanning 25 counties in New York State. Inclusive of social, behavioral, and medical service providers, our network has helped over 24,000 community members – with over 1,250 programs and services, over 580 organizations, and more than 38,000 requests for services (currently at ~2,000 requests/month and increasing). We're focused on making *strategic*, *iterative* improvements – always with our North Star in mind: ***improve health*** for the underserved and marginalized members of our community.

We are a cross-functional team with leadership expertise in technology, transformation, health plan operations, care coordination, clinical care, and community organization management. Our front-line team has deep, lived experience in the communities we serve across New York.

Below, we provide comments in response to the questions posed in the RFI.

QUESTIONS FOR CONSIDERATION:

1. WHAT ARE EXAMPLES OF SUCCESSFUL COLLABORATIONS INVOLVING EQUITABLE DATA BETWEEN THE FEDERAL GOVERNMENT AND (A) TRIBAL, TERRITORIAL, LOCAL, AND STATE GOVERNMENTS, OR (B) LOCAL COMMUNITIES?

The majority of data sharing between the federal government and tribal, territorial, local, and state governments occurs at an aggregate level, which does not meet the definition of equitable data. Race and ethnicity information remains aggregated into broad groups, including 'unknown.' There are a few specific examples where there is data sharing at the disaggregated/individual level between local, state, and federal government – but these arrangements are the exception and are often small data sets and not useful/actionable, and the processes to do so are not scalable. For example, the annual reporting of pediatric influenza deaths from local to state health departments is aggregated by the CDC. However, the individual reporting is still limited by traditional demographic variables, such as broad race/ethnicity categories. Little (or nothing) has been done around how to make/provide individual data that is useful to prevent issues downstream.

The elephant in the room is that the data being captured is often not correct – systems may not have the variety of options available for the right information to be categorized and organizations capturing the information are not being held accountable to collecting it. Often organizations are selecting 'unknown' or 'other.'

2. AMONG EXAMPLES OF EXISTING FEDERAL COLLABORATIONS WITH (A) TRIBAL, TERRITORIAL, LOCAL, AND STATE GOVERNMENTS OR (B) LOCAL COMMUNITIES INVOLVING EQUITABLE DATA, WHAT LESSONS OR BEST PRACTICES HAVE BEEN LEARNED FROM SUCH COLLABORATIONS?

No obvious best practices have been established.

3. WHAT RESOURCES, PROGRAMS, TRAINING, OR OTHER TOOLS CAN FACILITATE INCREASED DATA SHARING BETWEEN DIFFERENT LEVELS OF GOVERNMENT (TRIBAL, TERRITORIAL, LOCAL, STATE, OR FEDERAL) RELATED TO EQUITABLE DATA?

Data is a valuable resource, but the real value lies in the use of data for the betterment of communities. This requires not only having access to equitable data, but also having reliable mechanisms to safely capture, store, and protect the data, as well as competence and ability to use the data.

Given that the current lack of equitable data sharing necessitates a heightened focus on improving access to equitable data, resources are needed to support the infrastructure for entities to insource, store, and protect equitable data sets. The infrastructure needs will likely be greater at the local and tribal levels than at the state level.

Across all levels, training will be needed to enhance the research communities understanding of and access to tools that support equitable data collection and analytic methods. Tools to help users and researchers assess the types of data needed to inform the intended use and application would also be helpful to prevent acquisition of data with no specific purpose.

4. WHAT RESOURCES, PROGRAMS, TRAINING, OR OTHER TOOLS CAN EXPAND OPPORTUNITIES FOR HISTORICALLY UNDERREPRESENTED SCHOLARS AND RESEARCH INSTITUTIONS TO ACCESS AND USE EQUITABLE DATA ACROSS LEVELS OF GOVERNMENT?

No response.

5. WHAT RESOURCES, PROGRAMS, TRAINING, OR TOOLS CAN INCREASE OPPORTUNITIES FOR COMMUNITY-BASED ORGANIZATIONS TO USE EQUITABLE DATA TO HOLD GOVERNMENT ACCOUNTABLE TO THE AMERICAN PUBLIC?

One of the greatest successes of numerous models of support for community-based organizations (CBO) through social care or community hubs and other such backbone organizations has been the ability to standardize and scale the data collection and analytic capacity of CBOs. Therefore, investing in the creation and expansion of social care or community network hubs is a de facto investment in equitable data collection at the local level.

In addition to investing in social care hub models, resources are needed to help both social care hubs and CBOs have a way to link their data to other large data sets, such as health surveillance, social determinants data, employment, and education data. Both access and resources to support a shared data infrastructure help to move the needle toward true intersectional data analysis, a critical need of and far more actionable for CBOs than the state/national levels. These mechanisms to amplify local data collection through shared data sets allows for more robust analysis and increases the CBOs ability to act on building their future and improving their current investments and programs.

6. WHAT RESOURCES, PROGRAMS, TRAINING, OR TOOLS CAN MAKE EQUITABLE DATA MORE ACCESSIBLE AND USEABLE FOR MEMBERS OF THE PUBLIC?

By supporting a more robust infrastructure for equitable data collection and sharing, a notable outcome of those efforts should be a decrease on the respondent burden of individual community members. Entities should have a mechanism to understand and speak to how that outcome has been achieved.

Community members should have an easy way to know the data resources that are available to them and be supported in their ability to access and use the data. There must also be pathways that allow community members to validate and continue to contribute to the process, from collection to analysis.

Community leaders and champions will need to be recruited to ensure the greatest representation is achieved and that resources are well known. Culturally and linguistically appropriate guides will be needed to support community members through the process. The programs should be available through multiple channels, tailored to different comfort levels with language and digital literacy.

7. IN WHICH AGENCIES, PROGRAMS, REGIONS, OR COMMUNITIES ARE THERE UNMET NEEDS, BROKEN PROCESSES, OR PROBLEMS RELATED TO PARTICIPATION AND ACCOUNTABILITY THAT COULD BE REMEDIED THROUGH STRONGER COLLABORATIONS AND TRANSPARENCY AROUND EQUITABLE DATA?

Competition adds a burdensome layer of complexity that leads to broken systems and expensive duplication that adds no value. An obvious example of competition is the refusal of private managed care organizations to share data with regional convener entities such as regional health information exchanges or social care hubs (aggregators of social care data). But competition can also be seen among CBOs working in the same geographic area competing for scarce resources to address a social need. Collaborations are needed at all levels and between all parties with a stated goal to improve equity.

At the government level, the underfunding of local health departments remains a critical problem, made much worse by the pandemic. The local health department structures that are bound by county/city lines have become a significant contributor to disconnection and discoordination in this mobile and digitally enabled society. Data siloes exist between state agencies and remain the dominant barrier between health systems and MCOs within the same communities.

Sincerely,

Erica Coletti
Chief Executive Officer
Healthy Alliance

Response to Request for Information: Equitable Data Engagement and Accountability

Submitted by: Steering Committee for Community Learning through Data Driven Discovery
Contacts:

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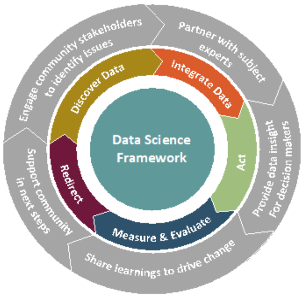
1. What are *examples of successful collaborations* involving equitable data between the Federal government and (a) Tribal, territorial, local, and State governments or (b) local communities?

Community Learning through Data Driven Discovery (CLD3) is a successful collaboration process in which the Cooperative Extension System engages with communities of all sizes and their constituents – residents, families, farmers, ranchers, youth, businesses, and government officials – to take advantage of and leverage new techniques for collecting and analyzing data to understand better and address their issues. The Cooperative Extension System is a unique Federal-State-Local partnership with a presence in almost every county in the U.S. County-based educators work with local citizens and interest groups to solve problems and draw on expertise at Land Grant Universities for science-based information.



CLD3 is built on a research base of data science. In practice, it is supplemented by the long-standing traditional research of contemporary Extension programs. The critical innovation in **CLD3** is, as its name suggests, data-informed community-based research, where the community participates in asking and answering the questions that drive data gathering and the creation of data insights relevant to program or policy decisions. We have successfully tested the model in several communities in three states - Virginia, Iowa, and Oregon - and other states are working to replicate the **CLD3** approach in their communities. Two complementary pilot efforts demonstrated that the Cooperative Extension System (CES) is well positioned to build data science capacity in communities, including often overlooked rural places. The two pilot programs are:

- ***Towards a National Community Learning Network*** – $1M funded by the Bill & Melinda Gates Foundation to pilot the use of data science to unravel complex, community challenges and advance economic mobility across Virginia, Iowa, and Oregon.

- ***Three-State Data Science for the Public Good Coordination Innovation Network*** – $1M funded by US Department of Agriculture, National Institute of Food and Agriculture, Agriculture and Food Research Institute, Food and Agriculture Cyberinformatics Tools program in the three states.

Data science research partnerships with Cooperative Extension contribute to the shaping and placement of data insights into the hands of local decision-makers and promote civic engagement among a diverse group of Cooperative Extension, university, and national stakeholders. As demonstrated through the pilots, these partnerships enabled communities to equitably access and utilize data that promotes economic, social, and environmental well-being.

2. Among examples of existing Federal collaborations with (a) Tribal, territorial, local, and State governments or (b) local communities involving equitable data, *what lessons or best practices have been learned from such collaborations*?

The **CLD3** pilot demonstrations led to the creation of two notable public goods that can be scaled nationally:

1) Equipping Cooperative Extension with the skills and knowledge to effectively enhance their engagement with communities in identifying and applying data-driven insights to community problems through the **CLD3** process; and
2) Developing a data commons infrastructure to accelerate the advancement of these community-based projects and Cooperative Extension programming.

Since 2020, lessons learned through the conduct of numerous projects in the three originating states were summarized in brief reports. The projects covered a wide array of community-identified priorities from addressing barriers to health care access and use in Patrick County VA to understanding declining ridership and dissatisfaction with the Marshalltown IA public bus system. These and other examples can be accessed through this link: https://datascienceforthepublicgood.org/economic-mobility/community-insights/case-studies

The pilot programs further clarified the unique value of the **CLD3** approach in promoting diversity, equity, and inclusion as part of the outreach process. **CLD3** engages a wide variety of stakeholders across disparate geographic, political, social, and economic contexts. This engagement includes stakeholders' unique perspectives in establishing the project scope and purpose, promoting a 'not about us without us' approach, and leveraging local perspectives that drive data-informed decision-making.

3. What resources, programs, training, or other tools *can facilitate increased data sharing between different levels of government (Tribal, territorial, local, State, or Federal) related to equitable data*?

Cooperative Extension professionals know how to work with communities and involve university researchers in community-based research through engaged scholarship. Communities across the country collect a wide range of data but are experiencing difficulties accessing their own and other relevant open data to gain insights into problems they are experiencing. Several Extension programs across the country are experimenting with different engagement models around **CLD3,** but these remain disconnected and uncoordinated. What is needed is to scale up **CLD3** nationally to train Extension professionals in all states, which will take congressional authorization and funding. The Extension Committee on Organization and Policy and the Joint Council of Extension Professionals are two national organizations representing Extension professionals that are working to build a cohesive national program based on the **CLD3** work to date.

The National Agricultural Research, Extension, and Teaching Policy Act of 1977 (NARETPA) provides purposes to guide USDA's research and educational programs and is the appropriate legislative vehicle to establish a national program. When Congress takes up the Farm Bill reauthorization in 2023, it has the opportunity to provide an additional purpose for Cooperative Extension and to authorize funding for scaling up **CLD3** to a nationwide program that provides communities with access to data and analyses to inform their decisions.

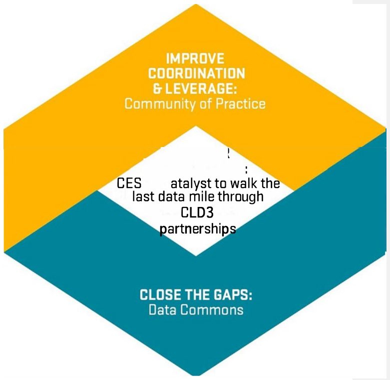
> **Proposed Additional Purpose:** *Develop and sustain a national network of Community Learning through Data Driven Discovery (CLD3) partnerships that integrates data science and Cooperative Extension expertise. Support the network with a curated National Data Commons to ensure equitable, evidence-based program and policy development and practice.*

Harnessing data through the **CLD3** process provides a pathway for evidence-based insights into community infrastructure (e.g., operations, resilience, sustainability), environmental conditions (e.g., water quality, air quality, noise), and people (e.g., economic conditions, activities, health). Cooperative Extension, working with their land-grant and public university researchers, can address community problems in new ways using **CLD3**. Additional resources will be needed to bring this data revolution and **CLD3** to these communities. These partnerships will empower communities of all sizes to harness, integrate, and leverage insight from their own data flows to form a new evidence-based foundation for democracy.

Additional federal funding would be needed to:

- **Create a *CLD3 Community of Practice*** – connect CES with local government officials and other constituents through a Community Learning through Data-Driven Discovery process and 'reach back' to the university to collaborate with data science researchers via engaged scholarship.

- **Evolve *National Data Commons*** – enhance current CES situation analyses and programming reports through geospatial mapping and analysis of local administrative data, federal and state data, and social media. Develop and curate processes to support data discovery, sharing, access, analytics, and evaluation for data-driven decision-making across the CES ecosystem.



4. What resources, programs, training, or other tools *can expand opportunities for historically underrepresented scholars and research institutions to access and use equitable data across levels of government*?

To enable this enhanced role, Extension professionals working at 1862, 1890 (Historically Black Colleges and Universities), and 1994 (Tribal Colleges) Land Grant Universities would work collaboratively to develop, deploy, and curate data science processes and establish communities of practice. A new USDA program "Learning to Leading: Cultivating the Next Generation of Diverse Food and Agriculture Professionals (NEXTGEN)" could be the source of funding for ensuring the diversity of Extension programs and professionals providing **CLD3** programming. Diverse CES professionals and public universities should be involved to convene communities and leverage university research in response to issues and problems identified by local and state governments and community stakeholders. An additional benefit of this enhanced role would be the development of the local and state government workforce with data analytics capacity and experience.

5. What resources, programs, training, or tools *can increase opportunities for community-based organizations to use equitable data to hold the government accountable to the American public*?

CLD3 empowers communities to answer their most pressing problems by using their own, often underutilized, data. In the first step of the process, a facilitated conversation around data discovery is held- where local and administrative data holdings are identified that can illuminate the problem at hand. The evidence-based leadership training empowers communities to more effectively incorporate data in support of the public good.

6. What resources, programs, training, or tools *can make equitable data more accessible and useable* for members of the public?

At the conclusion of the **CLD3** projects, the data tools, underlying code, and results are shared publicly to help scale learnings.

7. In which agencies, programs, regions, or communities *are there unmet needs, broken processes, or problems related to participation and accountability* that could be remedied through stronger collaborations and transparency around equitable data?

The **CLD3** model can work for communities of interest and place of all sizes. However, geographically isolated and rural communities can particularly benefit from this process. Federal statistics often do not provide the granularity needed to accurately assess rural places because of suppression. Helping local communities utilize the power of their own data to drive change helps to provide more equitable access to the tools and resources needed to engage in evidence-based decision making.

RFI: Advancing Equity with Community Data Partnerships: We Need to Hear from You

Due: October 3, 2022

On behalf of Elizabeth Beatriz, PhD

I. Introduction

I am deeply enthusiastic about the *Vision for Equitable Data* laid out by the Equitable Data Working Group. For public health and related sectors to meet their missions both today and into the future, a commitment to the pursuit of equitable data collection, use, and sharing is essential to data modernization efforts.

While the rest of this response will outline specific examples to address the questions outlined in the “Request for Information: Equitable Data Engagement and Accountability”, I wish to underscore the key principle that guides my approach to equitable data in this Introduction.

The aim of equitable data can only be realized when the experiences and voices of those experiencing inequities are centered throughout the data lifecycle. Absent intentionally centering those who have been marginalized, data cannot achieve its aim of being meaningful or actionable and is likely to perpetuate and reinforce the systems of oppression and injustice at the root cause of these inequities. This requires not only data disaggregation – which certainly is necessary – but also engagement with communities about meaningful groupings that align with their lived experiences and identities. Massachusetts examples (i.e., development of rural clusters and the COVID-19 Community Impact Survey) are expanded on below in Section 3: Data for Accountability. It requires community input into the questions surrounding accountability, including defining “success” and the quality of services and programs in alignment with community needs (see “The Racial Equity Data Road Map” in Section 3: Data for Accountability), and providing sufficient context to both understand and act on the data (see the Public Health Data in Section 2: Data Sharing and the Racial Equity Data Road Map in Section 3: Data for Accountability). Finally, it requires acknowledging Federal and State governments as data stewards in service to their residents and those on whom they hold data and, consequently, their responsibility and duty in sharing that data back to communities.

II. Data sharing

Data sharing between (e.g., Federal and State) and within (e.g., between different agencies) levels of government are critical to lessen the burden on individuals related to duplicate data collection efforts as well as lessening the gaps and limitations of any one data source and providing key opportunities for data linkage needed for data contextualization and identifying opportunities for intervention.

An exemplar of data sharing in Massachusetts is the Public Health Data Warehouse (PHD)[1]. Initially developed in response to the opioid overdose epidemic in Massachusetts and now key to addressing inequities in maternal morbidity and mortality, the PHD links almost 30 state and federal administrative datasets to provide a robust and comprehensive dataset of Massachusetts residents. Through the linkage of these datasets, MDPH was able to gain a fuller picture of health inequities in Massachusetts, including being able to understand the intersectional identities of Massachusetts residents (e.g., unhoused veterans, Black residents who do not live in Boston), contextual and structural influences of inequities (e.g., the impact of community-level inequities), and numerically small groups (e.g., postpartum people who were incarcerated in the year before delivery). These types of linkages not only allow for opportunities to overcome limitations of individual datasets, which often have incomplete demographic and/or geographic data, but also provide clear opportunities for where policies, practices, and funding are most needed to support equity by explicitly acknowledging the numerous systems with which we each interact.

III. Data for accountability

To truly be accountable, data must be meaningful and appropriately capture what is most important to our communities. To do this to fidelity, government must question what constitutes "meaningful data" and expand and invest in a more inclusive definition that reflects the reality of those experiencing inequities. This includes engaging in community-led or community-driven analyses in which a "successful" outcome is defined by the community – and have accountability measured against community definitions of success. This process of reflection and refinement may reveal a need for a broader understanding of data, including more consistent integration of linked and/or multi-level data, mixed methods data (i.e., qualitative and quantitative), and complementary data sources (e.g., survey data paired with administrative data), and requires context to make appropriate conclusions. Additionally, to be accountable, communities and populations most impacted by inequities should inform: 1) data collection tools such that they can see their identities accurately reflected in the collection tools and 2) analytic approaches to granularity and aggregation of data such that the data are meaningful and actionable. One tool for engaging in these types of processes and two examples of this approach from Massachusetts are below.

The "Racial Equity Data Road Map: Data as a Tool Towards Ending Structural Racism" is a comprehensive and practical toolkit that guides users in the use of data to promote racial equity, with a focus on quality improvement and accountability.[2] These tools range from racial

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[1] "Public Health Data Warehouse (PHD) | Mass.Gov," accessed September 26, 2022, https://www.mass.gov/public-health-data-warehouse-phd.

[2] "Racial Equity Data Road Map | Mass.Gov," accessed September 26, 2022, https://www.mass.gov/service-details/racial-equity-data-road-map.

equity readiness assessments to guides for community engagement to reframing and data contextualization. In Massachusetts, several programs have used this guide to not only make their data and analyses more equitable but also to identify previously unquantified programmatic inequities which have led to programmatic improvements.

In response to community-elevated need, MDPH prioritized the revision of Sexual Orientation and Gender Identity (SOGI) data standards, which were adopted in 2019. These data standards allowed for more inclusive options of SOGI identities in efforts to better reflect the identities of populations who had historically been left out of data collection efforts. One of the first demonstrations of the power of these standards was the COVID-19 Community Impact Survey (CCIS)[3], which aimed to identify the inequitable impacts of the COVID-19 pandemic on health and social determinants of health. CCIS was able to elevate the needs of those with specific SOGI identities (e.g., queer, questioning, asexual, bisexual) that would not have been visible if LGBTQ+ identities had been aggregated.

However, there may be approaches when community-informed data aggregation is essential for equitable accountability. An example of this may be the grouping of small groups or geographies that have a shared identity and/or work together to share resources. Often existing surveillance systems do not capture meaningful data for small municipalities, particularly that of rural communities. County-level data skews data toward larger city centers and obscures health outcomes and disease in small rural communities. Additionally, many rural communities work with neighboring towns but cross county lines making county-level data unrepresentative of the reality of these communities. Through partnership with the Massachusetts Rural Health Council, MDPH developed a method to cluster rural community data in a way that is both methodologically sound and representative of the ways that rural towns work with each other to share resources and culture[4]. This approach has allowed for a better understanding of funding impacts and health needs that were otherwise unreported.

IV. Access and use of data for members of the public

The role that governmental entities have in collecting, aggregating, and making sense of data for the collective good is unique within American society. Alongside this distinct role is a fundamental responsibility to those about whom data is collected to give that data back, and, accordingly, give the power of that data back to the people.

Partnership with existing, trusted community-based organizations can be an effective way to share data equitably. Partnerships where this approach has been successful ensure that the

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[3] "COVID-19 Community Impact Survey | Mass.Gov," accessed September 26, 2022, https://www.mass.gov/resource/covid-19-community-impact-survey.

[4] "State Office of Rural Health Rural Definition | Mass.Gov," accessed September 26, 2022, https://www.mass.gov/service-details/state-office-of-rural-health-rural-definition.

community-based organizations have any data and technical ability to use the data (and, if not, provide technical assistance and training to build these skills), value community experience in making meaning of the data, allow community-based organizations to inform data dissemination more broadly, and develop true bidirectional relationships that support transforming the data to action to promote equity.

Another promising approach to public access to meaningful data – while still protecting individuals' confidentiality – is the use of publicly accessible data visualization platforms. While these have proliferated in recent years, it is important that they incorporate the same best practices previously mentioned – data disaggregation into the meaningful groups and ensuring that platforms are accompanied by data interpretation guides to support public use of the data. In addition to these, data visualization platforms should be flexible allowing the public to ask questions of the data that are most important to them.

Note: I am the Acting Director of Office of Statistics and Evaluation in the Bureau of Community Health and Prevention at the Massachusetts Department of Public Health and Affiliated Faculty at the Institute for Social Justice and Health Equity Research at Northeastern University. The views presented here are my own and do not reflect the official position of the Massachusetts Department of Public Heath, Commonwealth of Massachusetts, or Northeastern University

A little but late, alas!

1. Examples of successful collaborations involving equitable data between the Federal government and (a) Tribal, territorial, local, and State governments, or (b) local communities include…

2. Lessons learned and equitable data best practices within these collaborative contexts include…

- Equitable data best practice: Development of data sharing standards must include co-design and co-development with historically marginalized communities. For instance, the CARE framework for indigenous data stewardship is a co-developed initiative with indigenous populations.

3. Resources, programs, training, or other tools that facilitate equitable data sharing between different levels of government include…

- The AllofUs project is an initiative that includes a broader and more diverse representation of genetic data to inform equitable clinical outcomes.

4. Resources, programs, training, or other tools can expand opportunities for historically underrepresented scholars and research institutions to access and use equitable data across levels of government include…

- ISchool Inclusion Institute (I3). An immersive year-long program for historically marginalized high school students in computer and information science.

5. Resources, programs, training, and tools that increase opportunities for community-based organizations to use equitable data in order to hold government accountable to the American public include…

- Diversity metrics such as the University of Arizona’s diversity data dashboard.

6. Resources, programs, training, and tools that make equitable data more accessible and useable for members of the public include…

7. The agencies, programs, regions, and communities that suffer from unmet needs, broken processes, or problems related to participation and accountability, and which could be remedied through stronger collaborations and transparency around equitable data include…

The Missing MIllion's report: We need a greater representation of Latinx cyberinfrastructure professionals, especially at HSI. https://www.rti.org/publication/missing-millions/fulltext.pdf

Smart metrics to show the energy consumption of computing to support development of "green algorithms."

Sarah

*** My working hours may not be your working hours. Please do not feel obligated to reply outside of your normal work schedule ***

Sarah Bratt
Assistant Professor | she/her/hers
University of Arizona School of Information (iSchool)
tweet [redacted] **web** sarahbratt.com | >https://orcid.org/0000-0002-3642-4425<

Recent publications:
Qin, J., Hemsley, J., & Bratt, S. (2022) *Forthcoming*. Collaboration Networks and Career Trajectories: What do Metadata from Data Repositories Tell Us? *Proceedings of the Association for Information Science and Technology.*

Qin, J., Hemsley, J., & Bratt, S. (2022). The Structural Shift and Collaboration Capacity in GenBank Networks: A Longitudinal Study. *Quantitative Science Studies.*

October 3, 2022

NSTC Subcommittee on Equitable Data
Office of Science and Technology Policy
Eisenhower Executive Office Building
[redacted]
Washington, DC 20504

Re: Engagement and Accountability RFI

Dear Dr. Ross:

The CODATA Center of Excellence in Data for Society at the University of Arizona (CODATA at UA) is the US-based policy research institute of the International Science Council's Committee on Research Data, or CODATA. We provide policy training and research to deliver evidence-based tools and guidance on the use of data assets in society, academia, industry, and government. In particular, we promote the adoption for FAIR data sharing practices that implement **F**indable, **A**ccessible, **I**nteroperable, and **R**e-usable data stewardship. FAIR data supports equitable access to the nation's data assets by providing an accountability framework for the management of all data that is not otherwise restricted for privacy and security reasons.

The FAIR principles are well known throughout the data stewardship community of practice, however, this framework remains unfamiliar to many of the policymakers, decision makers, and department leads throughout the nation's state and local agencies that are tasked with managing these public assets. We therefore advise that **OSTP should work with Federal agencies to establish a data science corps that is tasked with facilitating the integration of State and local data with Federal data according to FAIR data principles and within FAIR data stewardship best practices. We further recommend the establishment of a FAIR Fellows training and placement program, which would provide policy and stewardship training to qualified candidates in every state and territory.**

This training should leverage existing programs, such as AAAS S&T Policy Fellowship; the Virginia Academy of Science, Engineering and Medicine COVES Fellowship (>http://www.vasem.org/covesfellowship<); and the CODATA at UA FAIR Fellows program (https://ceds.arizona.edu/), which specifically trains fellows for this purpose.

Thank you,

Merc Fox

Executive Director, CODATA at UA
Senior Researcher, Udall Center for Studies in Public Policy | Native Nations Institute
The University of Arizona
Tucson AZ | Washington DC
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Book an Appointment

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We respectfully acknowledge the land and territories of Indigenous peoples. CODATA at UA is co-located in Tucson AZ on O'odham and Yaqui lands, and in Washington DC on Piscataway, Pamunkey, and Nacotchtank (Anacostia) lands. Work is performed on Yesan (Tutelo) lands on the banks of the New River. Today, Arizona is home to 22 federally recognized tribes, with Tucson being home to the O’odham and the Yaqui. Committed to diversity and inclusion, the University strives to build sustainable relationships with sovereign Native Nations and Indigenous communities through education offerings, partnerships, and community service.

3: What resources, programs, training, or other tools *can facilitate increased data sharing between different levels of government (Tribal, territorial, local, State, or Federal) related to equitable data* ?

NYC has made available their syndromic surveillance data within a day of the emergency department (ED) visits, but when we searched for similar data from the other 61 NSS jurisdictions, the data was mostly not available, or only available with lengthy application process. It seems counterproductive during a pandemic that we lack this information for most jurisdictions. It's incredibly impressive that we know how many people visited Brooklyn EDs with respiratory symptoms yesterday, but it's disappointing no other jurisdictions even have this information available a month after the ED visits. We needed this information for our publication but only had access to NYC data.
Rivera R, Rosenbaum JE, Quispe W. Excess mortality in the United States during the first three months of the COVID-19 pandemic. Epidemiol Infect. 2020 Oct 29;148:e264. doi: 10.1017/S0950268820002617. PMID: 33115546; PMCID: PMC7653492.

We have addressed death count timeliness in the following publication. We found some states were exemplary in having timely data available, and others were extremely slow, and it was not explainable by region of country or political orientation: a high GDP blue state like Connecticut was extremely slow and a lower GDP state like Maine was extremely fast. Utah was among the fastest. States need to learn from each other how to have efficient mortality data releases.

Rosenbaum JE, Stillo M, Graves N, Rivera R. Timeliness of provisional United States mortality data releases during the COVID-19 pandemic: delays associated with electronic death registration system and weekly mortality. J Public Health Policy. 2021 Dec;42(4):536-549. doi: 10.1057/s41271-021-00309-7. Epub 2021 Nov 3. PMID: 34732841; PMCID: PMC8564267.

5. What resources, programs, training, or tools *can increase opportunities for community-based organizations to use equitable data to hold government accountable to the American public* ?

The problem of substandard water and sewer infrastructure in areas with many Black residents has been well-established, but we do not have access to adequate data. Catherine Flowers has worked as an advocate on lack of sewage and water adequacy in rural areas in the South with large Black populations. Housing data from American Housing Survey requires a fee. Including information about water and sewer infrastructure adequacy in the AHRQ SDOH toolkit would be extremely helpful for research. Literally the best information I have been able to find is 1990 Census figures by state for percent of houses with municipal sewer (data attached). Information by county by year through the present would be very helpful. We have some information about bathroom and kitchen adequacy in public data, but that's not quite the same thing as lack of adequate sewage disposal and clean home water.

On the positive, I love the AHRQ SDOH database, and it's on the right track: https://www.ahrq.gov/sdoh/data-analytics/sdoh-data.html

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[redacted]

About the UCLA Center for Health Policy Research

Since its founding in 1994, the UCLA Center for Health Policy Research (UCLA CHPR) has produced high-quality, objective, and evidence-based research and data that have informed effective policymaking and improved the lives of millions of Californians. In 2001 UCLA CHPR launched the California Health Interview Survey (CHIS), the largest state-based population health survey in the U.S. CHIS collects data on health status, health habits, insurance status, and social determinants of health for adults, teens and children. CHIS continues to collect an annual sample of over 20,000 households with a constant commitment to producing data centered on health equity.[i] To ensure the data was accessible by all organizations and health leaders regardless of technical skill, the UCLA CHPR created a free, easy-to-use, web-based query system, AskCHIS. Throughout the years we have used metrics from the system and feedback from users to inform additional tools, including AskCHIS Neighborhood Edition (NE), and Health Profiles, which deliver health estimates on top topics for multiple age groups, racial/ethnic groups, and geographic regions (including counties, legislative districts, regions, SPAs and HHAS). Additionally, UCLA CHPR offers training on utilizing CHIS data tools and harnessing the power of data in advocacy. We have also provided special training for media and legislative staff. Through the success of CHIS, we have expanded our equitable data research portfolio with the creation of the UCLA Data Equity Center and the Native Hawaiian Data Policy Lab. It is through the lens and experience from CHIS and these two projects that we provide our comments to the RFI.

UCLA Data Equity Center

The Data Equity Center is a new center based at the UCLA Center for Health Policy Research, created to provide technical assistance to data projects around the country to help improve data equity. The mission of the Data Equity Center is to increase representation of marginalized populations in data and to reduce barriers in access to data especially among marginalized communities who have been unrepresented or invisible in the data platforms that inform policies. The Data Equity Center will also be curating a repository of resources to address barriers to data equity that will be publicly available. We encourage agencies, programs and organizations to turn to the Data Equity Center as a repository of expertise, resources, and tools, as well as a source of technical assistance.

In addition to the Data Equity Center itself, our team would like to share the following comments and suggestions.

Some recommendations across several of the questions posed in the RFI. For example, having a strong commitment to Dissemination of data and data products is likely to produce resources and tools that will facilitate data sharing across levels of government (Q3), expand opportunities for historically underrepresented scholars and research institutions to access and use data (Q4), increase opportunities for community-based organizations to use data (Q5), and make data more accessible and useable for members of the public (Q6). For example, the California Health Interview Survey is a state level survey that is widely used at the state, county and local levels.[ii] The data and products are used by advocates, policy makers, community organizations, and state and local health departments. This is due in part to dissemination efforts which have produced a number of resources and tools including:

1. Reports and publications targeted to a variety of audiences from the general public, to community-based organizations, to policy makers, as well as academics.
2. Online query system that supports quick and easy searches for health statistics for the state of California as well as for counties and regions in the state
3. Data dashboards that provide data on smaller population groups or on timely topics
4. Public Use Data Files that provide comprehensive statewide data files on a variety of topics and are free and downloadable

In addition, survey data are an essential source of monitoring the health and health care needs of the U.S. populations as a whole and identifying the specific needs of smaller populations or communities. Users of health datasets seeking to identify and quantify the health disparities of smaller communities often encounter challenges of measurement and racial-ethnic classification. These challenges include: inconsistent data collection and coding methods and survey weighting decisions that affect the representativeness of samples of respondents across surveys. Imprecision in health estimates for smaller racial/ethnic group can lead to poor public health planning and policy formulation and may dampen opportunities for wider allocation of non-health social protection resources that impact health.

In our work with survey researchers, they have routinely expressed the need for more guidance on approaches to collecting, tabulating, and disseminating data on race and ethnicity; they have also expressed challenges with regards to accessing datasets. The following are high-level areas we have identified as those which would make data more accessible and useable to the public:

- Release pooled multiyear public-use files that include more detailed race/ethnicity data. Pooling multiyear data reduces the disclosure risk that may be associated with providing more detailed race data.
- When small sample sizes prohibit the inclusion of any of racial/ethnic subgroups, datasets should include information on the overall population. For example, with the American Indian and Alaska Native (AIAN) population it is preferable to include the overall AIAN category along with the single-race AIAN category to expand tabulation options for the AIAN population. In cases where disclosure risk prevents the release of measures identifying any AIAN subgroup, such as single-race non- Latino AIAN, survey administrators should consider publicly releasing at a minimum an overall AIAN indicator that combines single-race AIAN and AIAN of more than one race into one category. This indicator would allow continued access to data on AIAN populations when disclosure concerns prevent the analysis of AIAN subgroups. The Native Hawaiian/Pacific Islander group should also be separately reported from the Asian American group.
- Reduce cost/time for accessing restricted data. If it is not possible for smaller community information to be included in public-use datasets for some surveys, the accessibility of that survey's restricted data becomes extremely important for obtaining information. This is especially critical for surveys that are the primary source of information on a health topic. Current procedures for accessing federal statistical research data centers are time-consuming and expensive and demand resources that

are often unavailable to members of these marginalized populations. Enabling access to this data in ways that protect respondents will help to reduce these inequities and encourage efforts to develop policies to improve the health of communities.

The Native Hawaiian Pacific Islander (NHPI) Data Policy Lab

The NHPI Data Policy Lab was born of the COVID-19 pandemic,[22] when community groups throughout the United States approached the UCLA CHPR about the lack of NHPI data in counts of infection rates in known diasporas in different states. Anecdotal data in April 2020 indicated high rates within the community but monitoring systems aggregated NHPI data with Asian-American or 'Other' designations, masking the true extent of the impact in this culturally tight-knit community. Soon after, The NHPI Data Policy Lab developed data mining techniques to expose the real numbers of those impacted in this community, alerting community groups to the need, and enabling health officials to create specific outreach programs for this population.

The NHPI Data Policy Lab is now a reputable source for NHPI data translators, educators, collaborators, and conveners. Since its formation in May 2020, the NHPI Data Policy Lab has supported the targeted community by increasing their access to health and health indicator data for use in program planning, community building, advocacy, and informing policy. The NHPI Data Policy Lab has an extensive track record in assisting NHPI community groups through in-language data education, group data trainings, and conducting data needs assessments to address barriers and gaps in data. Because of the Lab's support, community partners have successfully advocated at the U.S. House of Representatives Ways and Means Committee, the Congressional Asian Pacific American Caucus, the Congressional Tri-Caucus, and several state and county health jurisdictions throughout the U.S.

Additional comments in response to specific questions are below:

1. What are examples of successful collaborations involving equitable data between the Federal government and (a) Tribal, territorial, local, and State governments, or (b) local communities?

In California, the NHPI Data Policy Lab has been integral in helping local community coalitions in COVID-19 response. Members of The NHPI Data Policy Lab regularly attend virtual community convenings to provide COVID-19 data reports and education on case, death and vaccine rates. The NHPI Data Policy Lab has also produced a California county-level dashboard to visualize COVID-19 impacts on NHPIs across the state that the community relies on for accurate and reliable data. We provide thorough trainings on how to navigate the platforms to ensure usability among community and health professional data users. This support has shown high impact in regions such as the Inland Empire where an NHPI coalition successfully leveraged the Lab's data and data-education to make disaggregated NHPI COVID-19 data publicly accessible. This advocacy effort uncovered hidden NHPI disparities, giving community-based organizations the evidence needed to garner support for NHPI-targeted interventions.

Recently, the NHPI Data Policy Lab has given recommendations to the California Department of Public Health on the shortcomings of the Califronia Health Places Index, which fails to capture vulnerable NHPI communities. The metric disproportionately lacks consideration of NHPIs in resource allocation and vaccine distribution. This effort to educate and communicate with data producers on NHPI data inequities further emphasizes the NHPI Data Policy Lab's role as a local data intermediary.

2. Among examples of existing Federal collaborations with (a) Tribal, territorial, local, and State governments or (b) local communities involving equitable data, *what lessons or best practices have been learned from such collaborations*?

Form the NHPI Data Policy Lab Collaborations, we have learned the following:

1. We are using the findings of a Community Data Needs Assessment to inform the development of the data platform and training materials.
2. We conduct "report back" meetings to provide community respondents to findings from the Community Data Needs Assessment.
3. We work not only with traditional organizations, but also civic clubs, and school districts to address and improve outcomes among the targeted population groups.
4. Relationships of mutual benefit, and provision of technical assistance are useful in asking the community for a formal commitment to partnerships.

3. What resources, programs, training, or other tools *can facilitate increased data sharing between different levels of government (Tribal, territorial, local, State, or Federal) related to equitable data*?

The Data Equity Center is housed in the National Network of Health Surveys (Network). The Network, a project of the UCLA Center for Health Policy Research, is a group of over 200 health survey leaders, data custodians and users all interested in advancing data projects across the country at national, state and local levels. Because the Network membership includes representatives and users of data across different levels of government, the Network can be a resource for facilitating data sharing across levels.

In addition, the Network curated a series of technical assistance workshops designed to improve the disaggregation of race and ethnicity measures in health data sources. Workshop topics include: considerations for data collection and processing, question wording and response sets, mitigating disclosure risk, user experience, weighting strategies, disaggregating data decision-making, and legal and regulatory guidance. Recordings and slides from these workshops are available.

The NHPI Data Policy Lab has established dashboards that have automated data scraping from publicly available datasets. With the shared resources from the UCLA CHPR, we have a bench of researchers in data science, statistical analysis, data dissemination and training specialists, and policy analysts. Through our Communications team, we have hosted webinars featuring the NHPI Data Policy Lab dashboards—both for the state and national levels.

The Health Data program, a program of the UCLA Center for Health Policy Research, could help expand opportunities for underrepresented scholars and research institutions to access and use data. Through in-person and on-line workshops, the Health DATA Program helps policymakers, community groups and health and advocacy organizations to understand and use credible data in their programmatic and policy development work. Although the program's training and workshops has focused on health data, the concepts can be applied to other types of data.

5. What resources, programs, training, or tools *can increase opportunities for community-based organizations to use equitable data to hold government accountable to the American public*?

The Health Data program, a program of the UCLA Center for Health Policy Research, could help increase opportunities for community-based organizations to use data. Health DATA conducts training courses, in-person and online workshops, and technical assistance sessions to build knowledge and skills to access, understand, and apply data to program planning, advocacy, and policy development. One initiative of the Health Data Program was the Data & Democracy Initiative which had the goal of increasing data and research capacity of community-based organizations. Results of an evaluation of this initiative suggest that this intensive, short-term training program led to significant gains in data and research self-efficacy among community-based organization staff.[iii]

6. What resources, programs, training, or tools *can make equitable data more accessible and useable* for members of the public?

User friendly data access tools and training are key components to improving access to data and allowing communities the ability to understand themselves better and develop solutions and policy ideas. With COVID-19 data a number of innovative data dashboards were developed by various academic and non-academic entities, allowing for quick visual display of data that could be easily interpreted and used by communities. Training community users as well as building a pipeline of data scientists, particularly from communities have been historically underserved, would improve access, use, and interpretability of data by the public it the data are intended to serve.

7. In which agencies, programs, regions, or communities *are there unmet needs, broken processes, or problems related to participation and accountability* that could be remedied through stronger collaborations and transparency around equitable data?

American Indian/Alaska Native/Indigenous populations:

American Indian and Alaska Native (AIAN) people are underrepresented and often invisible in data and research. AIAN health data capacity is impeded by the quality of information collected, released, and reported on AIANs in population-based surveys. AIANs are either put in a residual "other" category or, typically, depicted as single-race non-Latinx AIANs.[iv] Moreover, variations in approaches to classifying racial and ethnic populations in federal and state health statistics have substantial implications for how we measure health status, access to healthcare, healthcare quality, and health equity.[v] There is considerable variation across surveys in their measurement of the AIAN population based on survey classification, tabulation, and weighting approaches. Administrators should consider the effects of rendering politically and socially marginalized populations invisible in public use data sets when making decisions about whether to release this data. Recommendations for improving AIAN data capacity include releasing pooled multiyear public use data files that include more detailed race/ethnicity data, including information on the overall AIAN population in data files, noting when conclusions about the AIAN population are based solely on single-race non-Latinx AIANs, and streamlining access to restricted use data files that contain more detailed racial/ethnic information.

Native Hawaiian and Pacific Islander (NHPI) populations:
Health inequities in Native Hawaiian and Pacific Islander (NHPI) populations have been perpetuated and exacerbated by decades of data inequity. The COVID-19 pandemic underscored the public health neglect of small communities, such as NHPIs, in part due to a lack of publicly accessible data compounding a community that has gone unreported and underreported, not just in health, but in all social determinants of health (SDoH).

Asian Americans:
Asian Americans are the fastest-growing racial/ethnic group in the U.S., representing more than 50 ethnic groups and speaking over 100 different languages, but national health data rarely collect information needed to disaggregate AANHPI into smaller groups to capture this diversity.[vi]

"Invisible Subgroups in Aggregated data"
Although large national surveys may include racial and ethnic and sexual subpopulations and sexual orientation and gender identity classification in data collection, sample sizes are often too small to permit meaningful data analysis. Barriers to disaggregation cited included the lack of stakeholder interest, inadequate funding, lack of space on questionnaires, as well as methodologic challenges, such as the inability to obtain an adequate sample size and poor questionnaire design. Recommendations include mandating disaggregation; establishing research community resources for addressing challenges in following mandates and guidelines; publishing best practices on oversampling, identifying community needs, and collecting data when resources are limited.

Thank you for considering this comment.

Ninez Ponce, PhD, MPP – Director of the UCLA Center for Health Policy Research

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[i] Ponce NA. Centering Health Equity in Population Health Surveys. *JAMA Health Forum.* Published online December 2, 2020. doi:10.1001/jamahealthforum.2020.1429

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[iv] Becker TL, Babey SH, Shimkhada R, Scheitler AJ, Ponce NA. 2020. Limited Access to Health Data on American Indian and Alaska Natives Impedes Population Health Insights. Los Angeles, CA: UCLA Center for Health Policy Research. Available here: https://healthpolicy.ucla.edu/publications/Documents/PDF/2020/AIAN-policybrief-nov2020.pdf

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[vi] Shimkhada, R., Scheitler, A.J. & Ponce, N.A. Capturing Racial/Ethnic Diversity in Population-Based Surveys: Data Disaggregation of Health Data for Asian American, Native Hawaiian, and Pacific Islanders (AANHPIs). *Popul Res Policy Rev* **40**, 81–102 (2021). https://doi.org/10.1007/s11113-020-09634-3

Hi there,

Thanks for the opportunity to submit a request for equitable federal data. Relating to:

- Question #4: What resources, programs, training, or other tools *can expand opportunities for historically underrepresented scholars and research institutions to access and use equitable data across levels of government* ?
- Question #7: In which agencies, programs, regions, or communities *are there unmet needs, broken processes, or problems related to participation and accountability* that could be remedied through stronger collaborations and transparency around equitable data?

We'd like to be able to access data on proposal submissions and awards and any merit review scores and award sizes for research and non-research proposals at NSF, DOE, NASA, and other federal funding agencies, broken down by race/ ethnicity/ sexual orientation / gender/ disability status/ veteran status/ small area geography/ institution/ career stage] so that we can assess when there have been inequitable funding disparities and potential mechanisms underlying them. We recognize that census and federal definition categories have changed over the years and that data may be incomplete, but accessibility, transparency, and data availability would be helpful.

Thank you,
Aradhna

Aradhna Tripati (she/they)
Presidential Awardee in Science and Engineering - California Academy of Sciences - Fellow, Geochemical Society, European Association of Geochemistry, Geological Society of America, American Geophysical Union - Founding Director, Center for Diverse Leadership in Science

UCLA | Institute of the Environment and Sustainability | Earth, Planetary, and Space Sciences | Atmospheric and Oceanic Sciences | American Indian Studies Center

Web: >https://tripati-lab.netlify.app/< | Twitter: [redacted]
Meeting link: https://ucla.zoom.us/my/zoomwitharadhna | Scheduler: https://calendly.com/aradhnat/15min

UCLA's Basic Needs Resource Guide

Video - Where do you see infinity or boundlessness in the world? - Yayoi Kusama and the Broad Museum
Panel - Confronting the Climate Crisis - CNN
Keynote – Racism and culture in STEM and society - Unpacking Diversity

The American Indian Studies Center and the Center for Diverse Leadership in Science at UCLA acknowledge the Tongva peoples as the traditional land caretakers of Tovaangar (Los Angeles basin, So. Channel Islands) and are grateful to have the opportunity to work for the taraaxatom (indigenous peoples) in this place. As a land grant institution, we pay our *respects to Honuukvetam (Ancestors), ‘Ahiihirom (Elders), and ‘eyoohiinkem (our relatives/relations) past, present and emerging.*

City of Philadelphia Response to the Equitable Data Engagement and Accountability Request for Information

Direct any additional questions to Julia Hinckley, Director of Policy and Deputy Chief of Staff to Mayor Jim Kenney, at [redacted]

1. ***What are examples of successful collaborations between the Federal government and (a) Tribal, territorial, local, and State governments or (b) local communities involving equitable data?***

Departments in the City of Philadelphia use federal data broadly in three ways. First, the City uses federally produced data products for planning. Second, City agencies sometimes receive data for statutorily authorized purposes to administer local, state, and federal programs. Third, the City of Philadelphia collaborates with federal agencies to plan new policies and evaluate existing policies using data. This third category is presumably the most interesting and relevant to the use of equitable data – but as described in the response to question 7, projects that originate at the local level have had particular challenges.

Use of Pre-Made Federal Data Products

- The City of Philadelphia Office of Homeless Services (OHS) uses data from the Department of Housing and Urban Development's systems, including LSA, HIC, Sage, Stella and the National EHV dashboard. OHS also received technical assistance from HUD to help set up and operationalize our racial equity committee in our local CoC.
- The City routinely uses Census Bureau data products, like annual reports on poverty. The Census Bureau release of the Supplemental Poverty Measure data allowed the City to estimate the impact the expanded Child Tax Credit could have had on Philadelphians in poverty if the City were able to effectively reach them. This data helped us coalesce partners around a strategy of outreach and assistance. SPM data also helps the City better understand how we can strengthen our benefits access work to enroll more residents in programs for which they are eligible

Use of Federal Data for Program Administration

- The City of Philadelphia Department of Revenue receives data from the Internal Revenue Service (IRS) as part of the State Information Sharing program. This program has been successful in identifying unregistered or underpaying taxpayers in the City of Philadelphia for several different business taxes but has not been able to be used to conduct an equity analysis of tax administration.

Use of Federal Data for Planning and Evaluation

- The City of Philadelphia Office of Community Empowerment and Opportunity was supported by the White House and Treasury Department through the simplified filing portal from Code for America, getctc.org. This was not only useful in helping Philly families access the credit, but in gathering data on how many people we reached. Code for America was able to provide the City with aggregate data on the number of Philly households by zip code that used the tool, the dollars in CTC and stimulus payments claimed, and the time it took to claim the funds. This allowed the City to see where how our outreach efforts in the lowest income zip codes of Philadelphia were having an impact in reaching people and directing them toward the tool

2. ***Among examples of existing Federal collaborations with (a) Tribal, territorial, local, and State governments or (b) local communities involving equitable data, what lessons or best practices have been learned from such collaborations?***

Overall, establishing data sharing routines with the federal government has been a challenge. In order to do our work most effectively, City government requires a legal and secure way to receive identified, person-level or event-level data about our residents. Types of data might include their participation in federal benefits programs (e.g., Social Security), residency changes, military participation/veteran's status, income information, and more.

Having these types of data in an identified, person-level format would allow the City to link the data to our own records of service provision to improve out outreach/enrollment, to monitor program implementation, and to measure our impact. The City has the data infrastructure and technical expertise to manage Protected Health Information and Federal Tax Information in the Office of Integrated Data for Evidence and Action (IDEA) and the Department of Revenue, respectively. Most importantly, this data could allow the City to better target our efforts to the most vulnerable Philadelphians and ensure we are maximizing out impact.

For example, understanding who is accessing various types of federal assistance (e.g., Social Security) could provide up to date contact information for Social Security recipients so we can help enroll them in our local Senior Citizen Property Tax or Water discount programs or help us ensure those seniors *not* receiving Social Security benefits have the information and support they need to access benefits to which they are entitled.

3. ***What policies, resources, programs, training, or other tools can facilitate increased data sharing between different levels of government (Tribal, territorial, local, State, or Federal) around equitable data?***

What is most needed is clear guidance that identified, person-level data sharing among local, state, and federal agencies is legal as long as specific conditions (security, privacy, use cases, etc.) are met. When laws related to data or data-sharing are unclear, locally developed legal opinions understandably error on the side of caution. Projects across the City, from health agencies to tax agencies, have not moved forward because of hesitancy to interpret federal law incorrectly.

Government agencies should absolutely have the freedom and flexibility to say they *won't* share data if not mutually beneficial, but too often the answer is, "We want to, but we *can't.*" Protecting client privacy must be one of our highest priorities but balanced with the risk of harm caused by unnecessary and inequitable administrative burdens, when the necessary data already exist and are sitting unused. In addition to written guidance, a federal technical assistance agency for local/state government law departments attempting to interpret federal law in specific situations would be extremely helpful. A technical assistance agency might also be able to offer trainings in addition to one-on-one consultation.

A second area where the federal government could be of help is with the creation of inclusive data standards. Too often, different agencies are asked to collect data differently for similar constructs — different fields, different response options, or different formats (e.g., select one vs. select all that apply).

Standards should be routinely updated and implemented across agencies, so at the local level we can implement those same standards across our own agencies without pushback about federal reporting requirements. Alignment of minimum data collection requirements and standards among federal government agencies that would translate into a more aligned system requirements among other levels of government.

4. ***What policies, resources, programs, training, or other tools can expand opportunities for historically underrepresented scholars and research institutions to access and use equitable data across levels of government?***

While the City of Philadelphia does not itself employ and train scholars, the City routinely works with research institutions to plan and evaluate programs. Most academic partnerships are with local academic institutions where the university covers the costs of research.

The City could better partner with historically underrepresented scholars and institutions if the federal government provided funding and forums to connect with such researchers. This could be a scholar research network or a clearinghouse where the City could post projects that need academic support and evaluation.

5. ***What policies, resources, programs, training, or tools can increase opportunities for community-based organizations to use equitable data to hold government accountable to the American public?***

While the City of Philadelphia is not a community-based organization (CBO), the City often collaborates with CBOs. The federal government could increase opportunities for CBOs to use equitable data by increasing the use and availability of interactive dashboards that can be accessed and used to evaluate overall performance of the government, allocating funding for research and analysis of data with the expressed purpose of sharing that data with the public and, where available, disaggregating data based on demographics (race, ethnicity, gender, etc.)

6. ***What policies, resources, programs, training, or tools can make equitable data more accessible and useable for members of the public?***

See response to question 5.

7. ***In which agencies, programs, regions, or communities are there unmet needs, broken processes, or problems around participation and accountability that could be remedied through stronger collaborations and transparency around equitable data?***

For nearly all government programs, the administrative burdens placed on vulnerable communities (low-income, immigrant, communities of color, seniors, etc.) are too high. Typically, this takes the form of means testing and regular recertification of income status to maintain benefits when data sharing could auto-enroll, pre-qualify, recertify, or at least pre-populate these types of forms/applications. There is a “time tax” placed on our most vulnerable residents that could and should be remedied by government to improve equity.

Additionally, as noted in the response to question 3, the slowness and difficulty in creating data sharing agreements has created challenges in collaboration between the federal government and the City of Philadelphia.

The Philadelphia Mayor's Office sought to evaluate effective outreach strategies to increase uptake of the expanded Child Tax Credit by combining local human services data and federal tax information. The City conducted a randomized control trial in which the City used local human services data to gather contact information to text, call, and mail residents who could benefit from (and might have been at risk of missing out on) the expanded Child Tax Credit. The City worked with an IRS-affiliated researcher at Georgetown University to design the intervention and study, and the partnership was built with the understanding that the IRS would evaluate and provide aggregate information on whether residents who received different types of outreach ultimately did claim the Child Tax Credit. The project was a unique opportunity to use equitable data by combining information about the most vulnerable Philadelphia residents with concrete outcome data from tax records.

While the City did conduct the outreach to residents, the City has yet to sign a data-sharing agreement or receive any aggregate data from the IRS. This presents an unfortunate missed opportunity. A more collaborative and efficient process for federal/local partnership and data-sharing could have allowed the City to learn quickly from this initial round of outreach and apply learnings to inform not only the efforts to help people claim the remainder of the Child Tax Credit, but all efforts to expand and improve benefits access.

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National Advocates for
Asian American, Native Hawaiian &
Pacific Islander Health

October 3, 2022

National Science and Technology Council (NSTC) Subcommittee on Equitable Data
Office of Science and Technology Policy
Eisenhower Executive Office Building
[redacted] NW
Washington, DC 20504

Submitted via email at [redacted]

Re: Engagement and Accountability RFI

Dear Chief Data Scientist Ross,

The Asian & Pacific Islander American Health Forum (APIAHF) sincerely appreciates the opportunity to submit comments in response to the Request for Information on Equitable Data Engagement and Accountability.

With longstanding relationships with over 150 community-based organizational partners in over 40 states and the territories, APIAHF is the nation's oldest and leading health advocacy organization dedicated to improving the health and well-being of over 25 million Asian American (AA), Native Hawaiian (NH), and Pacific Islander (PI) communities. For over 35 years, APIAHF has worked to improve access to and the quality of care for AA and NH/PI communities, many of whom are predominantly immigrant, limited English proficient (LEP), and may be new or unfamiliar with the U.S. healthcare system.

We draw upon our extensive experience in addressing the health inequities that AA and NH/PI communities face and our understanding of the needs and barriers faced by AA and NH/PI communities. Our comments primarily focus on the following questions:

- What resources, programs, training, or other tools can facilitate increased data sharing between different levels of government related to equitable data?
- What resources, programs, training, or tools can increase opportunities for community-based organizations to use equitable data to hold government accountable to the American public?
- In which agencies, programs, regions, or communities, are there unmet needs, broken processes, or problems related to participation and accountability that could be remedied through stronger collaborations and transparency around equitable data?

What resources, programs, training, or other tools can facilitate increased data sharing between different levels of government related to equitable data?

Prioritize short and long-term investments in data infrastructure to enable increased data sharing. One of the main impediments to data sharing in public health stems from an outdated data infrastructure which does not allow data to be shared across multiple platforms and sources. Without investments in the data infrastructure itself, successful data sharing is not possible. In the short term, this means investments in technology and human capabilities, while in the long-term, it entails the migration of legacy data systems to modern, equity-oriented data systems.[1] State and local health jurisdictions that rely on outdated and underfunded data systems need to have the resources to update data systems and to migrate existing data to newer, leaner, and more adaptable platforms. The COVID-19 pandemic especially brought to light the consequences of the underinvestment in the public health infrastructure in the U.S. and the need for sustained investments, including in health information technology.

Not only do systems need to be updated, but standards established that enable data sharing between different health care entities and public health departments at the federal, state, and local levels. This means agreed upon, transparent data-sharing and interoperability requirements that incentivize the exchange of health data across health care systems, levels of government, and public health entities in ways that promote health equity. With better quality, linked data, government agencies can use the information to leverage from other sources to support and collaborate with community partners to better understand and meet community needs. For example, Health Level 7 Fast Healthcare Interoperability Resources (HL7 FHIR) are standards that are designed to allow for quick and efficient data exchanges because they adopt standards and concepts already existing and familiar to software developers.[2] At the same time, there must be additional standards that ensure that these data exchanges lead to ways of addressing health disparities rather than deepening them by balancing these data-sharing efforts with trust-building with communities and addressing privacy concerns.

Increase resources dedicated to workforce training and technical assistance on data-sharing across levels of government and for community-based organizations. Data is only as impactful as the people who collect, analyze, disseminate, and report the data. The promotion of equitable data requires training the workforce and providing technical assistance so that people understand what makes data equitable. Data sharing is more likely to occur when there is agreement on and guidelines for how the data will be used and for what purpose. For example, the Centers for Medicare and Medicaid Services (CMS) Office of Minority Health (OMH) offers health equity technical assistance resources for organizations interested in advancing health equity through data collection and analysis.[3] However, more resources need to be dedicated to fostering a culture that normalizes equitable data such as a plan for data equity that serves as a guide for how entities will promote equitable data through data-sharing, collection and reporting. Training a workforce to value equitable data should go beyond mandatory training on structural racism and bias in data collection, analysis and reporting to building an organizational culture that prioritizes equitable data and data practices. One way of advancing equitable data practice is through principle-aligned practices for the data life cycle, from acquisition to disposition, that protect human subjects and create a less harmful and more just data environment.[4]

What resources, programs, training, or tools can increase opportunities for community-based organizations to use equitable data to hold government to the American public?

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[1] Robert Wood Johnson Foundation, *Charting a Course for an Equity-Centered Data System: Recommendations from the National Commission to Transform Public Health Data Systems*, October 2021. Available at: https://www.rwjf.org/en/library/research/2021/10/charting-a-course-for-an-equity-centered-data-system.html

[2] The Office of the National Coordinator for Health Information Technology, *What is HL7 FHIR?* Available at: https://www.healthit.gov/sites/default/files/page/2021-04/What%20Is%20FHIR%20Fact%20Sheet.pdf

[3] For more information: https://www.cms.gov/About-CMS/Agency-Information/OMH/equity-initiatives/Health-Equity-Technical-Assistance

[4] Marcus Gaddy and Kassie Scott (Urban Institute), *Principles for Advancing Equitable Data Practice*, (June 2020). Available at: https://www.urban.org/sites/default/files/publication/102346/principles-for-advancing-equitable-data-practice_0.pdf

Require the disaggregation of race and ethnicity data across all federal and local agencies by revising and expanding Office of Management and Budget (OMB) categories. For decades, AA & NH/PI communities have urged for data disaggregation. However, since 1997 there have been no changes made to OMB Directive No. 15, Standards for Maintaining, Collecting, and Presenting Federal Data on Race and Ethnicity (OMB standards). For 25 years, these minimum standards have limited the categories by which federal agencies collect data on race and ethnicity. While we commend the current ongoing process to review the OMB Standards, without a change in the Standards, federal and state agencies as well as community-based organizations cannot be armed with the baseline tools needed to advance equitable data.

Since the OMB Standards were last re-visited, we have witnessed significant change in the population makeup within AA & NH/PI communities. AA and NH/PIs comprise the fastest growing population in the U.S., and AAs are projected to grow more than 100% between 2030 and 2060, while the NH/PI population is projected to grow by nearly 50%.[5] To account for these changes, APIAHF has previously urged OMB to require agencies to follow the question format used in the U.S. Census's 2015 National Content Test (NCT) Final Report, (Figure 26, page 88) which includes checkboxes for six of the largest AA as well as six of the largest NH/PI populations plus listing the next three populous populations as "for example" write-in groups.[6] Additionally, APIAHF has recommended that these categories not be static, but regularly updated so that when subgroup population sizes change in relative size over time, new checkbox categories are added to reflect the change in population sizes.

Some states have taken the lead in implementing data disaggregation. In 2021, the state of New York passed data disaggregation legislation which requires all state agencies, boards and commissions that already collect demographic data to collect more granular data on AA & NH/PI groups and languages spoken. Agencies must disaggregate data for the ten most populous AA groups, along with Native Hawaiian, Guamanian, Chamorro, and Samoan groups. This legislative change would not have been possible without the decades of advocacy by AA and NH/PI community-based organizations demanding better data that reflects the diversity of our communities.

Federal, state, and local governments as well as community-based organizations depend on data to assess and distribute resources. Data that is not disaggregated cannot be equitable because it renders entire communities invisible and their needs unknown and unaddressed. Not only does the lack of disaggregated data make communities invisible, but they also fuel racist misconceptions and myths about populations- for example, the "healthy minority" misperception and "model minority" myth that Asian Americans are healthier and better off than other communities of color.[7]

Increase access to equitable data for limited English proficient (LEP) populations by expanding the quantity and diversity of language services related to the collection, analysis, and reporting of federal data. Existing federal laws and regulations, including Title VI of the Civil Rights Act of 1964, Executive Order 13166, Section 1557 of the ACA, and Language Access Plans generated by agencies, require protections for limited English proficient populations. However, in-language resources and support services are significantly lacking when it comes to data collection, analysis, and reporting. One in three Asians Americans and one in ten Native Hawaiian/Pacific Islanders are limited English proficient. In the absence of sufficient language services, many AA & NH/PI communities are unable to participate in, contribute to, or use equitable data. Considering the limited English proficiency of AA & NH/PI as well as other LEP communities, federal agencies should at minimum develop a language assistance program in data collection, analysis, and dissemination efforts.

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[5] U.S. Census Bureau, *Demographic Turning Points for the United States: Population Projections for 2030-2060*, (February 2020). Available at https://www.census.gov/content/dam/Census/library/publications/2020/demo/p25-1144.pdf

[6] APIAHF comment letter available at: https://www.apiahf.org/resource/comment-letter-to-the-office-of-management-and-budget-2017/

[7] Stella Yi et al, *The Mutually Reinforcing Cycle of Poor Data Quality and Racialized Stereotypes that Shapes Asian American Health*, Health Affairs 41:2, (February 2022). Available at: https://www.healthaffairs.org/doi/full/10.1377/hlthaff.2021.01417

The increased availability of language services related to the collection, analysis, and reporting of race and ethnicity data would increase opportunities for more community-based organizations to use equitable data. An example of a best practice is using interpreters to assist LEP persons in completing surveys and in-language guides/pamphlets that explain how the data that is collected will be used. These efforts to reach LEP populations should be done by recruiting and training trusted community organizers, including community health workers and patient navigators, who have cultivated strong relationships with community members.[8]

Foster and strengthen partnerships with community-based organizations that are already producing and using equitable data by providing resources and support, such as grants and financial assistance. Because of the lack of disaggregated data for the populations they serve, many community-based organizations undertake time consuming and expensive data collection for their own, including data collection utilizing in-language services. In January 2022, APIAHF in collaboration with the NYU Center for the Study of Asian American Health (NYU CSAAH) and community-based partners developed the National Covid-19 Rapid Needs Assessment survey to understand COVID-19 related needs and knowledge within AA and NH/PI communities, which was translated into Arabic and 11 Asian languages.[9] Federal agencies should identify and encourage such efforts by making available more resources, including financial assistance.

In which agencies, programs, regions, or communities, are there unmet needs, broken processes, or problems related to participation and accountability that could be remedied through stronger collaborations and transparency around equitable data?

Require state health agencies to standardize race and ethnicity categories as well as instructions on how race and ethnicity data is collected, using ACA Section 4302 as a minimum standard. Despite guidelines such as section 4302 of the Affordable Care Act which since 2012, has required population health surveys used in federal health programs, to collect and report data on race, ethnicity, sex, primary language, and disability status, race and ethnicity data of enrollees in federal health programs, including Medicaid and Medicare, are incomplete and inaccurate. Additionally, these inaccuracies have been found to be more common for certain beneficiaries, including Asian/Pacific Islander beneficiaries.[10] The lack of accurate and complete race and ethnicity data of enrollees in federal health programs impede the ability to assess and address health disparities writ large.

Data on Medicaid beneficiaries provide a key example. State Medicaid agencies vary widely in the number of categories they use to collect race and ethnicity data as well as how these variables are named and combined to create aggregated categories.[11] As a result, it is nearly impossible to understand the experiences of Medicaid beneficiaries as well as to understand the racial and health disparities experienced by beneficiaries at the national level. The ability to collect meaningful, reliable health data that is accurate, timely, and complete means enforcing and prioritizing standardization of categories and collection methods, such as how questions soliciting answers on health surveys are worded.

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[8] White House Initiative on Asian Americans and Pacific Islanders Interagency Working Group Data and Research Subcommittee, *Best Practices for the Disaggregation of Federal Data on Asian Americans and Pacific Islanders*, (March 2016). Available at: https://www.hhs.gov/sites/default/files/mar2016-whiaanhpi-data-disaggregation-report.pdf

[9] APIAHF, *National Multilingual COVID-19 Survey to AA & NH/PI Communities Finds Confidence in Vaccination and Widespread Misinformation*, (July 2022). Available at: https://www.apiahf.org/press-release/national-multilingual-covid-19-survey-to-aa-nh-pi-communities-finds-confidence-in-vaccination-and-widespread-misinformation/

[10] U.S. Department of Health and Human Services Office of Inspector General Data Brief, *Inaccuracies in Medicare's Race and Ethnicity Data Hinder the Ability to Assess Health Disparities*, (June 2022), OEI-02-21-00100. Available at: https://oig.hhs.gov/oei/reports/OEI-02-21-00100.pdf

[11] Heather Saunders and Priya Chidambaram (Kaiser Family Foundation), *Medicaid Administrative Data: Challenges with Race, Ethnicity, and Other Demographic Variables*, April 2022. Available at: https://www.kff.org/medicaid/issue-brief/medicaid-administrative-data-challenges-with-race-ethnicity-and-other-demographic-variables/

Thank you again for the opportunity to provide comments. We sincerely commend ongoing federal efforts to advance equitable data – data that allow for rigorous assessment of the extent to which government programs and policies yield consistently fair, just, and impartial treatment of all individuals, including those who have been historically underserved, marginalized, and adversely affected by persistent poverty and inequality- and we hope that our responses help inform the establishment of mutually beneficial collaborations between federal agencies, other levels of government, civil society and the research community. If you have any further questions or concerns, please contact us at [redacted]

Sincerely,

[redacted]

Juliet K. Choi
President & CEO

King County
Housing
Authority

NSTC Subcommittee on Equitable Data, Office of Science and Technology Policy
Eisenhower Executive Office Building
[redacted]
Washington, DC 20504

October 3, 2022

To the Subcommittee:

The King County Housing Authority (KCHA) is committed to advancing equity in our operations, data collection and analysis, and community engagement. We welcome this opportunity to inform the Subcommittee's efforts to learn how Federal agencies can support collaboration among local government, the community, and researchers around the production and use of equitable data in its Request for Information on Equitable Data Engagement and Accountability (87 FR 54269). Attached is our response to questions in the RFI.

Sincerely,

[redacted]
r s y o nson
Senior Director, Policy, Research and Social Impact Initiatives Department

King County Housing Authority Response to Request for Information on Equitable Data Engagement and Accountability

1. **What are examples of successful collaborations between the Federal government and (a) Tribal, territorial, local, and State governments or (b) local communities involving equitable data?**

The "Data Across Sectors for Health and Housing" (DASHH) project is an example of a data-sharing collaboration among three local government entities that collect and report data to the federal government. The King County Housing Authority (KCHA), with the Seattle Housing Authority (SHA), successfully partners with Public Health-Seattle/King County (PHSKC) on an ongoing data-linkage project that merges administrative data from the public housing authorities (PHAs) and Medicaid/Medicare to create a longitudinal dataset. (The PHA data are primarily from HUD form 50058 that is submitted to the Public and Indian Housing (PIH) Information Center (PIC) data system). The data linkage work has been supported by the Robert Wood Johnson Foundation in a grant to PHSKC.

The purpose of this multi-year effort is to learn more about the relationship between health and housing and inform how public housing authorities can leverage housing supports for better resident health and health equity. KCHA uses the data to identify health conditions that are prevalent among residents overall and among sub-populations and local geographies to uncover any disparities; and to develop and evaluate programming to address health care needs (such as connecting residents to behavioral health treatment).

A central product of DASHH is a public-facing dashboard hosted by King County, which can be found at: www.kingcounty.gov/health-housing. Under careful data sharing agreements and security protections, this open data product adheres to privacy rules and allows for community perusal of the data, expanding access to the information and therefore accountability for our work focused on intersections between health and housing.

The DASHH partnership has spawned original research studies. PHSKC obtained funding through a HUD Notice of Funding Availability (NOFA) *Examining Long-term Outcomes Following Exit from HUD-Assisted Housing*, with the housing authorities as sub-grantees to help inform the work. PHSKC has performed a series of analyses examining predictors of positive and negative exits as well as post-exit outcomes, such as rates of homelessness, health care utilization, and income growth. Initial results provide evidence that positive exits—those due to reasons such as earning enough income to no longer need housing subsidy—are associated with better health and housing stability. They are also able to identify which individuals and households are more likely to have better or worse outcomes. A report will be completed by the end of this year.

The DASHH data linkage also makes possible rigorous research that leverages the "natural experiment" presented by PHA's use of lotteries to provide access to housing vouchers. A research team led by Craig Pollack at Johns Hopkins University is analyzing child health care outcomes of voucher recipients, comparing outcomes of those who randomly gained earlier access to housing subsidies in comparison to households who remain on waitlists. The goal is to produce causal evidence of the health impacts of housing vouchers. The work is ongoing.

KCHA also routinely shares data with partner organizations serving households that receive “special purpose” housing vouchers focused on specific subpopulations experiencing housing instability and homelessness. These include Veterans Affairs Supportive Housing (VASH), Family Unification Program (FUP) for families with child welfare system involvement, Non-Elderly Disabled (NED)/Mainstream vouchers, and Emergency Housing Vouchers (EHV) for individuals and families experiencing homelessness. We track and share referral and demographic data with the relevant federal and state agencies, our local Continuum of Care, and community-based organizations (CBOs) to support efficient operational processes and we use the information to analyze access by demographic sub-groups, geography, and referring CBOs to assess whether access to vouchers is equitable.

2. **Among examples of existing Federal collaborations with (a) Tribal, territorial, local, and State governments or (b) local communities involving equitable data, what lessons or best practices have been learned from such collaborations?**

A central lesson we have learned is the importance of engaging with communities in our use and interpretation of data. Administrative data systems are developed and implemented by those in power to serve operational needs, and may not reflect the interests and priorities of the communities they serve. Data may not be comprehensive and data quality can be low when the structure, language, and method of data collection is tailored only to a homogenous group.

Engaging with communities on additional, more meaningful data collection and analysis is necessary. For example, continuing the DASHH example above, we can identify behavioral health conditions as high-prevalence among KCHA recipients of housing subsidies, but to identify effective interventions, we need more information to understand causes and what the community and individuals desire for potential solutions. Otherwise, we run the risk of offering programming nobody uses. In 2020, KCHA operated a pilot program referring residents to behavioral health services, but program uptake was low, due in part to the pandemic but also due to a mismatch with community preferences, which could have been revealed earlier if residents were engaged in a collaborative meaning-making process around the data analysis and if residents were a partner in the program design.

3. **What policies, resources, programs, training, or other tools can facilitate increased data sharing between different levels of government (Tribal, territorial, local, State, or Federal) around equitable data?**

Data sharing takes time and specialized skillsets. Government agencies need sufficient staffing—

managers, facilitators, programmers, and analysts—to develop data sharing agreements and policies around data security and the protection of personally identifiable information; extract, transfer, clean, analyze, visualize, and report on the data; and communicate with government, research, and community partners all along the way. Appropriate hardware and software are needed—fast processing speeds to handle large datasets and complex analytics, and increasingly sophisticated statistical and dashboard applications. Training in data visualization and equitable evaluation is also important.

Obtaining sufficient resources for this work is challenging; it is not part of core administrative budgets for public housing authorities. KCHA is a "Moving to Work" agency, which means that we have more flexibility in allocating staffing resources than most public housing authorities, enabling us to maintain a small research and evaluation team that participates in DASHH and other collaborative efforts (such as Creating Moves to Opportunity (https://opportunityinsights.org/paper/cmto/). We have also obtained private funding to support this team, whose work informs, improves, and impacts not only KCHA but also the national policy landscape. Including funding for data sharing in core administrative budgets is necessary to make all public entities able to participate in data collaborations and enhance transparency and accountability of the full breadth of public services.

4. **What policies, resources, programs, training, or other tools can expand opportunities for historically underrepresented scholars and research institutions to access and use equitable data across levels of government?**

It is important to consider power imbalances and cultural constraints when designing funding opportunities, which should be aimed to build internal capacity within historically underrepresented scholars and research institutions. Funding opportunities should include robust and diversified outreach activities, which would help engage underrepresented researchers and improve access to equitable data.

5. **What policies, resources, programs, training, or tools can increase opportunities for community-based organizations to use equitable data to hold government accountable to the American public?**

It is beneficial to formulate a clear theory of change that makes a link between the impacts of community based organizations (CBOs) and accountable and transparent practices within government. Government funding opportunities should increase funding to CBOs that will allow them to build internal capacity to develop and implement evaluation practices and provide external (publically available) equitable data for ongoing collaboration and accountability.

6. What policies, resources, programs, training, or tools can make equitable data more accessible and useable for members of the public?

It can often be difficult to initiate the process of data-sharing, particularly for small agencies with no in-house expertise. Making available model data-sharing agreements and technical assistance would be helpful for local government entities just getting started.

Providing resources/staff capacity to develop layperson-friendly communication products and explain results in person is just as important as the technical data analysis work. KCHA's research & evaluation team spends time translating technical research articles into brief summaries and holding "lunch & learns" to discuss results with staff. They also develop dashboards with visual data displays and presentations that translate findings into examples of potential programmatic and policy responses to increase uptake and impact from data collaborations.

MITRE's Response to the OSTP RFI on Equitable Data Engagement and Accountability

October 3, 2022

For additional information about this response, please contact:
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[redacted]

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About MITRE

MITRE is a not-for-profit company that works in the public interest to tackle difficult problems that challenge the safety, stability, security, and well-being of our nation. We operate multiple federally funded research and development centers (FFRDCs); support public-private partnerships across national security and civilian agency missions; and maintain an independent technology research program in areas such as artificial intelligence, intuitive data science, quantum information science, health informatics, policy and economic expertise, trustworthy autonomy, cyber threat sharing, and cyber resilience. MITRE's 9,000-plus employees work in the public interest to solve problems for a safer world, with scientific integrity being fundamental to our existence. We are prohibited from lobbying, do not develop or sell products, have no owners or shareholders, and do not compete with industry. Our multidisciplinary teams (including engineers, scientists, data analysts, organizational change specialists, policy professionals, and more) are thus free to dig into problems from all angles, with no political or commercial pressures to influence our decision making, technical findings, or policy recommendations.

Good data is essential for making well-informed decisions, managing organizational costs and benefits, innovating, and successfully achieving mission outcomes—which includes ensuring that "government programs and policies yield consistently fair, just, and impartial treatment of all individuals."[1] MITRE not only supports Chief Data Officers throughout the federal government as they develop and implement their data strategies and governance programs, but also has direct experience assisting federal agencies leverage other government and private-sector data to meet critical mission needs. Per the Federal Acquisition Regulation, FFRDCs can have unique access to both sensitive government data and proprietary private-sector data—and both the government and the public sector have regularly trusted MITRE to manage third-party access and leveraging of their data. Multi-party collaboration on ethical data collection, protection, access, and usage is fundamental to our work in this space.

Introduction and Overarching Recommendations

An overarching observation from this RFI and the administration's prior document, *A Vision for Equitable Data,* is the assumption that equitable data has already been collected and efforts can thus be predominantly focused on access and use. In practice, however, these aspects aren't isolated events, but are rather interconnected aspects that both follow the collect-access-use progression and contain feedback loops such that insights gained from access and use will impact future collection activities. As such, MITRE recommends that the community's work on this equitable data topic be more holistically scoped and coordinated to drive the impacts desired.

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[1] A Vision for Equitable Data: Recommendations from the Equitable Data Working Group. https://www.whitehouse.gov/wp-content/uploads/2022/04/eo13985-vision-for-equitable-data.pdf

Questions Posed in the RFI

1. What are examples of successful collaborations involving equitable data between the Federal government and (a) Tribal, territorial, local, and State governments, or (b) local communities?

This Administration encouraged the use of American Rescue Plan funds to support Tribal, territorial, local, and state (TTLS) data infrastructure and expanding reporting requirements for disaggregated data collection across key programs as a part of funding activities to institutionalize expectations for allocating resources and assessing equity at the state and local levels. "Agencies and program offices will need to invest in the statistical, evaluation, and data science expertise necessary to design and conduct robust equity assessments using their administrative data, consistent with the Foundations for Evidence-Based Policymaking Act of 2018 ('Evidence Act') and the Equity EO."[2] TTLS agencies can collaborate on equitable data through policies and standards that encourage transparency in allocation of resources.

Related lessons learned from the administrative equity assessment and evaluation activities undertaken by state and local levels on equitable data include:[3]

- Establish policies and standards for administering funding and supporting administrative costs to design equitable project data collection, evaluation, and analysis systems and structures that target underserved communities and create opportunities for those who have been systematically excluded in the past.
- Support program evaluation and evidence-based resourcing, such as: data analysis resources to gather, assess, and share equity data; develop shared equitable data infrastructure; encourage community outreach and engagement activities for TTLS governments.

State data centers (SDCs) are the official representatives for the Census State Data Center Program.[4] The value added by SDC members includes enhancing Census data with other information, such as economic statistics or population forecasts, which may be produced in-house or come from sources other than the Bureau. Combining and interpreting Census data with other key measures is a value SDC members provide to the public. Census data helps inform funding and community programming and can be used to inform business strategy, support advocacy efforts, and better understand neighbor characteristics and resources, including equitable data such as race, age, and sex. The U.S. Commission on Civil Rights has found that "data collection and reporting are essential to effective civil rights enforcement, and that a lack of effective civil rights data collection is problematic."[5] SDCs can support community, researchers, advocates, and policymakers with access to disaggregate data and identify disparate impacts of government programs and services for diverse population groups.

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[2] Ibid.

[3] Ibid.

[4] State Data Center Clearinghouse. 2022. Census Bureau, https://www.census.gov/about/partners/sdc/related-sites.html. Last accessed September 28, 2022.

[5] Are Rights a Reality? 2019. U.S. Commission on Civil Rights, https://www.usccr.gov/files/pubs/2019/11-21-Are-Rights-a-Reality.pdf.

2. Among examples of existing Federal collaborations with (a) Tribal, territorial, local, and State governments or (b) local communities involving equitable data, what lessons or best practices have been learned from such collaborations?

Lesson Learned: Adding lived experience narratives in equitable data collections is critical.

The Treasury's Community Development Financial Institutions (CDFI) fund "plays an important role in generating economic growth and opportunity in some of our nation's most distressed communities."[6] To help support overall program investment and management activities, the CDFI fund has been collecting equitable data from several sources, including the U.S. Census, Federal Reserve Economic Data, Statistics of U.S. Businesses, the Consumer Financial Protection Bureau, Esri, and the U.S. Department of Agriculture Economic Research Service. The CDFI fund is using this equitable data to better understand the distribution of disability concentrations, SNAP benefits, unemployment, household burden, subprime credit populations, housing prices, food deserts, and housing availability for low-income communities.

To support the Treasury's Learning Agenda[7] goal to assess the impact of the CDFI investments to alleviate poverty, an open question emerged around whether existing equitable data provided sufficient causal insights into the factors driving persistent poverty. MITRE's analysis found that the diversity of communities is shaped by a variety of formative experiences and distinct contemporary environments. This analysis hints at complexities beyond the underlying patterns of poverty, which are not fully appreciable by purely statistical methodologies and existing equitable data sources. MITRE found that additional information from the local communities that were the ultimate recipients of these funds clarified the analysis. See **Error! Reference source not found.** in the appendix for a categorization of additional equitable data elements derived from qualitative interviews.

Lesson Learned: Predictive models incorporating community voices enable proactive interventions to address equity issues before they emerge or are exacerbated.

MITRE further analyzed this issue for CDFI and created a four-step model for deriving insights from an inductive "bottom-up" approach (see **Error! Reference source not found.** in the appendix). This includes designing participatory and qualitative research methods to include the voices of people with low income and the realities (barriers) of their lives into CDFI research, as well as developing data dashboards to explore poverty patterns and anticipating and proactively supporting downward trending communities before they become PPCs. A similar, but more generic, model could be developed for broader equitable data collections.

Lesson Learned: Usable and accessible visualizations/dashboards enable more, and more diverse, stakeholders to engage with data.

Uploading equitable data into accessible, interactive, web-based dashboards can help bring both the federal and local communities together under a common umbrella. This helps:

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[6] What Does the CDFI Fund Do? 2022. Department of Treasury, https://www.cdfifund.gov/. Last accessed September 23, 2022.

[7] FY 2022-2026 Department of the Treasury Learning Agenda. 2021. Department of the Treasury, https://home.treasury.gov/system/files/266/Treasury-FY2022-2026-LearningAgenda.pdf.

- Federal agencies and other stakeholders better understand the unique milieu of barriers within each community and use that knowledge to design integrated solutions
- Local communities find other communities like their own and identify what lessons they may be able to learn from one another that can lead to better outcomes

See **Error! Reference source not found.** in the appendix for an example of a MITRE-developed equitable data web dashboard.

Lesson Learned: Sharing promising practices and standards for equitable data sharing among practitioners and users bolsters the impact of equity-improving efforts.

MITRE's qualitative analysis uncovered additional data elements that mapped into the equitable data framework (see **Error! Reference source not found.**). TTLS governments—having learned and applied strategies in connection with their federal funding allocations—can apply these data elements to address equity throughout all their operations. Further, TTLS entities can share standards on successful equity strategies and best practices to include items such as:

- Data infrastructure
- Equity assessments
- Equity evaluation methods and tools
- Goal setting
- Identifying high-need populations
- Engaging underserved communities so people can have a voice in their own future
- Collecting performance data to track progress toward advancing equitable outcomes

3. What resources, programs, training, or other tools can facilitate increased data sharing between different levels of government (Tribal, territorial, local, State, or Federal) related to equitable data?

MITRE suggests that three resources can facilitate increased data sharing among different levels of government, historically underrepresented scholars and research institutions, community-based organizations, and the public: (1) MITRE's deliberately inclusive and stakeholder-driven set of tools and approaches supporting data-sharing partnerships in the Public-Private Partnerships Accelerator Toolkit (P3TK); (2) the MITRE Social Justice Platform's Fairness, Agency, Inclusion, and Representation (FAIR) Framework for designing research on equity data focused on the lived experiences of individuals within communities; (3) outreach, training, and program-driven adoption by TTLS of equity data and data standards embodied in federal workplace surveys.

P3TK. Because the data that can best address a given topic (e.g., how well government programs and policies serve different populations) often comes from multiple sources, MITRE sees analogies to considerations within data-sharing partnerships. Based on its experiences shaping and supporting data-sharing partnerships, MITRE created P3TK for general use in accelerating successful collaboration among the affected/interested parties and has applied P3TK in supporting a variety of partnerships. One example is the Identity Theft Task Refund Fraud (IDTTRF) Information Sharing and Analysis Center (ISAC). The ISAC involves collaboration among federal and state agencies, tax return preparation companies, and others to proactively mitigate issues with multi-sourced data, which disproportionately affects taxpayers with lower income. Through secure data sharing, the social harm of IDTTRF is ameliorated—the IRS Commissioner has noted that "thousands of taxpayers were protected from victimization as a result of the efforts of the ISAC Partnership."[8] The P3TK resource advocates for collaboration predicated on principles of trust-building, transparency, representation, and partner-driven design and operation including shared decision making. P3TK also offers practical guidance to address interagency and cross-sector collaboration; governance and protocol for collaboration; ethics, principles, agreements, and legal compliance; and other topics relevant to the affected entities (partners) actively co-designing and cooperating on their data-sharing initiative.

FAIR. While innovation and collaboration can unlock the benefit of data sharing, including community voices is crucial for improving data integrity and producing equitable, sustainable solutions (see the lesson learned in Question 2, above). When local communities share their lived experiences—knowledge, beliefs, patterns, and expectations encapsulated within daily living and cultural norms that go beyond pure quantitative statistical data—that drives better understanding of the causal factors and outcomes that should be the focus of the data-centric research and/or collaboration to improve government program design. To that end, MITRE's FAIR Framework designs equity into data sharing and analysis collaboratives through community voices and systems thinking. Since data sharing doesn't happen simply because one wants it to, the FAIR Framework provides a new way to encourage data sharing so that it is driven by stakeholders' perspectives of the problems/solutions. Without FAIR, data sharing may have limited participation/adoption and resulting models may be theoretically accurate but realistically ineffective or inequitable.[9]

The FAIR Framework is a systematic methodology that enables qualitative and quantitative research on structural factors—such as poverty, health, education, and employment—that may drive inequality. FAIR integrates community voices to identify and explore the architecture of disparities and the design of equity. This helps clarify the structural elements that lead to a community's experience of inequity or adverse outcomes such as persistent poverty or health disparities. FAIR captures factors impacting people's daily lives and identifies data and models that would have otherwise remained unanticipated and hidden to those outside of the impacted community. This approach also allows researchers to uncover unconscious biases and assumptions.

By using resources and tools like P3TK and FAIR, data sharing—across levels of government, among historically underrepresented researchers, and with community-based organizations—is foundationally accelerated and enhanced. These methods help stakeholders tangibly experience seeing themselves in, actively contributing to, and deriving benefit from the data-sharing work. This kind of practical, stakeholder-driven approach to data sharing results in substantially increased buy-in, higher levels of participation (more, and more diverse, entities actively

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[8] Security Summit. 2021. Internal Revenue Service, https://www.irs.gov/newsroom/security-summit. Last accessed September 28, 2022.

[9] FAIR Framework: Designing Equity through Community Voices and Systems Thinking. 2022. MITRE, https://sjp.mitre.org/insights/60f1e225b1d934001a56df51. Last accessed September 28, 2022.

contributing to the work), and more impactful and equitable outcomes (due to the power of more data from so many perspectives, inclusion of community voices, and strengthened collaboration).

Federal survey standards. The federal government should support TTLS government adoption of federal surveys, such as the Federal Employee Viewpoint Survey[10] that measures diversity, equity, inclusion and accessibility (DEIA) and the Government Pulse Survey,[11] through investment in awareness and usage training and programs that connect adoption to grant performance and budgets. These surveys collect information on historically underrepresented groups providing further segmentation and targeting decision making and investments in more equitable ways. Increased adoption of these established questionnaires will lead to a greater set of survey results data available for federal and TTLS government, historically underrepresented scholars and research institutions, and community organizations to use. Adoption of federal survey standards will also promote clear and consistent indicators of inclusion and equity at state and local levels and related benchmarking, informing investments and interventions. Further, adopting consistent measurement approaches promotes transparency and increases trust in government practices and services.

4. What resources, programs, training, or other tools can expand opportunities for historically underrepresented scholars and research institutions to access and use equitable data across levels of government?

The examples provided for Question 3 also apply for this community. MITRE also recommends the federal government expand historically underrepresented scholars' and research institutions' access to/adoption of three data resources—Census Bureau, EEOC, and Department of Labor data—through targeted training and outreach programs. As shown by loci of researchers proximal to national laboratories, when agencies deliberately partner with entities (e.g., providing access to data, knowledge about that data, analytic and subject matter expertise, funding scholarships and grants) to foster the entity's expertise in an area, that local investment in talent and capabilities pays dividends for decades to come through workforce development, knowledge sharing (e.g., publications), innovation, and economic growth.

An issue for historically underrepresented scholars beyond access is limited knowledge and experience with equitable research practices and sources, including training on SDC data and methodologies and practices to support equity assessment for policymaking and program implementation. Educational programs that build knowledge and skills in evaluation and data analysis of TTLS data sources would be beneficial.

5. What resources, programs, training, or tools can increase opportunities for community-based organizations to use equitable data to hold government accountable to the American public?

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[10] Governmentwide Management Reports. 2022. Office of Personnel Management, https://www.opm.gov/fevs/reports/governmentwide-reports/. Last accessed September 28, 2022.

[11] Government-Wide Pulse Survey Pilot. 2022. General Services Administration, https://d2d.gsa.gov/report/government-wide-pulse-survey-pilot. Last accessed September 28, 2022.

The examples provided for Question 3 also apply to community-based organizations.

6. What resources, programs, training, or tools can make equitable data more accessible and useable for members of the public?

The CDFI example in response to Question 2 and the examples provided for Question 3 also apply here. In addition, MITRE recommends that National Science Foundation invest in cloud environments that could be shared among the stakeholder segments (e.g., historically underrepresented researchers, the public) noted in this RFI to boost access to equitable data, and as suggested for artificial intelligence in the Open Knowledge Network Roadmap.[12]

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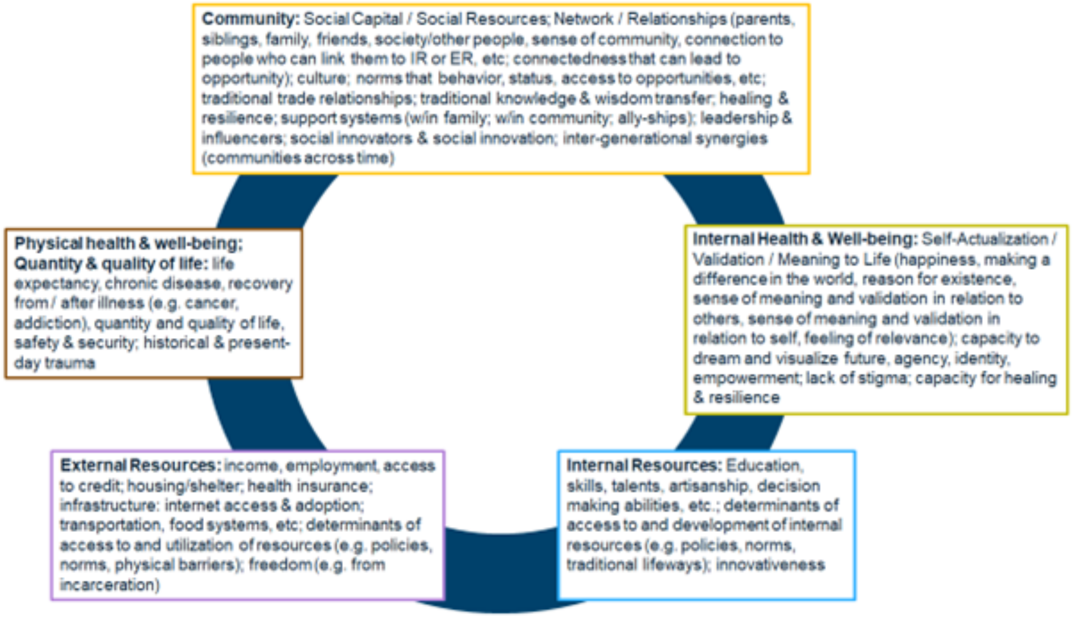
[12] Open Knowledge Network Roadmap: Powering the Next Data Revolution. 2022. National Science Foundation, https://nsf-gov-resources.nsf.gov/2022-09/OKN%20Roadmap%20-%20Report_v03.pdf.

Appendix – Illustrations



Community: Social Capital / Social Resources; Network / Relationships (parents, siblings, family, friends, society/other people, sense of community, connection to people who can link them to IR or ER, etc; connectedness that can lead to opportunity); culture; norms that behavior, status, access to opportunities, etc; traditional trade relationships; traditional knowledge & wisdom transfer; healing & resilience; support systems (w/in family; w/in community; ally-ships); leadership & influencers; social innovators & social innovation; inter-generational synergies (communities across time)

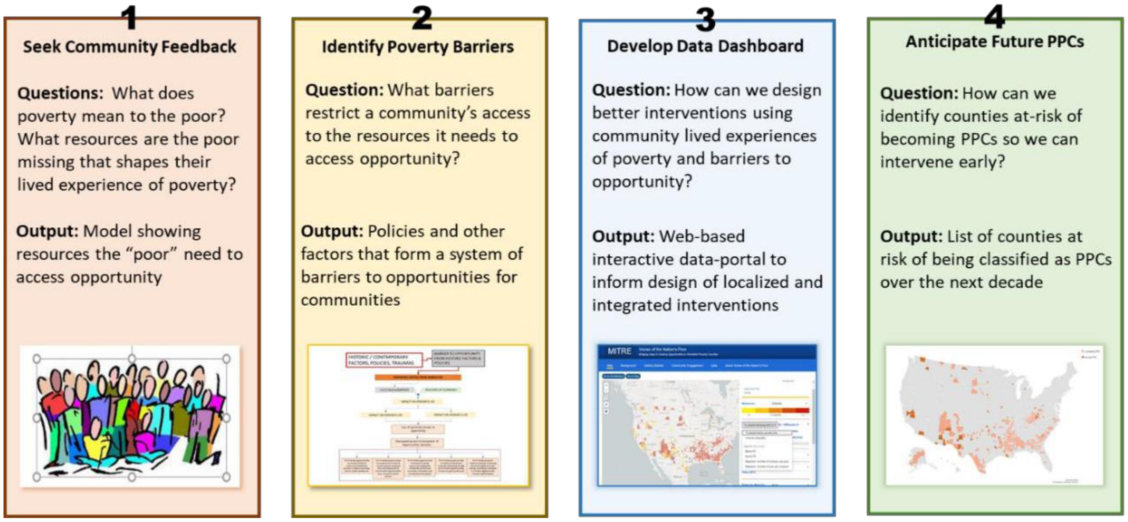
Physical health & well-being; Quantity & quality of life: life expectancy, chronic disease, recovery from / after illness (e.g. cancer, addiction), quantity and quality of life, safety & security; historical & present-day trauma

Internal Health & Well-being: Self-Actualization / Validation / Meaning to Life (happiness, making a difference in the world, reason for existence, sense of meaning and validation in relation to others, sense of meaning and validation in relation to self, feeling of relevance); capacity to dream and visualize future, agency, identity, empowerment; lack of stigma; capacity for healing & resilience

External Resources: income, employment, access to credit; housing/shelter; health insurance; infrastructure: internet access & adoption; transportation, food systems, etc; determinants of access to and utilization of resources (e.g. policies, norms, physical barriers); freedom (e.g. from incarceration)

Internal Resources: Education, skills, talents, artisanship, decision making abilities, etc.; determinants of access to and development of internal resources (e.g. policies, norms, traditional lifeways); innovativeness

Figure 1. Equitable data types derived from community interviews. Reproduced from "Voices of the Nation's Poor – A Proposed Methodology to Improve Outcomes for Persistent Poverty Counties," MITRE Technical Report MTR210506, September 2021.



1 **Seek Community Feedback**

Questions: What does poverty mean to the poor? What resources are the poor missing that shapes their lived experience of poverty?

Output: Model showing resources the "poor" need to access opportunity

2 **Identify Poverty Barriers**

Question: What barriers restrict a community's access to the resources it needs to access opportunity?

Output: Policies and other factors that form a system of barriers to opportunities for communities

3 **Develop Data Dashboard**

Question: How can we design better interventions using community lived experiences of poverty and barriers to opportunity?

Output: Web-based interactive data-portal to inform design of localized and integrated interventions

4 **Anticipate Future PPCs**

Question: How can we identify counties at-risk of becoming PPCs so we can intervene early?

Output: List of counties at risk of being classified as PPCs over the next decade

Figure 2. Four ways to expand and enrich community-centered equitable data research. Reproduced from "Voices of the Nation's Poor – A Proposed Methodology to Improve Outcomes for Persistent Poverty Counties," MITRE Technical Report MTR210506, September 2021.

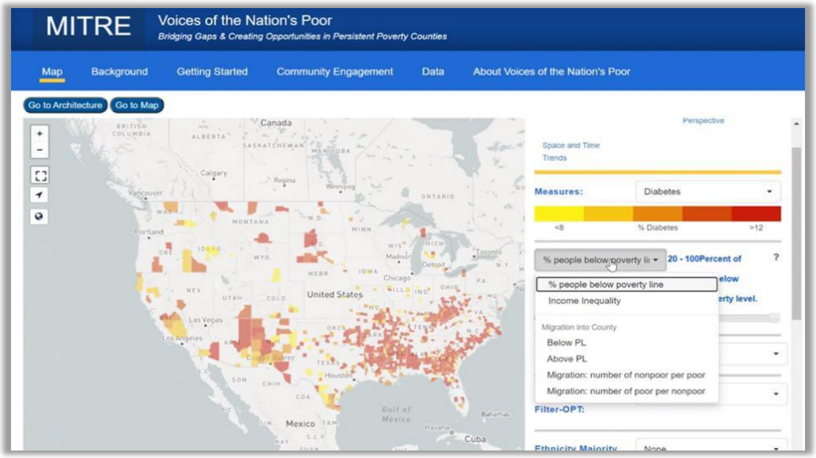


Figure 3. MITRE "Voices of the Nation's Poor" web-based equitable data dashboard. Reproduced from "Voices of the Nation's Poor – A Proposed Methodology to Improve Outcomes for Persistent Poverty Counties," MITRE Technical Report MTR210506, September 2021.

URBAN
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October 3, 2022

Denice Ross
NSTC Subcommittee on Equitable Data
Office of Science and Technology Policy
Eisenhower Executive Office Building
[redacted]
Washington, DC 20504

RE: Engagement and Accountability RFI

To Whom It May Concern:

We write to offer public comment on the request for information published on August 30, 2022 (2022-19007). We are employed by the Urban Institute—a nonprofit research and policy organization based in Washington, DC—but we are presenting our own views and the views shared in this response do not reflect the Urban Institute, its trustees, or its funders.

The federal government has entered a promising period of advancing a whole-of-government equity agenda that prioritizes equitable data as a guiding force of this effort. Urban Institute researchers have produced a substantial body of work to change the norms and practices of data use to advance equity.

This submission contains responses to each of the seven questions in the request for information. For questions or to request a follow-up dialogue or discussion based on this response, please contact Jonathan Schwabish, Senior Fellow, a [redacted] nd Amy Elsbree, Associate Vice President for Communications, a [redacted]

1. **What are examples of successful collaborations between the Federal government and (a) Tribal, territorial, local, and State governments or (b) local communities involving equitable data?**

   - Coordinated by the Urban Institute, the National Neighborhood Indicators Partnership (NNIP) is a learning network of independent partner organizations in more than 30 cities that strives to ensure all communities have access to data and the skills to use information to advance equity and well-being across neighborhoods. The network documented several cases of our local members collaborating with grantees implementing federal place-based initiatives during the Obama era, including Choice Neighborhoods (St. Louis), Promise Neighborhoods (San Antonio and Washington DC), and Sustainable Communities (Kansas City). NNIP partners provide assistance in data collection, interpretation, and dissemination that help the planning, program management, and reporting in these and other cities. There are many other examples (e.g., the Department of Justice Byrne Grant), and several partners (e.g., Indianapolis, Hartford, and Philadelphia) continue to support Promise Neighborhoods.
   - We recommend looking at the lessons learned on using data for equitable outcomes from both the Promise Neighborhood Initiative and the Sustainable Communities Initiative. For one reflection, see the essay "New Ways of Using Data in Federal Place-Based Initiatives: Opportunities to Create a Results Framework and to Raise the Visibility of Equity Issues" by Victor Rubin and Michael McAfee in the edited volume *What Counts: Harnessing Data for America's Communities*. The Urban Institute has provided technical assistance and produced

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valuable guides and tools in supporting the Promise Neighborhoods grantees in using data to improve outcomes for children and youth over the past several years.

- As one example of a federal program that invests in both data access and capacity, the U.S. Department of Health and Human Services Office of Minority Health made grants in two communities to help people access and use data to reduce health disparities and inequities. One grantee, Community Information Now (CI:Now) in Bexar County, Texas (San Antonio), the local NNIP partner, is integrating data on health outcomes with subcounty data on social determinants of health such as income, education, and housing. The grant will support the design of an online data portal that makes it easy for both beginner and advanced data users to access the data. The grant also supports outreach, training, and technical assistance to help people understand and use the data. Core partners in the grant include The Health Collaborative, the C3HIE health information exchange, the San Antonio Metropolitan Health District, and the City of San Antonio Information Technology Services Department.

2. **Among examples of existing Federal collaborations with (a) Tribal, territorial, local, and State governments or (b) local communities involving equitable data, what lessons or best practices have been learned from such collaborations?**

   - *Making a Difference with Data: NNIP and Federal Place-Based Initiatives* summarizes the findings from the National Neighborhood Indicators network. We found that the collaborations with locally embedded institutions with data capacity were successful because they brought the combination of mission alignment, technical skills, community engagement experience, and local knowledge.
   - Among the many recommendations in the Urban Institute's recent *Do No Harm Guide: Additional Perspectives on Data Equity* report is the research communities' practice of taking from people and communities without providing any benefits back to the communities. The various authors of that report make several recommendations on how to engage in better and more constructive ways with underrepresented groups and communities including building stronger relationships between the research team and community; weaving consent into every step of the research process; including community and representatives in data interpretation; and learn the community's history and humanize the data.

3. **What policies, resources, programs, training, or other tools can facilitate increased data sharing between different levels of government (Tribal, territorial, local, State, or Federal) around equitable data?**

   - HHS/OPRE has contracted with Urban to create a series of "equity consultations" with their research and evaluation staff. One team participating in the workshop series is their Division of Data Improvement. This series can serve as a tool to ensure that everyone involved with data throughout the data life cycle is trained in centering equity in their goals, processes, and systems. A portion of this work focuses on considerations around data sharing.
   - The National Center for Education Statistics, Bureau of Labor Statistics, the World Bank, and other groups have convened advisory groups consisting of people across multiple sectors to provide specific guidance and advice on different aspects of their work. Such external advisory boards can serve to provide additional equity-focused perspectives on data sharing, data analysis, data communication, and more.
   - The Statistics of Income (SOI) Division of the Internal Revenue Service collects and curates a trove of tax data, which could offer enormous value for assessing equity impacts. SOI limits access to the raw data while publishing a public-use file for broader use, which is becoming increasingly difficult to protect. Urban researchers and data scientists are partnering with SOI to produce synthetic data that represent the statistical properties of the administrative data while protecting taxpayer privacy. Urban researchers have also built a prototype validation

server that would allow researchers to perform statistical analyses on the unaltered administrative data, using programs they develop and test using the synthetic data, without ever revealing confidential information.

- More generally, researchers and analysts need to make a greater commitment to honor and respect data provided by underserved and underrepresented people and communities. There are countless stories of researchers being invited into people's homes and communities, relying on them to provide data and insights, and violating that trust. Researchers, who stand to benefit from the work, too often employ paternalistic practices that erase identities and perpetuate harmful stereotypes. See the Urban Institute's recent Do No Harm Guide: Additional Perspectives on Data Equity, for more examples, details, and recommendations.

4. **What policies, resources, programs, training, or other tools can expand opportunities for historically underrepresented scholars and research institutions to access and use equitable data across levels of government?**

   - A lack of engagement with community members and people represented in state and local data systems has resulted in a lack of trust and rightful opposition to data efforts that are not transparent and inclusive. With a focus on building trust with communities for data use, the public and social sectors can apply data to make programs and policies more ethical, effective, and sustainable. The *Envisioning a New Future: Building Trust for Data Use* framework outlines four broad ways to build trust: enact and refine laws and regulations related to data; apply technical solutions to expand and control data access; increase community data capacity; and establish and enhance governance for data and data systems.

   - NNIP has developed eight goals for the network to improve the use of data in advancing racial equity. Our network has been collecting examples of how to operationalize them and supporting the community of practice in improving how we provide community data services. We have found it productive to collect in one place the various aspects of both process and outcome and of both internal organizational culture and external relationships to see the intersections and different paths to more equitable data practice.

   - Trainings and technical assistance for community-based organizations and individuals to engage with data. Urban's Community-Engaged Methods Resource Center is designing a training based on existing components and materials Urban staff created for various participatory research projects at the federal, state, and local levels. Across a series of yet-unreleased projects, Urban researchers are exploring the barriers different community organizations that serve communities of color face when applying for federal grants including lack of representative data, burdensome reporting and budgeting requirements, and institutional challenges of being smaller organizations.

   - The 2022 National Academies report, *Measuring Sex, Gender Identity, and Sexual Orientation*, details specific, actionable recommendations for ways to collect data on gender and sexuality in more actionable and useful ways.

5. **What policies, resources, programs, training, or tools can increase opportunities for community-based organizations to use equitable data to hold government accountable to the American public?**

   - The Urban Institute's Elevate Data for Equity webpage curates lists of resources on building community data capacity, as well as equitable data practice. It also features two briefs designed to support researchers and communities working towards more equitable data practice.

     i. Local philanthropy has an important role in facilitating community capacity to use data on their own behalf, including holding their governments accountable. The first brief, *Investing in Data Capacity for Community Change*, makes the case for why local foundations should invest in community data capacity, as well as different paths for how they can invest.

    ii. The second brief, *Principles for Advancing Equitable Data Practice*, introduces the Belmont Report's principles and provides related practices and resources to help data experts at all levels integrate the principles into their work and move toward more equitable data practice.

- In Urban's August 2022 report, *Lessons from Local Leaders: How Federal Agencies Can Help Ensure Data-Driven and Equity-Centric Infrastructure Investment*, we heard that easing subcontractor flow-down provisions would make it easier for community-based organizations to partner with local agencies for grant applications and have an official seat at the table.

  Federal agencies should provide more detailed guidance in grant language about how community-based organizations can become involved from the outset in a project proposal, including who is eligible to receive funding and who is eligible to be listed as a partner on a grant application, what partnership structures could look like, what types of activities community-based organizations could lead, and how to start conversations with local agencies to propose collaborations.

6. **What policies, resources, programs, training, or tools can make equitable data more accessible and useable for members of the public?**

- Urban's September 2022 report, *Advancing Racial Equity through Federally Funded Public Transit, Bicycle, and Pedestrian Projects*, is a guide for local actors applying to federal funding in the transportation space (a webinar featuring the guide's lead author can be viewed here). We expect that resource to help fill an important gap in this space. Specifically, the guide will

    i. provide six categories of data sources and tools to help applicants make evidence-informed project selection decisions and answer key questions related to racial equity; and
    ii. demonstrate how these indicators can address key priorities in bike, pedestrian, and public transit funding opportunities, using application criteria from competitive grants funded under the Bipartisan Infrastructure Law. The guide focuses on these modes of transportation due to inequities in who benefits and suffers from traditional car-centric investment.

- The Spatial Equity Data Tool enables nontechnical audiences to easily assess the racial, economic, and geographic disparities present in user-uploaded data to identify if resources are equitably distributed and the datasets used in decisionmaking are representative. In seconds, the tool performs analyses that would have previously been prohibitively expensive, such as comparing representativeness over time, across policy domains, and even across jurisdictions. The tool is a valuable resource for government officials tasked with allocating resources, advocacy organizations measuring progress toward equity goals, and members of the public seeking to advance more equitable distribution of resources in their communities. Since its launch in October 2020, the tool has been widely used by policymakers at all levels of government as well as by members of the public to examine the placement of traffic cameras, the distribution of child care centers, and the locations of new construction, among many other uses.

- The Urban Institute's *Do No Harm Guide* series (two reports are currently available with additional materials forthcoming in the coming months) provides a number of lessons on how to collect, analyze, share, and communicate data more equitably and inclusively. The first *Do No Harm Guide* focuses on several specific, practical ways people working with data can be more equitable in their work including be cognizant of the language that is used to describe people and communities; consider how demographic data are collected in surveys in terms of order and answer options; take an equitable approach to ordering results; and take an equitable perspective when using colors and icons in data visualizations.

- As outlined by the RFI, one key characteristic of equitable data is that it is disaggregated by demographic information, geographic information, or other variables that enable insights on disparities in access to, and outcomes from, government programs, policies, and services. One key impediment to accessing equitable data is the lack of sufficiently disaggregated data—particularly a lack of data disaggregated by race and ethnicity. For example, such information is missing in credit bureau data, which has inhibited efforts to examine how credit scores affect racial homeownership gaps and to challenge the use of credit screens in hiring. Imputation is a powerful tool for expanding access to equitable data by appending racial and ethnic identifiers onto datasets lacking that information. Although failing to disaggregate data by race and ethnicity can pose considerable harm to Black people, Indigenous people, and other people of color, efforts to fill data gaps using imputation can risk the same or even greater harm, particularly if done without a proactive focus on equity. Urban has produced resources outlining standards and recommendations for the field on how to ethically and empathetically use imputation to disaggregate data for racial equity as well as a case study providing actionable guidance for analysts and data users.

- In other cases, sufficiently disaggregated data may exist but are not made publicly available to protect the privacy of individuals in the data. For example, in our research on equitable use of data and technology in cities, we learned that many cities default to keeping their administrative assets private as they don't have the in-house capacity to use data privacy tools like synthetic data to release disaggregated data that preserves resident privacy. Urban is partnering with Allegheny County on a pilot to apply Urban's expertise in safe data technologies to help them release disaggregated human service utilization data. We are also developing resources and trainings to help other localities use these data privacy methods to responsibly expand the amount of equitable data they make available to the public.
- Data, data visualizations, and government content should be made accessible to everyone. Content creators need to be mindful of the needs of people with vision, physical, intellectual, and other disabilities. It is a fundamental human right to have equal access to information and, to date, data and data-related content more often than not fails to provide content equitably. To date, the federal 508 compliance guidelines are implemented differently and inconsistently across government agencies.
- By some estimates, there are between 350 and 450 languages spoken across the United States. Data and data-related content provided in only two languages (e.g., English and Spanish) therefore excludes a large swath of Americans. Further, when it comes to collecting data around gender and sexuality, direct translation to other languages is not straightforward—for example, see the National Academies of Sciences report, *Measuring Sex, Gender Identity, and Sexual Orientation*. Additional research and guidance on these issues is necessary to be more equitable and inclusive to a broader audience.

7. **In which agencies, programs, regions, or communities are there unmet needs, broken processes, or problems around participation and accountability that could be remedied through stronger collaborations and transparency around equitable data?**

   - Urban's report, *Lessons from Local Leaders: How Federal Agencies Can Help Ensure Data-Driven and Equity-Centric Infrastructure Investment* described three ways in which these goals could be met:
     i. Community engagement on Infrastructure Investment and Jobs Act grants in the transportation and brownfields spaces (i.e., grants administered by DOT and EPA) was often treated as perfunctory. Community meetings were not always inclusive or representative, and community feedback and priorities were typically not incorporated throughout the life cycle of a project.
     ii. Many local actors we spoke with reported a lack of federal guidance on methodologies that attempt to quantify the racial equity and environmental justice impacts of their projects. They feared backlash from taking creative approaches with equitable data on their applications. Other Urban research, including a recent comprehensive review of The Rockefeller Foundation's 100 Resilient Cities program, highlights the variety of challenges

    local city planners and managers face to make their areas resilient in the face of "chronic stresses and acute shocks."

    iii. Many applicants did not have the time and capacity to access and analyze equitable data to build application narratives and called for increased federal investment in local data infrastructure, grant writing support, and technical assistance.

- Perhaps now more than ever, there is a greater need to fill wholesale data gaps within and between government agencies, especially as they relate to underrepresented groups and communities. There is a lack of centralized data systems to collect and analyze data for certain groups, especially Tribal nations. Uniform processes do not yet clearly exist to help agencies or other groups equitably collect and classify people along various demographic characteristics and their intersections, including race, ethnicity, gender, and sexuality. Urban's recent report, *Do No Harm Guide: Additional Perspectives on Data Equity*, highlights the experiences of these and other underrepresented groups in the data and data communication spaces.

We thank our colleagues Elsa Falkenburger, Alena Stern, John Sankofa, and Rita Ko for their thoughtful review and contributions.

Thank you for your consideration.

Sincerely,

Jon Schwabish
Senior Fellow

Rekha Balu
Co-Vice President, Office of Race & Equity Research

Judah Axelrod
Data Scientist

Kathryn L.S. Pettit
Principal Research Associate

BOSTON
UNIVERSITY
Boston University Center for Antiracist Research

October 03, 2022

Submitted via https://www.regulations.gov

Attn: NSTC Subcommittee on Equitable Data
Office of Science and Technology Policy
Eisenhower Executive Office Building
[redacted] Washington, DC 20504

Re: 87 FR 54269, OSTP Docket No. 2022-19007, Boston University Center for Antiracist Research Response to Request for Information; Equitable Data Engagement and Accountability

Dear Members of the NSTC Subcommittee on Equitable Data:

The Boston University Center for Antiracist Research ("the Center") is a nonpartisan, nonprofit, university-based research center that seeks to devise novel and practical ways to understand, explain, and solve seemingly intractable problems of racial inequity and injustice. We foster exhaustive research, policy innovation, data-driven educational and advocacy campaigns, and narrative-change initiatives to build an antiracist society that ensures equity and justice for all.

The collection and publication of equitable data is a critical aspect of understanding and dismantling racism.[1] The Request For Information describes equitable data as "data that allow for rigorous assessment of the extent to which government programs and policies yield consistently fair, just, and impartial treatment of all individuals, including those who have been historically underserved, marginalized, and adversely affected by persistent poverty and inequality." This includes racial and ethnic demographic data. When governmental agencies and jurisdictions do not comprehensively collect racial and ethnic data or share that data with one another and the public, it is impossible to accurately track and disrupt manifestations of racism.

Data equity thus requires three things: (1) comprehensive racial and ethnic data

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[1] "Executive Order On Advancing Racial Equity and Support for Underserved Communities Through the Federal Government," *White House Briefing Room* (Jan. 20, 2021), www.whitehouse.gov/briefing-room/presidential-actions/2021/01/20/executive-order-advancing-racial-equity-and-support-for-underserved-communities-through-the-federal-government/.

collection, (2) standardization of data collection methods across jurisdictions and levels of government, and (3) public access to that data. The collection of racial and ethnic data helps illustrate where inequities exist; the standardization of data collection allows for comparisons across jurisdictions and levels of government; and the publication of data allows for assessments of the effectiveness–or ineffectiveness–of government programs and policies at mitigating racism.

This comment responds to the Request for Information's questions regarding the improvement of data sharing between levels of government, and public accessibility of equitable data.[2] We offer the following recommendations with the aim of improving the quality and accessibility of racial and ethnic demographic data, so that researchers, advocates, policymakers, and the public can better assess whether government programs and policies promote racial equity or inequity. These recommendations are informed by our prior publications and ongoing research regarding the collection and reporting of data that reveal racial and ethnic inequities.[3]

An Initiative to Support and Encourage the Centralized Management of Equitable Data within Levels of Government in order to Facilitate Data Sharing Across Levels of Government (responding to question #3)

There are four factors that currently inhibit the collection and sharing of equitable data: 1) an undefined data strategy at each level of government;[4] 2) the absence of a point person responsible for coordinating data sharing across levels of government;[5] 3) non-standard operating procedures around data collection and reporting that make it difficult or impossible to compare data

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[2] Office of Science and Technology Policy, "Request for Information; Equitable Data Engagement and Accountability," *Federal Register* (Sept. 2, 2022), www.federalregister.gov/documents/2022/09/02/2022-19007/request-for-information-equitable-data-engagement-and-accountability.

[3] Neda A. Khoshkhoo *et al.*, "Toward Evidence-Based, Antiracist Policymaking: Problems and Proposals For Better Racial Data Collection and Reporting," *Boston University Center for Antiracist Research* (June 2022), www.bu.edu/antiracism-center/files/2022/06/Toward-Evidence-Based-Antiracist-Policymaking.pdf.

[4] Russell T. Vought, "Federal Data Strategy — A Framework for Consistency," Office of Management and Budget (June 4, 2019), www.whitehouse.gov/wp-content/uploads/2019/06/M-19-18.pdf. Provided a mission statement, principles, and practices to provide a government-wide vision for how agencies should manage and use data only at the federal level of government.

[5] Andrew Westrope, "Chief Data Officers in Place in Over Half of U.S. States," *Governing* (Jan. 14, 2020), https://www.governing.com/now/cdos-are-growing-now-more-than-half-of-us-states-have-them.html#:~:text=Evolution%20of%20the%20State%20CDO&text=Of%20the%2022%20states%20that,Oklahoma%2C%20West%20Virginia%20and%20Wisconsin; Domeyer *et al.*, "Government data management for the digital age," *McKinsey & Company* (Sept. 20, 2021), www.mckinsey.com/industries/public-and-social-sector/our-insights/government-data-management-for-the-digital-age.

across jurisdictions;[6] and 4) public officials that have not been trained or prepared to maintain data quality and governance.[7]

As discussed further below, the Office of Science and Technology Policy ("OSTP") could address several of these deficiencies by (1) encouraging the establishment of Chief Data Officers ("CDO") *within* levels of government; and (2) creating an Intergovernmental Council of Chief Data Officers to facilitate communication *across* levels of government.

Encourage the Establishment of Chief Data Officers

One way for the federal government to facilitate the collection, standardization and publication of racial and ethnic data is to encourage the establishment of Chief Data Officers within levels of government.

First, CDOs would be responsible for developing a data strategy that sets forth a vision and plan for how to use data to improve government performance and integrate equitable data into the administration of government programs and policy. A comprehensive data strategy would include collection, reporting, storage, analysis, acquisition, and sharing activities. This strategy would also include a plan for reporting data across levels of government.

Second, CDOs would be responsible for coordinating the execution of their data equity strategies across agencies at their level of government and with other levels of government. They would also be responsible for serving as the central point of contact for executive officials administering programs in furtherance of the data strategy. When executives of different levels of government collaborate on policy decisions or government programs, their respective CDOs would equip them to proceed in a manner that is informed by equitable data.

Third, CDOs would be responsible for implementing uniform data collection and reporting standards – including for racial and ethnic data collection. The current lack of such uniform standards inhibits sharing and comparing data across levels of government. With respect to racial and ethnic data, variations in data collection methods inhibit comparisons that facilitate observation and tracking of manifestations of racism. CDOs would also be responsible for

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[6] Khoshkhoo *supra*, note 3.

[7] Brian Eastwood, "Chief data officers don't stay in their roles long. Here's why," *MIT Sloan School of Management* (Sept. 1, 2022), https://mitsloan.mit.edu/ideas-made-to-matter/chief-data-officers-dont-stay-their-roles-long-heres-why.

managing existing data repositories – many of which are incomplete, contain errors, and are incompatible with each other.[8] Uniform standards facilitate more effective sharing of equitable data between levels of governments.

Finally, CDOs would be responsible for overseeing training and upskilling programs in equitable data collection. A CDO would be the focal point of accountability for maintaining data quality and governance within their jurisdiction. This includes establishing and enforcing standard operating procedures and addressing regulatory and legal compliance matters.

Currently, the status of CDOs in the United States is inconsistent across states and localities. While most states (39) have adopted CDOs,[9] recent reports indicate only 4 counties[10] and 12 cities[11] have CDOs.

The OSTP can support data sharing between levels of government by supporting the establishment of CDOs in jurisdictions where they do not yet exist.[12] These CDOs would improve data collection and management within their designated levels of government by establishing standard procedures, and would improve data sharing across levels of government by establishing channels of communication with one another.

It is essential that CDOs have expertise in collecting and analyzing of racial and ethnic data. Notably, recent studies of private sector CDOs have found that as many as 80% identify as white males, and there is a prevailing homogeneity in their professional backgrounds – namely over 20 years of experience in the technology industry.[13] We recommend the OSTP encourage different levels of government to 1) prioritize expertise in the collection and analysis of racial and

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[8] Ruth T. Perot and Mara Youdelman, "Racial, Ethnic, and Primary Language Data Collection in the Health Care System: An Assessment of Federal Policies and Practices," 21, *The Commonwealth Fund* (Sept. 1, 2001), www.commonwealthfund.org/sites/default/files/documents/___media_files_publications_fund_report_2001_sep_racial__ethnic__and_primary_language_data_collection_in_the_health_care_system__an_assessment_of_fed_perot_racialethnic_492_pdf.pdf.

[9] Colin Wood, "The state chief data officer is here to stay," Statescoop (Mar. 27, 2022), www.statescoop.com/state-chief-data-officer-2022/.

[10] "Chief Data Officers: Which State and Local Governments Have a CDO?" *Government Technology* (July 6, 2018), www.govtech.com/people/chief-data-officers-which-state-and-local-governments-have-a-cdo.html.

[11] Data-Smart City Solutions, "Who Are America's City Chief Data Officers?" *Bloomberg Center for Cities at Harvard University* (Dec. 7, 2020), https://datasmart.ash.harvard.edu/news/article/data-leadership-at-the-executive-level-761.

[12] Strategy& "In the age of data, why are there so few Chief Data Officers?" *PwC* (2021), www.strategyand.pwc.com/de/en/functions/digital-cloud-data-strategy/cdo-2021/strategyand-cdo-study-2021.pdf.

[13] *Id.*

ethnic data and 2) take steps to examine inequity in the hiring of those responsible for equitable data.

Establish an Intergovernmental Council of Government Chief Data Officers

The federal government could further facilitate equitable data collection, sharing, and publication by establishing a formal structure for communication and collaboration among CDOs. This could take the form of an Intergovernmental Council of CDOs that would be tasked with setting standard procedures for racial and ethnic data collection. These standards would facilitate comparisons across levels of government, improving the ability of governments and the public to assess how government policies and programs promote or inhibit racial equity.[14]

Examples of the kinds of standards an Intergovernmental Council of CDOs might set include: determining clear, executable standards for collecting equitable data, including racial and ethnic data; setting data storage files in formats that can be easily processed by researchers; and providing a central location with reproducible data examples.

Currently, there are professional conferences that bring together state and local data officials,[15] as well as the Federal CDO Council,[16] and the State CDOs Network,[17] which aim to standardize best practices within their respective levels of government.

An Intergovernmental Council of CDOs would add the critical function of facilitating standardization and reporting across levels of government, allowing for comparative analyses regarding the racialized impact of particular policies and programs. We also recommend that the Council include representatives of community organizations with experience regarding racial and ethnic data collection, who can inform CDOs about gaps and deficiencies.

Continuously Improved and Standardized Racial and Ethnic Categories Used in Equitable Data Collection (responding to question #3)

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[15] CDO Network USA, "Summary," *The Network Group* (Accessed Oct. 3, 2023), https://thenetwork-group.com/us-chief-data-officer-network/; "Chief data & analytics officers government 2023" *Coriniumm* (Accessed Oct. 3, 2023), https://cdao-gov.coriniumintelligence.com/.

[16] "About us" *CDO Federal Council* (Accessed Oct. 3, 2023), https://www.cdo.gov/about-us/.

[17] "State Chief Data Officers Network" *Georgetown University Beeck Center* (Accessed Oct. 3, 2023), https://beeckcenter.georgetown.edu/projects/state-cdo-network/.

Data equity requires improvement of the racial and ethnic categories used for data collection, standardization of those categories across reporting entities, and regularly updating the categories to reflect changing conceptions of race.

Racial and ethnic data collection can shed light on racial inequities, and thereby shed light on the racist policies and practices causing those inequities, but only if the categories used for data collection closely approximate racialized experiences. The more these categories reflect racialized realities, the better we can understand how racism manifests and how it can be mitigated. An example of this is when distinct racialized groups are classified as white, when that is at odds with how they are racialized in society and their experience as frequent targets of racial subordination.

Currently, federal agencies and many local and state agencies use the racial and ethnic categories promulgated by the OMB, which have not been updated since 1997.[18] In many instances, these categories are broad, outdated, or inaccurate.[19] As a result, large groups with disparate racialized experiences are lumped together,[20] and more people are identifying as "Other Race" in data collection efforts.[21] This lumping together of groups with distinct experiences of racism, coupled with the growing use of the "Other Race" category, can lead to data confusion and obscure the true extent of inequities.

However, if states make individual choices about how to improve the racial categories, the lack of standardization precludes comparisons across jurisdictions. As our Center noted in a recent report on the matter, "[s]tate and local sources of racial and ethnic data often vary in standards for how to report, what to report, when to report it, and even whether to report it at all."[22] The lack of uniform standards "has meant that existing data repositories are incomplete, contain errors, are usually incompatible with each other, and are

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[18] "2020 Census Informational Questionnaire, " *U.S. Census Bureau* (Accessed Oct. 3, 2023), www2.census.gov/programs-surveys/decennial/2020/technical-documentation/questionnaires-and-instructions/questionnaires/2020-informational-questionnaire-english_DI-Q1.pdf. "American Indian or Alaska Native," "Asian," "Black or African American," "Native Hawaiian or Other Pacific Islander," and "White," and two ethnic categories "Hispanic" and "Not Hispanic."

[19] Khoshkhoo *supra*, note 3, at 1, 49.

[20] *Id.*

[21] Hansi Lo Wang, "1 in 7 People Are 'Some Other Race' on the U.S. Census. That's a Big Data Problem," *NPR* (Sept. 30, 2021), www.npr.org/2021/09/30/1037352177/; Eric Jensen *et al.*, "2020 Census Illuminates Racial and Ethnic Composition of the Country," United States Census Bureau (Aug. 12, 2021), www.census.gov/library/stories/2021/08/2020-united-states-population-more-racially-ethnically-diverse-than-2010.html.

[22] Khoshkhoo *supra*, note 3, at 2.

often internally inconsistent over time, jurisdictions, subjects, and levels of analysis."[23]

Accordingly, we recommend both improving the racial categories that are used for data collection, and standardizing those categories across jurisdictions. We recognize the complexities of this subject, and this Fall we are convening scholars and advocates to examine ways the categories can be amended to better approximate experiences of structural racism. Our policy recommendations will be released in 2023.

Improving the racial and ethnic categories used for data collection is not a one-time endeavor. Tracking racism requires updating the categories to reflect changing conceptions of race – and, thus, changes in racialized experiences. A continuously improved and standardized system would allow robust analysis and comparisons across levels of government and over time. Federal leadership is best suited to promulgate such standards.

Integrate Public Transparency and Accountability into Data Sharing Programs

Equitable data is that which "allow[s] for rigorous assessment" of government programs.[24] Accordingly, data sharing between levels of government only furthers the goal of equity if data is also made accessible to the public.

We recommend publishing the standards that an intergovernmental council of CDOs would produce. This would empower scholars, advocates, lawmakers, research centers, and community-based organizations to access equitable data and hold their governments accountable for failures and successes in promoting equity.

Conclusion

The Center recommends facilitating data equity by improving racial and ethnic data collection, standardization, and publication. The establishment of CDOs, collaboration among those CDOs, and engagement with community advocates can further these objectives, and allow for more rigorous assessments of the racialized impact of government policies and programs.

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[23] *Id.,* at 1, 49.

[24] Khoshkhoo *supra*, note 3.

BOSTON
UNIVERSITY

Boston University Center for Antiracist Research

October 03, 2022

Submitted via https://www.regulations.gov

Attn: NSTC Subcommittee on Equitable Data
Office of Science and Technology Policy
Eisenhower Executive Office Building
[redacted] Washington, DC 20504

Re: 87 FR 54269, OSTP Docket No. 2022-19007, Boston University Center for Antiracist Research Response to Request for Information; Equitable Data Engagement and Accountability

Dear Members of the NSTC Subcommittee on Equitable Data:

The Boston University Center for Antiracist Research ("the Center") is a nonpartisan, nonprofit, university-based research center that seeks to devise novel and practical ways to understand, explain, and solve seemingly intractable problems of racial inequity and injustice. We foster exhaustive research, policy innovation, data-driven educational and advocacy campaigns, and narrative-change initiatives to build an antiracist society that ensures equity and justice for all.

The collection and publication of equitable data is a critical aspect of understanding and dismantling racism.[1] The Request For Information describes equitable data as "data that allow for rigorous assessment of the extent to which government programs and policies yield consistently fair, just, and impartial treatment of all individuals, including those who have been historically underserved, marginalized, and adversely affected by persistent poverty and inequality." This includes racial and ethnic demographic data. When governmental agencies and jurisdictions do not comprehensively collect racial and ethnic data or share that data with one another and the public, it is impossible to accurately track and disrupt manifestations of racism.

Data equity thus requires three things: (1) comprehensive racial and ethnic data

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[1] "Executive Order On Advancing Racial Equity and Support for Underserved Communities Through the Federal Government," *White House Briefing Room* (Jan. 20, 2021), www.whitehouse.gov/briefing-room/presidential-actions/2021/01/20/executive-order-advancing-racial-equity-and-support-for-underserved-communities-through-the-federal-government/.

collection, (2) standardization of data collection methods across jurisdictions and levels of government, and (3) public access to that data. The collection of racial and ethnic data helps illustrate where inequities exist; the standardization of data collection allows for comparisons across jurisdictions and levels of government; and the publication of data allows for assessments of the effectiveness–or ineffectiveness–of government programs and policies at mitigating racism.

This comment responds to the Request for Information's questions regarding the improvement of data sharing between levels of government, and public accessibility of equitable data.[2] We offer the following recommendations with the aim of improving the quality and accessibility of racial and ethnic demographic data, so that researchers, advocates, policymakers, and the public can better assess whether government programs and policies promote racial equity or inequity. These recommendations are informed by our prior publications and ongoing research regarding the collection and reporting of data that reveal racial and ethnic inequities.[3]

An Initiative to Support and Encourage the Centralized Management of Equitable Data within Levels of Government in order to Facilitate Data Sharing Across Levels of Government (responding to question #3)

There are four factors that currently inhibit the collection and sharing of equitable data: 1) an undefined data strategy at each level of government;[4] 2) the absence of a point person responsible for coordinating data sharing across levels of government;[5] 3) non-standard operating procedures around data collection and reporting that make it difficult or impossible to compare data

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[2] Office of Science and Technology Policy, "Request for Information; Equitable Data Engagement and Accountability," *Federal Register* (Sept. 2, 2022), www.federalregister.gov/documents/2022/09/02/2022-19007/request-for-information-equitable-data-engagement-and-accountability.

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across jurisdictions;[6] and 4) public officials that have not been trained or prepared to maintain data quality and governance.[7]

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Data equity requires improvement of the racial and ethnic categories used for data collection, standardization of those categories across reporting entities, and regularly updating the categories to reflect changing conceptions of race.

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CENTER
FOR
DATA
INNOVATION

October 3, 2022

NSTC Subcommittee on Equitable Data
Office of Science and Technology Policy
Eisenhower Executive Office Building
[redacted]
Washington, DC 20504

Re: Engagement and Accountability RFI

On behalf of the Center for Data Innovation (datainnovation.org), I am pleased to submit this response to the Office of Science and Technology Policy's (OSTP) request for information (RFI) on the collection and use by federal agencies of equitable data—a term which OSTP uses to refer to "data that allow for rigorous assessment of the extent to which government programs and policies yield consistently fair, just, and impartial treatment of all individuals."[1]

The Center for Data Innovation is the leading think tank studying the intersection of data, technology, and public policy. With staff in Washington, London, and Brussels, the Center formulates and promotes pragmatic public policies designed to maximize the benefits of data-driven innovation in the public and private sectors. It educates policymakers and the public about the opportunities and challenges associated with data, as well as important data-related technology trends. The Center is a part of the nonprofit, nonpartisan Information Technology and Innovation Foundation.

In response to the RFI, the Center offers three main recommendations: 1) OSTP should support partnerships that bolster access to high-performance computing of historically underrepresented groups in the field; 2) OSTP should promote robust data literacy curriculums in U.S. schools to ensure more Americans have opportunities to make use of data about themselves and their communities; and 3) OSTP should prioritize closing the "data divide"—the social and economic inequalities that result from a lack of collection or use of data about individuals or communities—to improve the effectiveness of data-driven services and decision making.

Please find our responses to the relevant questions in the document below.

Sincerely,

Gillian Diebold

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[1] "A Vision for Equitable Data: Recommendations from the Equitable Data Working Group," White House, April 2022, https://www.whitehouse.gov/wp-content/uploads/2022/04/eo13985-vision-for-equitable-data.pdf.

CENTER FOR DATA INNOVATION

Policy Analyst
Center for Data Innovation
[redacted]

4. What resources, programs, training, or other tools can expand opportunities for historically underrepresented scholars and research institutions to access and use equitable data across levels of government?

High-performance computing (HPC) is essential for solving many data-intensive computational problems in a wide range of fields, including engineering, biology, and Earth science. Increasing access to HPC for traditionally underrepresented groups in science and engineering will help ensure that researchers from all backgrounds can access and use data equitably. Partnerships that coordinate the sharing of computing resources between the federal government and universities, particularly Minority-Serving Institutions (MSIs) that include Historically Black Colleges and Universities, Hispanic-Serving Institutions (HSIs), and Tribal Colleges and Universities (TCUs) will create a direct connection with traditionally underrepresented communities and newly collected data as well.[2]

Such partnerships existed from 1997 to 2004 with the support of the National Science Foundation (NSF) through the Education, Outreach, and Training Partnership for Advanced Computation Infrastructure (EOT-PACI), an effort that included dozens of institutions and organizations to coordinate the sharing of computing resources with MSIs.[3] More recently, the NSF Inclusion across the Nation of Communities of Learners of Underrepresented Discoverers in Engineering and Science (INCLUDES) initiative works to enhance the participation of underserved communities in scientific research.[4] The INCLUDES program has provided more than $7 million in funding for the Computing Alliance of Hispanic-Serving Institutions but that is the only current initiative to advance minority participation in computing.[5] Similar efforts need to target HBCUs and TCUs, and reestablish grants that fund HPC resources at MSIs. Industry-university partnerships, such as the partnership between the University of Florida and NVIDIA, can also expand access to AI computing capabilities.[6]

6. What resources, programs, training, or tools can make equitable data more accessible and useable for members of the public?

One important step to improving the accessibility and useability of equitable data is improving data literacy for Americans of all backgrounds. Many organizations and individuals face barriers to using data,

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[2] Hodan Omaar, “How the United States Can Increase Access to Supercomputing,” (Center for Data Innovation, December 2020), https://datainnovation.org/2020/12/how-the-united-states-can-increase-access-to-supercomputing/.

[3] “NSF EPIC Press Release,” last modified April 2005, http://mvhs.shodor.org/epic/pressrelease.html.

[4] “About Us: NSF INCLUDES,” accessed November 6, 2020, https://www.includesnetwork.org/new-a/about-us.

[5] “NSF INCLUDES Alliance: Computing Alliance of Hispanic-Serving Institutions,” accessed November 6, 2020, https://www.nsf.gov/awardsearch/showAward?AWD_ID=1834620&Histo.

[6] Hodan Omaar, “Industry-University Partnerships to Create AI Universities” (Center for Data Innovation, July 2022), https://www2.datainnovation.org/2022-ai-universities.pdf.

including a lack of technical skills.[7] Improving data literacy would not enable more Americans to develop in-demand job skills to participate in the growing data economy, but it would also allow them to better understand public data and decisions based on that data.

At the local, state, and federal levels, data literacy can be bolstered by improving educational programs in data science and related disciplines, beginning in K-12 schools.[8] Strong programs in math, statistics, and computer science can equip students with the skills necessary for advanced data literacy. This training should continue through higher education, where degrees in technical fields also can provide the highly skilled workforce needed to participate in the data economy. Programs that reduce disparities in data literacy will also reduce the digital use divide, or the gap between those that use technologies in ways that augment and transform their daily lives and those that use technology passively. These divides go hand-in-hand and increasing data literacy will necessarily increase digital literacy.

7. In which agencies, programs, regions, or communities *are there unmet needs, broken processes, or problems related to participation and accountability* that could be remedied through stronger collaborations and transparency around equitable data?

The data divide refers to the social and economic inequalities that result from a lack of collection or use of data about individuals or communities.[9] Many individuals and communities across the United States lack the data necessary to benefit from data-driven innovation. The data divide has emerged between the data-haves and the data have-nots, and these inequities can significantly impact how individuals and communities participate in the data economy.[10] Opportunities to benefit from data vary based on different demographic and geographic factors. Whether or not data-driven services and data-driven decision-making works for someone often depends on where they live and their background. Historically underrepresented communities typically face the widest data gaps resulting from this lack of equitable data collection.

Instances of inequitable data systems pose the biggest threat to participation in the data economy as they can encompass communities of all sizes, characteristics, and locations. These systems collect and store data needed for key services, such as education, financial services, public health, and more. But, disparities occur when these systems have weak or nonexistent infrastructure. Moreover, some system data might exist but have steep barriers to access, like data siloes. For example, in education, schools cannot take advantage of data-driven technologies when they lack the systems necessary to collect and

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[7] Gillian Diebold, "Closing the Data Divide for a More Equitable U.S. Digital Economy," (Center for Data Innovation, August 2022), https://datainnovation.org/2022/08/closing-the-data-divide-for-a-more-equitable-u-s-digital-economy/.
[8] Daniel Castro, Joshua New, John Wu, "The Best States for Data Innovation," (Center for Data Innovation, July 2017), https://www2.datainnovation.org/2017-best-states-data.pdf.
[9] Gillian Diebold, "Closing the Data Divide for a More Equitable U.S. Digital Economy," (Center for Data Innovation, August 2022), https://datainnovation.org/2022/08/closing-the-data-divide-for-a-more-equitable-u-s-digital-economy/.
[10] Ibid.

utilize high-quality data. As a result, students, families, and administrators are forced to make decisions about enrollment or interventions based on incomplete or inaccurate data. Some states have Statewide Longitudinal Data Systems (SLDSs) that store data on education from early childhood to the workforce (P-20W), but other states still lack this type of specialized system. This leaves data siloed and often inaccessible to key stakeholders. While some students and families have access to data about their entire educational journey, others lack this type of information, meaning they must make consequential decisions with unequal knowledge. As of 2017, only 17 states and the District of Columbia had fully linked SLDS systems.[11]

A similar situation arises with financial services. Credit scores determine everything from whether someone qualifies for a mortgage or car loan, but also whether they can obtain certain services without a deposit, or even apply for a lease or a job. Credit agencies often lack the necessary data infrastructure to collect and score individuals based on “alternative” data sources, such as rent or utility payments, cell phone bills, or cash-flow data in a bank account. As a result, many consumers have limited or no credit history.[12] As of 2020, 21 percent of U.S. adults do not have a credit card and 19 million are considered “unscoreable” due to insufficient or outdated data.[13] Agencies governing financial services need to expand the use of alternative credit to include more consumers in the financial system.[14]

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[11] “50-State Comparison: Statewide Longitudinal Data Systems,” Education Commission of the States, last modified December 14, 2021, https://www.ecs.org/state-longitudinal-data-systems/.

[12] “Data Point: Credit Invisibles,” Consumer Financial Protection Bureau, May 2015, https://files.consumerfinance.gov/f/201505_cfpb_data-point-credit-invisibles.pdf.

[13] Ibid.

[14] Gillian Diebold, “Congress Should Expand Use of Alternative Credit Data,” *Center for Data Innovation,* March 8, 2022, https://datainnovation.org/2022/03/congress-should-expand-use-of-alternative-credit-data/.

Stanford MEDICINE | Health Care

October 3, 2022

NSTC Subcommittee on Equitable Data
Office of Science and Technology Policy
Eisenhower Executive Office Building
[redacted]
Washington, DC 20504

Re: Engagement and Accountability RFI

To Whom it May Concern:

Please find below Stanford Health Care's LGBTQ+ Health Program responses to several questions outlined in the White House Office of Science and Technology Policy (OSTP)'s Request for Information concerning how Federal agencies can better support collaboration with other levels of government, civil society, and the research community around the production and use of equitable data.

> **3. What resources, programs, training, or other tools *can facilitate increased data sharing between different levels of government (Tribal, territorial, local, State, or Federal) related to equitable data* ?**

In order to create equitable data and increased data sharing, we recommend the federal government require health care entities to create a mandated list of population health and health disparity assessment questions that will be universally collected, and then reported to a centralized system for population health data. Currently, hospital systems have little to no communication with other health care centers at a regional and national level when sharing population health records. Even in areas where there are shared agreements for open exchange of health information, population health data is typically not prioritized. All data reported this way would be population health without identifying information. Moreover, we recommend that all electronic health records be uploaded daily to a centralized population health database through an opt-out model. This revolutionary process would provide a robust picture of health equity across the United States.

With a tool to collect population health data from each Health Care Center, population health specialists can track health outcomes in each community, across geographic regions, and outcomes for populations across the United States. Additionally, this method will facilitate an accountability system the federal government can implement to engage healthcare centers struggling to collect inclusive data measures and work on quality improvement methods. For example, if a health system is reporting little to no gender identity or sexual orientation data, the federal government can provide technical assistance. This level of targeted intervention is only available with a nationwide population health data collection system.

4. What resources, programs, training, or other tools *can expand opportunities for historically underrepresented scholars and research institutions to access and use equitable data across levels of government* ?

We encourage research into the creation of a national population health data assessment questionnaire. This evidence based tool will evaluate validity of research questions that target different population health concerns. This can then be adopted and embedded into EHR workflows that will collect the data in a targeted way to ensure question fatigue is considered. We recommend training to facilitate how research questions can be embedded, asked, and followed-up on for clinical decision making and interventions based on the responses.

The aforementioned database will be accessible to the public so that all scholars, including underrepresented scholars, have equitable and comprehensive data to perform needed research. As it stands, the current approach is individualized, which can lead to underrepresented scholars who are focused on population health data specific to marginalized communities facing additional barriers to research and publications. An underrepresented scholar will need to find funding for their research from someone both supportive of them and their population specific interests, find an avenue to access the community they hope to engage, and finally, identify a journal willing to publish their research. This will facilitate broad reaching population health comparison and outcomes in their research proposals, and thus, make for more competitive and diverse studies.

5. What resources, programs, training, or tools *can increase opportunities for community-based organizations to use equitable data to hold government accountable to the American public* ?

The public access database for health equity will allow any health and social services program to pull data based on scholarship or population health concerns. This nationwide and intentionally inclusive and longitudinal database will allow centers that may not have access to such rich data sets the ability to create far more detailed and data supported arguments in accountability.

7. In which agencies, programs, regions, or communities *are there unmet needs, broken processes, or problems related to participation and accountability* that could be remedied through stronger collaborations and transparency around equitable data?

There is a current staggering deficit in the collection of sexual orientation and gender identity data. The fact this is not a mandated and reported field in federal government forms and questionnaires leaves the country with poor data concerning one of our most marginalized and underserved communities. It is imperative we immediately begin to collect this data across the country and measure health successes, positive outcomes, and best practices based on these outcomes. This endeavor will provide support for nondiscrimination clauses in healthcare. However, until we collect and analyze the data on a national scale, we will be moving insufficiently in this work.

We respectfully thank you for your consideration of our responses to OSTP's Request for Information.

Sincerely,

[redacted]

Bláz Bush, M.Ed (he or Bláz)
Executive Director, LGBTQ+ Health Program
Stanford Medicine

Jason Joseph Hill (he, him, his)
Associate Vice President for Government Affairs
Stanford Health Care - Stanford University

2022 Asian American, Native Hawaiian, and Pacific Islander (AA and NHPI) Roadmap for Data Equity in Federal Agencies

May 23, 2022

AAPI Data, in partnership with

National Council of Asian Pacific Americans (NCAPA)

TABLE OF CONTENTS

EXECUTIVE SUMMARY

This is the first in a series of reports from AAPI Data and the National Council of Asian Pacific Americans (NCAPA) pertaining to data equity as it pertains to Asian American, Native Hawaiian, and Pacific Islander (AA and NHPI) communities. This report is a scan of publicly available information, supplemented with correspondence with community organization leaders, on past activities and current plans to advance data equity for AANHPI communities at the federal level.

The report first defines what data equity means for our communities, researchers, and federal government agencies. Next, it provides a brief review of some recent data equity initiatives from AA and NHPI community organizations and researchers. The third section of the report covers the interagency work of prior presidential administrations that sought to advance data equity for AAs and NHPIs. The report also lays out the current state of data equity efforts at federal agencies that collect data on issues most relevant to AA and NHPI communities, establishing a baseline of knowledge to inform the next steps and future engagement with those agencies.

Finally, the report concludes with a series of recommendations that aim to achieve large-scale impact, through the framework of “DNA: Data, Narrative, Action.” These recommendations are informed by past and ongoing efforts initiated by Asian American and Native Hawaiian and Pacific Islander organizations and researchers, as well as related efforts to advance data equity initiated by federal agencies.

Moving forward, it is clear that our communities’ agenda with respect to data equity can be characterized as “disaggregation plus,” meaning that improved federal standards for data collection by detailed origins remain a high priority, but that the focus has expanded to include other important aspects of data equity such as timeliness, accessibility, human-centered design, community inclusion, and federal agency recognition of subject-matter expertise and population expertise among community organizations and researchers alike.

INTRODUCTION

The U.S. Census Bureau projects that the majority of the American population by 2045 will be people of color and that, by 2030, immigration will become the primary source of population growth in the United States due to the aging of the native-born population. With migration from Asian and Pacific Islander countries and territories constituting significant drivers of this population growth, and in order to help elevate the stories, narratives, and needs of our communities, it is vital that elected leaders, policymakers, stakeholders, and community members communities work together to design and produce research on Asian American, Native Hawaiian, and Pacific Islander (AA and NHPI) populations that are accessible, timely, and accurate.

While many public and private agencies and programs continue to group Asian Americans, Native Hawaiians, and Pacific Islanders into one super-category, major differences in cultural traditions, group histories, and modes of incorporation into the United States make it imperative for data pertaining to these communities to be collected, analyzed, and disseminated in a disaggregated fashion, and presented back to AA and NHPI communities in ways that are culturally appropriate and widely accessible.

Federal agencies continue to operate under the 1997 Office of Management and Budget standards for Classification of Federal Data on Race and Ethnicity, where agencies are required to collect and report data for five minimum race categories: American Indian or Alaska Native, Asian, Black or African American, Native Hawaiian or Other Pacific Islander, and White. Agencies are also required to have two categories for data on ethnicity: Hispanic or Latino, and Not Hispanic or Latino.

In order to better understand why data disaggregation by detailed origin is essential for AA and NHPI communities, we need to understand the diverse and varied histories of how Asians, Native Hawaiians, and Pacific Islanders came to be a part of the fabric of the United States. Migration, adaptation, integration, and backlash are all common themes in most histories of these diverse communities.

For Asians, the push and pull factors that drove migration to the United States were often a combination of economic and political turmoil at home and the promises of economic opportunity and mobility that America represented at the time. Chinese immigrants, facing unrest and famine during the Taiping Rebellion, arrived in large numbers in the middle of the 19th Century as laborers, first drawn by the gold rush in California, later by jobs building the first transcontinental railroad and the economies that emerged around the railroad. While initially praised for their work ethic, the number of Chinese immigrants grew and dispersed to other jobs and industries. With increasing numbers, they were seen as unwanted competitors for jobs for white laborers. Dehumanizing racial stereotypes of Chinese immigrants combined with the economic pressures of the depression triggered by the Panic of 1873 resulted in violent backlash against Chinese communities and culminated in the Chinese Exclusion Act of 1882, the nation's first racial exclusion act. Despite these restrictions, Chinese migrants continued to seek entry into the United States, creating America's first undocumented immigrants. In addition, there were always a small number of exceptions to Chinese exclusion, including students and refugees.

With Chinese immigrants explicitly banned, the demand for cheap labor for American agriculture and business needed another source. Each succeeding wave, first Japanese, then Indian, and finally Filipinos, continued the cycle of American commercial interests recruiting Asian laborers, increasing resentment and racial bias against these new communities, and ultimately bans on immigration and restrictions on citizenship and property ownership.

The Gentleman's Agreement of 1907-08 was a diplomatic arrangement in which the Japanese government agreed to limit Japanese migration to the United States, particularly of male laborers. However, family migration was still permitted, resulting in the continued growth of the Japanese community through family reunification and the migration of so-called "picture brides" from Japan to the United States. Japan's emergence as a world power forced the United States to pursue a diplomatic agreement rather than a legislative ban. Nevertheless, immigration was reduced and bans on naturalization and prohibitions of property ownership remained in place. For other Asians, particularly Indians, these restrictions came with the Immigration Act of 1917 which created a barred zone of immigration from British India through Southeast Asia. Chinese exclusion had been made permanent in 1904 and Korea, which by 1917 was under Japanese occupation, was covered by the Gentleman's Agreement.

That left Filipinos as the last Asian source of cheap labor for American agriculture and business interests. Because of the Philippines' status as a U.S. colony, Filipinos could freely migrate to America as U.S. nationals. However, this ended with the Philippine Independence Act of 1934, where the Philippines were granted independence after a 10-year transition period, but Filipinos were no longer considered U.S. nationals, and Filipinos in the U.S. lost their status.

The start of World War II resulted in a re-evaluation of naturalization and immigration from Asia. While China and the U.S. were wartime allies, bans on Chinese immigration became untenable and President Roosevelt signed a law in December 1943 ending Chinese exclusion, although extremely small national quotas made the policy change largely symbolic. In addition, Chinese residents were finally allowed to naturalize, the first Asian-origin groups to be allowed the opportunity to do so. At the same time, Roosevelt had signed Executive Order 9066 in February

1942 that forced the internment of Japanese Americans living in the U.S. mainland for the duration of the war. Other Asian communities also were allowed to immigrate and naturalize shortly after the end of World War II, as Cold War pressures prompted the United States to portray itself as a more welcoming nation. Still, restrictive quotas remained in place and fewer than 150 nationals were allowed to immigrate to the United States each year. Finally, the Immigration and Nationality Act of 1965 opened Asian immigration by lifting national quotas and creating three streams of immigration that form the core of today's immigration system: employment-based, family-based, and refugees/asylees. The act finally removed racist immigration barriers for Asians and resulted in the massive growth of the Asian American population that continues to this day. However, political and economic conditions continue to periodically feed a violent backlash against Asian Americans. One key moment in Asian American activism is the murder of Vincent Chin in 1982 during a time when the American automobile industry was struggling with workers blaming Japanese manufacturers for putting them out of work. Violence directed at Asian Americans during times of turmoil continues to this day, including years of violence against South Asians and Muslims after 9/11 and the recent growth of attacks on Asian Americans, Native Hawaiians and Pacific Islanders during the COVID-19 pandemic, with East Asians primarily feeling the brunt of violent attacks.

U.S. intervention in Southeast Asia and the impact of the Vietnam War, the Khmer Rouge genocide, and the Secret War in Laos resulted in the resettlement of over 1.5 million of Southeast Asian refugees between 1975 and 2000 from Vietnam, Laos and Cambodia. The trauma associated with war, genocide, political persecution and being uprooted from ancestral homes has resulted in great need for social and mental health services for refugees. The lack of disaggregated data on Asian Americans is the most harmful to refugee communities as their needs and challenges are often overlooked and hidden. In the early 2000's, a new wave of refugees from Bhutan, Myanmar (Burma), another wave of Hmong refugees from Thailand, and, most recently, Afghanistan were resettled across the country, often in metro areas with declining populations.

Finally, the Immigration Act of 1990 introduced three new immigration streams: Diversity Visas, H1-B employment visas, and Temporary Protected Status (TPS). The Diversity Visa program was especially important for growing the Bangladeshi and Pakistani immigrant populations in the United States. The Diversity Visa is a lottery-based program open to residents of any territory that had sent less than 50,000 employment- or family-based immigrants to the U.S. in the previous five years. Successful applicants receive permanent residency status for themselves and any spouse or children. The Diversity Visa program has especially boosted immigration from Bangladesh, Nepal, and Uzbekistan, with about 40,000 visas issued for each country since 1995. After these new immigrants settled in and established themselves, they were able to sponsor family members, leading to significant proportional increases in particular communities such as Bangladeshi Americans in New York and Michigan. In fact, migration from Bangladesh is now high enough that Bangladeshis are now ineligible for the Diversity Visa program. The H1-B visa programs accelerated immigration from India and China, bringing in highly skilled science and technology workers to the United States.[1] The majority of the foreign-born Asian American population in the U.S. have arrived since the introduction of the H1B visa program and this program has had a major influence on the economic status of the Asian American population as a whole. Finally, TPS allows the Department of Homeland Security to designate a country for TPS when conditions in the country prevent a safe return. TPS provides protection from removal, and authorization for employment and travel. TPS has enabled many Nepali to remain in the U.S. after the devastating earthquake in Nepal in 2015 and be active contributors to the economy as Nepal slowly recovers.

Native Hawaiians and Pacific Islanders share different histories and cultural heritage from Asian American populations, with the colonial, territorial, and military expansion of the United States playing a key role in their community formation, including a negative impact on economic security. Different historical circumstances have resulted in a complex system of formal and informal relationships between the Pacific Island nations and the United States.

After initial European contact in 1778, Hawaii's location in the Pacific made the country a center for explorers, whalers, and eventually the sugar industry. America's growing imperial ambitions at the end of the 19th Century would eventually lead to the overthrow of the Hawaiian monarchy and the U.S. annexation of the Hawaiian Islands. The U.S. military presence in Hawaii and the frequent shipping associated with supporting the military and trade with the mainland created opportunities for migration that many Native Hawaiians took. As U.S. citizens, Native Hawaiians are able to work and live anywhere in the U.S. legally, qualify for public benefits, vote in local and federal elections, and serve in the U.S. military.

Further colonial annexations have resulted in the Chamorro people having U.S. citizenship. The ancestral homelands of the Chamorros came under U.S. control first with Guam after the Spanish American War and then with the Northern Marianas Islands after Japan's defeat in 1945. Since that time the Northern Mariana Islands have entered into a commonwealth status with the United States while Guam remains a territory. As such, Chamorros can live and work legally in the United States, qualify for public benefits, and serve in the U.S. military. But as a territory, residents of Guam and the Northern Marianas are unable to vote in federal elections and have only non-voting delegates in Congress.

After the Tripartite Convention of 1899 divided the Samoan Islands into two, with Germany claiming the western islands and the U.S. the eastern island, the United States formally annexed American Samoa as a territory. However, because Congress has not passed an Organic Act for American Samoa, American Samoans are considered U.S. nationals and do not have birthright citizenship. American Samoans can live and work legally in the U.S., serve in the U.S military, and qualify for most federal benefits, but cannot vote while residing in the mainland. They must apply for naturalization to obtain all the rights and benefits of citizenship.

Other Pacific Islands would fall under U.S. hegemony during and after World War II. Citizens of the Federated States of Micronesia, Republic of the Marshall Islands, and Republic of Palau fall under three Compacts of Free Association, which confers the right to live and work in the U.S. as "non-immigrants" but are not eligible for most federal benefits and again must naturalize to gain access to all rights and benefits as citizens. The Compacts of Free Association are set to expire in 2023 for Micronesia and the Marshall Islands, and 2024 for Palau, and are currently being renegotiated.

Finally, people from the remaining Pacific Island nations are treated as any other immigrants and must apply for legal permanent residency in order to live and work in the U.S. These nations include Papua New Guinea, Solomon Islands, Nauru, Vanuatu, New Caledonia, Aoteroa, Tuvalu, Fiji, Tokelau, Samoa, Tonga, Nuie, Kiribati, and Cook Islands and make up the majority of the Pacific, but are fewer in number in the U.S.[2]

Having high quality data—by which we mean detailed, accurate, timely, and precise information that includes quantitative and qualitative data collections—will enable AA and NHPI communities to address various barriers associated with immigration-related experiences and statuses, language and other abilities, and the exercise of rights and access to benefits. High-quality data is also valuable to present accurate narratives about our communities, which includes not only combating negative stereotypes that propagate social division and harm, but also highlighting the immense contributions of Asian Americans, Native Hawaiians, and Pacific Islanders to American society. Finally, high-quality data is essential to identifying opportunities to build coalitions across a variety of racial and ethnic groups, to identify common solutions to shared challenges.

WHAT IS DATA EQUITY?

Data equity can be defined in several ways. As we elaborate below, data equity can be defined with a focus on its function or purpose, as a means to achieving the larger goal of racial equity, as well as with a focus on its process, involving several component parts. The former approach tends to answer the question of why we need more equitable data collections, while the latter approach tends to focus on the question of how data equity can be operationalized, with important roles for government agencies, community organizations, researchers, and the general public.

FUNCTIONAL APPROACHES TO DATA EQUITY

The federal government, through the April 2022 publication of a report by the Equitable Data Working Group, co-chaired by the White House Office of Science and Technology Policy (OSTP) and the Office of Management and Budget (OMB),[3] notes that equitable data "are those that allow for rigorous assessment of the extent to which government programs and policies yield consistently fair, just, and impartial treatment of all individuals. Equitable data illuminate opportunities for targeted actions that will result in demonstrably improved outcomes for underserved communities."[4] This is a *functional definition of data equity* that tends to focus on the motivational question of *why* data equity is important in the first place–as a critical means to achieve equity. This functional definition focuses on the ways in which data is used by policymakers and decision makers to allocate resources and take actions that demonstrably advance equity more generally (i.e., improving outcomes for underserved communities).

Asian American, Native Hawaiian, and Pacific Islander communities have been operating under some version of this functional definition of data equity for decades, including advocacy surrounding federal guidance on the collection of detailed ethnicity data in 1977 (as we detail later in this report) and the creation of the Asian-Pacific Islander racial category for the 1980 Census.[5] Advocacy for data collections by detailed Asian and Pacific Islander origins has continued since the 1970s—in fields ranging from education and health to housing and labor force participation—as AA and NHPI organizations have consistently highlighted the need for timely, detailed, and accurate data that can inform better decision making, policy development, and policy implementation.

PROCESS APPROACHES TO DATA EQUITY

Having long ago established the need for *why* data equity is essential to AA and NHPI communities, many community organizations and researchers have recently begun to dig deeper into matters of process, of answering the question of *how* we can produce more equitable data collections. In a letter written jointly by several AA and NHPI community organizations and researchers and submitted to Susan Rice, director of the White House Domestic Policy Council in September 2021,[6] the community/researcher coalition laid out a definition of data equity that included expanding federal minimum standards for data collection across all relevant agencies, and creating pilot programs or incentivizing agencies to expand their current data collection categories for AA and NHPIs beyond the newly created federal minimum standard.

Deeper dive into process: Data collection standards

Uniform data collection standards are an important condition for data equity for AA and NHPI communities. These standards include:

- Separate collection categories for self-reporting Asian, Native Hawaiian, and Pacific Islander populations

- Expanded collections categories for gender identity, including women and gender expansive individuals

- Implementing the American Community Survey practice of collecting information on nativity, including the country of birth of the individual and each parent

- Galvanize Diverse Partnerships Across Levels of Government and the Research Community

- Facilitate multiple self-identification responses for race and ethnicity to allow individuals to fully express their identities. This is especially important for Native Hawaiian, American Indian and Alaska Native communities where more than half of those communities identify as multiracial

Beyond expanded data collection standards, the group also defined data equity as the inclusion and incorporation of community and research expertise into all stages of data and research, including design, development, collection, compilation, processing, analysis, dissemination, and preservation, concepts that we elaborate further below.

- **Design and development** - During this stage of the research life cycle, decisions are made regarding what kinds of questions are to be answered, how those questions will be asked, and who are the people being studied. Language and cultural considerations need to be incorporated into design plans. Establishing an advisory committee made up of trusted members of the relevant communities is a best practice.
- **Collection and compilation** - The collection phase requires researchers to minimize the burden of participation and to reassure the subjects of the research that the information they provide will be protected and be used to benefit themselves and their communities. If possible, having individuals from the community participating in the collection and compilation of the data is ideal.
- **Processing and analysis** - Once the data is collected, the data needs to be processed in a way that both protects the confidentiality of the respondents and produces usable, accurate and timely data for the benefit of the communities involved. Researchers must consider how data is presented and have communities provide guidance on how to interpret the results. Researchers also must be clear about what the limitations of the data are.
- **Dissemination and preservation** - Data must be shared back to the communities that were studied in a format that is informative, easily understandable, and easy to access and maintain. Again user feedback on data dissemination tools or data formats is essential to maintain transparency.

When considering how to incorporate communities into data-related processes, it is important to also carefully weigh the benefits and risks to different communities associated with the data collection, analysis, and dissemination, to have those communities actively provide input in decision-making around maximizing benefits and minimizing risks, and to work with communities to ensure that ultimate goal of providing useful and accurate data back to community stakeholders is achieved.

Deeper dive into purpose: Recommendations of the EDWG

At the federal level, the collection of racial and ethnic data is essential for the functioning of the government, from enforcing the Voting Rights Acts to determining how federal funds are allocated to states, neighborhoods and communities. The Equitable Data Working Group charged by President Biden through the Executive Order 13985, on Advancing Racial Equity and Support for Underserved Communities Through the Federal Government (“Equity EO”), has issued a set of recommendations for best practices for federal agencies to improve data equity:

- Make Disaggregated Data the Norm While Protecting Privacy
- Catalyze Existing Federal Infrastructure to Leverage Underused Data
- Build Capacity of Robust Equity Assessment for Policy making and Program Implementation
- Galvanize Diverse Partnerships Across Levels of Government and the Research Community
- Be Accountable to the American Public

Overall, the federal government’s functional perspective (or “purpose focus”) on data equity is highly complementary with the process perspective on data equity advanced by community organizations and researchers alike. From the federal government’s perspective, the priority is on understanding which federal policies impact equity outcomes and to use data to identify and remove barriers to equitable access to government programs. From the community perspective, the focus is on the process of how voices and expertise from the community and researchers are incorporated into data processes that will lead to more accurate data and better outcomes for communities.

The focus of the Biden administration on system-wide improvements across the federal government to address equitable data represents an opportunity for AA and NHPI community advocates and leadership to coordinate the wide range of data equity initiatives currently underway.

ROLE OF THE OFFICE OF MANAGEMENT AND BUDGET IN DATA EQUITY

The Office of Management and Budget (OMB) plays a central coordinating role for the executive branch, with responsibility for developing and executing the federal budget, managing work across federal agencies, and coordinating and reviewing all significant federal regulations.[7] OMB plays a central role in data equity through its role in setting the minimum standards for data collection for race and ethnicity. While these standards are nominally for only federally-sponsored statistical data collection, the standard has become the de facto standard across all government levels and the private sector because of how data collected at those levels are often required to report back to federal agencies in a format that meets the OMB standards.

Non-federal surveys also make use of Census Bureau population counts and estimates, which adhere to the OMB standards, for designing surveys and sample frames. OMB also plays an oversight role over federal statistical agencies and periodically reviews the performance of agencies. It is through this role and OMB's oversight of the federal budget that policies and standards are enforced.

OMB issued the first Race and Ethnic Standards for Federal Statistics and Administrative Reporting in 1977. Prior to those standards, individual agencies employed inconsistent categories to collect race and ethnic data. Even across decennial censuses, there was considerable variability, especially for Asian categories. For example, the term "Hindu" was used from the 1920 to 1940 Censuses to describe Americans who immigrated from India, despite the fact that not all Indians were Hindus. For the 1950 and 1960 Censuses, both "Hindu" and "Korean" were removed as response options. "Korean" was included as a response option on the 1970 Census and "Asian Indian" as an option made its debut in the 1980 Census. [8]

The 1997 standards required data collection for four racial categories ("White," "Black," "American Indian or Alaskan Native," and "Asian or Pacific Islander"), and a separate ethnic category for Hispanic origin. The standards were created in response to both the increasing need for uniform standards of data collection so that data collected across different federal agencies would be compatible and to meet the requirements of Public Law 94-311 of June 16, 1976 that required federal agencies to collect, analyze, and publish data on “Americans of Spanish origin or descent.” The rapid growth of the AA and NHPI populations after the immigration reforms of the 1960s also created an urgent need to collect accurate data on these new Americans, especially as the federal government became more reliant on Census and other statistical data to enforce the new Voting Rights and Civil Rights Acts and to allocate funding for federal programs using statistically driven formulas.[9]

By the mid-1990s, there was a growing recognition that the increasing diversity of the Nation would require significant updates to the race and ethnic categories. What emerged from the public process were the 1997 OMB Standards. These standards began to address this diversity through two important changes. First, the standards allowed for survey respondents to select more than one racial or ethnic category. Second, through efforts by Native Hawaiian and Pacific Islander advocates, the standards required that federal statistical agencies at a minimum collect and report data for Native Hawaiian and Pacific Islander communities separate from Asians. Both changes allowed for Native Hawaiians and Pacific Islanders to gain access to more data that better characterizes the unique experiences of their communities. Distinct categories allowed for data to reveal the key differences among Asian, Native Hawaiian and Pacific Islander communities. For example, only 15 percent of individuals who identified in any way as Asian selected multiple race categories, while 70 percent of individuals who identified as Native Hawaiian and 51 percent of individuals who identified as other Pacific Islander opted for multiple race categories.[10]

While the 1997 standards did not require the disaggregation of Native Hawaiian data from Pacific Islander data, there is a growing awareness that key socioeconomic differences between the two groups continue to be obscured by combining the two communities for reporting. Similarly, the wide range of experiences in the Asian American community necessitates further data disaggregation for Asian groups for datasets that cover topics that can reveal those different experiences, such as immigration, English proficiency, languages spoken, education, poverty, etc.

PRIOR AA AND NHPI COMMUNITY AND RESEARCHER EFFORTS

Differential outcomes and resources within the broad AA and NHPI umbrella go unidentified and unaddressed due to lack of data on Asian Americans, Native Hawaiians, and Pacific Islanders has bound these diverse communities ever since the federal government decided to aggregate them into one category when the first OMB Race and Ethnic Standards for Federal Statistics and Administrative Reporting were issued in 1977. While it may have made sense statistically to combine these populations together to produce stable estimates, the results ended up burying the unique needs and challenges faced by various groups within the categories. There is a throughline going from the 1977 OMB standards that essentially codified AA and NHPI as a unit of analysis to the landmark Heckler Report on Black and Minority Health, with its controversial findings on the health status of AAs and NHPIs that ended up kick-starting AA and NHPI advocacy for data disaggregation and equity at the federal level.[11] The Heckler Report concluded based on aggregated data that AAs and NHPIs had no major health disparities compared to other race and ethnic groups. The aggregate data glossed over the specific health needs of distinct AA and NHPI groups and perpetuated the model minority myth.

Since the OMB standards were first introduced, AA and NHPI advocates and leaders have engaged in the implementation of the standards and advocated for changes to the standards themselves. Asian American community groups and leaders successfully pushed back against an effort to reduce the number of Asian and Pacific Islander categories for the 1990 Census, maintaining the status quo from the 1980 Census. Subsequent censuses have always included initial plans to reduce the number of check boxes for AA and NHPI categories and the AA and NHPI community has always rallied to successfully defend the check boxes. Advocacy around changing the OMB standards centered around two major issues: first, finding a way to collect and report NHPI data so that the needs of the communities under that category are highlighted and not subsumed under Asian American or other larger group data, and second, how to characterize the growing multiracial population and its implications on counting AAs and NHPIs.

The first challenge of where best to categorize NHPI populations was initially constrained during the review of the 1997 OMB Standards by OMB's reluctance to expand the number of major race categories beyond the four established ones:

“American Indian/Alaskan Native”, “Asian or Pacific Islander”, “Black”, and “White”. Even though the OMB standards were clearly minimum standards for data collection, many statistical agencies chose to implement them as the only standards. Therefore, during data collection, there was no way to indicate further detail beyond “Asian or Pacific Islander” and thereby foreclosing the possibility of generating distinct data on NHPIs. For context, at the time of the 1990 Census, Native Hawaiians represented just 3% of the total AA and NHPI category.[12] The Native Hawaiian community initially advocated for Native Hawaiians to be reclassified as American Indian and Alaskan Natives to create an indigenous peoples category. However, concerns were expressed by American Indian tribes over the dilution of their communities’ data and the impact on the special legal and political status of those tribes. Finally, consistent pressure from elected officials from the state of Hawaii, along with a well-organized public campaign to submit public comments to the OMB Federal Register Notice, resulted in OMB relenting and creating a fifth major race category, “Native Hawaiian or Other Pacific Islander.”

The question of how multiracial individuals could express their identity in federal statistics was also a contentious issue. Many Asian American advocates who were looking to build collective power sought to include additional Asian categories on census and survey forms, including multiracial Asian identities, and continue to classify those identities under the existing monoracial, mutually exclusive race construct.[13] However, among multiracial Asians, there was a need for recognition of their complex identities. Some advocated for a new multiracial category separate from the extant race categories because of a history of ostracism by monoethnic Asian Americans and a need to recognize their unique identities and experiences. Others also rejected the monoracial concept of racial identity but wanted to express all parts of their identities and ancestries and did not embrace the concept of a unitary multiracial category. In the end, the various multiracial advocates were able to reach a consensus and opted for instructions to “mark one or more” racial categories. [14]

Research and testing from the Census Bureau at the time showed that for most racial categories only two to 3 percent of the population would select multiple race categories. However, the research also showed that providing a multiple race option would result in more individuals indicating Asian, Native Hawaiian, and American Indian identities. For example, individuals who were both Black and Asian and were forced in the past to choose Black under the single race format were now able to also select Asian. This has subsequently been borne out in the 2000 and subsequent census results with substantially more people able to indicate Asian, Native Hawaiian, and American Indian categories than if they were restricted to single race categories. The 2020 Census results showed that 19,886,049 responded as Asian Alone while an additional 4,114,949 were multiracial Asians who may or may not have chosen Asian under a single race format. For Native Hawaiian, Pacific Islander, and American Indian populations in particular, multiracial individuals were a larger portion of their populations than single race individuals. For example, in the 2020 Census, 689,966 were monoracial NHPIs and 896,497 were multiracial NHPIs. In the end both sides of the debate got their data, with the Census Bureau publishing statistics for “Two or more races” and for “Asian American Alone or in Combination with Other Races”.

The updating of standards to include a Native Hawaiian and Pacific Islander category, separate from “Asian,” and OMB guidelines allowing multiple race identification not only improves the specificity and quality of data collection, but also reflects the power of community and research advocacy among Asian Americans and NHPIs with regard to data equity. [15]

COMMUNITY ADVOCACY AND ENGAGEMENT EFFORTS WITH FEDERAL AGENCIES

This section of the report summarizes some of the data equity initiatives undertaken by the AA and NHPI community and researchers directed at federal agencies. These initiatives seek to engage with federal agencies and ensure that community and research expertise are brought to bear on the data collection, analysis, and dissemination process. These examples show how AA and NHPI advocates for data equity are digging deep into both functional and procedural challenges to achieving data equity.[16]

Census Bureau

The Census Bureau through the years has created several different opportunities to engage with external stakeholders and data users to elicit comments and suggestions. Two main advisory committees, the Census Scientific Advisory Committee (CSAC) and the National Advisory Committee on Racial, Ethnic, and Other Populations (NAC). The CSAC primarily advises the Census Bureau on scientific developments that can be applied to any of the Census Bureau’s many programs and activities. The NAC advises the Census Bureau “on the identification of new strategies for improved census operations, survey and data collection methods, including identifying cost-efficient ways to increase census participation and reduce the undercount.”[17] The NAC was created in 2012 by combining the Census Advisory Committee (CAC) on the American Indian and Alaska Native Populations, the CAC on the Asian and Pacific Islander Populations, the CAC on the African American Population, and the CAC on the Hispanic Population. As far back as 1976, AA and

NHPI leaders had engaged with the Census Bureau through a Census Advisory Committee on the Asian and Pacific Americans Population for the 1980 Census.[18]

National Advisory Committee membership through the years has included academic researchers, AA and NHPI advocacy organizations, and business and community leaders. The current NAC is focusing on issues such as: 1) the implementation of differential privacy and its impact on timely release of essential data from the 2020 Census, 2) planning for the 2030 Census including revisiting the race and ethnicity questions for both the decennial census and the American Community Survey, and 3) concerns over declining response rates to the American Community Survey and the need for increased investments in community outreach.

AA and NHPI community organizations also engage the Census Bureau as part of the Federal Register process and other open calls for public comment. Often with major changes in survey methodology or data product design, the Census Bureau engages with a variety of experts and solicits public comments. In the past few years, AA and NHPI community organizations and researchers have responded to such notices as the 2016 review of OMB federal statistical standards, the proposed citizenship question on the 2020 Census, the proposed application of differential privacy to the 2020 Census data product releases, and the proposed Demographic and Housing Characteristics File (DHC) and Detailed Demographic and Housing Characteristics File (Detailed DHC). For example, Advancing Justice-AAJC in partnership with MALDEF issued a report examining the impact of differential privacy on redistricting data for Asian American and Latinos in 2021.[19] Community organizations and researchers, including those at AAPI Data, have also engaged with the Census Bureau on minimizing delays associated with the release of detailed origin data from the 2020 Census.[20] While the Census Bureau released various disaggregated population data tables within one to two years after the April 2010 Census data collection, it did not release a timeline for a similar data release until April 2022 after significant pressure and concerns raised by community organizations and researchers. The Census Bureau currently estimates that it will not be able to release disaggregated population data on Asian Americans, Native Hawaiians and Pacific Islanders until August 2023.[21]

Community partners have also weighed in on Census Bureau outreach plans and provided insights into messaging and motivations in the community. Once the Census went into the field, community partners engaged with the Census Bureau to identify gaps in response rates and to deploy volunteers and resources to encourage communities to participate in the Census. The COVID-19 pandemic showed the importance of local partners grounded in the communities they serve as those organizations could build census messaging into the new pandemic relief programs. For example, food banks and vaccine drives set up by community organizations would also provide census messaging or even partner with the Census Bureau to have enumerators on-site to get people counted.

Finally, community organizations as well as Census Bureau leaders have recognized the importance of sustaining community partnerships beyond each decennial cycle. In the past, the Census Bureau created national and regional community partnership programs for decennial census outreach and education efforts, and subsequently disbanded most of these networks after the conclusion of the census data collection period.

Health and Human Services

Data on the health status and disparities of AA and NHPI communities was one of the first areas where advocates saw the importance of disaggregated data and successfully sought change. The Asian & Pacific Islander American Health Forum (APIAHF) and the Association of Asian Pacific Community Health Organizations (AAPCHO), both of which emerged out of advocacy efforts in response to the Heckler Report, and their partner organizations have led efforts to increase the research and available data on AA and NHPI health disparities. Through their advocacy efforts, the National Center for Health Statistics began oversampling for Asian respondents in the National Health Interview Survey (NHIS) and the National Health and Nutrition Examination Survey (NHANES), and the revision of the standards for national population health surveys to include 7 additional Asian categories (Asian Indian, Chinese, Filipino, Japanese, Korean, Vietnamese, and Other Asian) and 4 additional Native Hawaiian, and Pacific Islander categories (Native Hawaiian, Guamanian or Chamorro, Samoan, and Other Pacific Islander) beyond the minimum OMB standards, to comply with Section 4302 of the Affordable Care Act.

In 2010, APIAHF released a report, Native Hawaiian and Pacific Islander Health Disparities, that summarized health disparities among Native Hawaiian and Pacific Islander populations. The three main data sources were the federally-sponsored National Health Interview Survey (NHIS), the Behavioral Risk Factor Surveillance System (BRFSS), and the Youth Risk Behavior Survey (YRBS). Most of the data is aggregated at the Native Hawaiian and Pacific Islander level, with some disaggregation provided where possible. The authors also warned that small sample sizes in these surveys yielded less reliable and less precise estimates, highlighting a primary challenge to data equity for NHPI communities.

On the 30th anniversary of the Heckler Report, APIAHF, New York University Center for the Study of Asian American Health, AAPCHO, Temple University Center for Asian Health, and Asian American Research Center on Health sponsored a special issue of the Journal of Healthcare for the Poor and Underserved: Shining the Light on Asian American, Native Hawaiian, and Pacific Islander Health. The special issue summarizes the history of data equity and spotlights the advances made in health disparity research as a result of the gains made in data equity.

In 2016, APIAHF released Public-Private Partnerships for Data Equity to highlight recommendations and best practices for building partnerships between community organizations and different levels of government in order to promote data equity. The report includes policy recommendations for forming said partnerships. It also includes a detailed history on advocacy efforts for health data equity for AA and NHPI communities.

In response to the COVID-19 pandemic, Arab Community Center for Economic and Social Services (ACCESS), APIAHF, the National Congress of American Indians (NCAI), the National Urban League, and UnidosUS released Policy Recommendations: Health Equity Cannot Be Achieved Without Complete and Transparent Data Collection and the Disaggregation of Data. This brief provides policy recommendations for improving data collection, reporting, and disaggregation by state health data systems in order to better understand health inequities among populations. It recommends data collection and reporting standards beyond the 1997 OMB standards. Out of this report emerged a guidebook for community leaders and advocates, Advocating for Data Disaggregation by Race and Ethnicity to help jump start advocacy at the state level for changes to the state health data systems.

Education

Educational data equity has been another area with a lot of activity within the AA and NHPI community. The National Commission on Asian American and Pacific Islander Research in Education (CARE) in partnership with White House Initiative on Asian Americans and Pacific Islanders (WHIAAPI), and support from ETS and Asian Americans/Pacific Islanders in Philanthropy (AAPIP) began iCount, a campaign to disaggregate AA and NHPI student data at the postsecondary level.[22] CARE also collaborated with APIA Scholars to engage in research and produce a series of reports that examine key issues affecting AANHPI student access and success in higher education.[23] The campaign resulted in three reports that use available data sources to highlight educational disparities among different AA and NHPI subgroups and to call for systemic changes at the institutional, state and federal levels in how educational data is collected and reported.

APIA Scholars also worked with institutional researchers in 2019 to examine data equity practices at colleges and universities, specifically from federally designated Asian American and Native American Pacific Islander Serving Institutions (AANAPISIs). This research highlights the use of cross-sectional and longitudinal institutional data in identifying the demographics of students participating in

AANAPISI programs and the impact these programs have on driving AANHPI student success.[24]

The Southeast Asia Resource Action Center (SEARAC) has also been active in the field. In 2013, SEARAC issued a report, Moving Beyond the "Asian" Checkbox (2013), which examined the comments submitted to the U.S. Department of Education's Request for Information on data disaggregation to identify opportunities for, challenges to, and existing models around large scale data disaggregation. In 2014 SEARAC led a national campaign, All Students Count, with local and national partners to advocate for government agencies to adopt data disaggregation laws and policies on AA and NHPI students. The effort helped to push Washington state, Minnesota, Rhode Island, and New York to pass data disaggregation laws and resulted in the U.S. Department of Education providing grant funding for states looking to disaggregate data for AA and NHPI students. In 2020, SEARAC issued Recommendations for Improved Federal Data on Asian Americans and Pacific Islanders (AAPI) that recommended that Congress pass laws regarding disaggregated data collection and a federal student-level data network to reduce analytical burden of postsecondary institutions, that education data standards from postsecondary institutions be revised, and that institutions themselves should be updating their own data processes.

Housing

The premier national coalition of AA and NHPI organizations focused on housing and community development, National CAPACD, has advocated for the Consumer Financial Protection Bureau (CFPB) to include disaggregated AA and NHPI categories in the Home Mortgage Disclosure Act (HMDA) reporting requirements. Starting in 2018, HMDA data now includes detailed disaggregated AA and NHPI data which allows for better tracking of the home mortgage industry and to identify potential predatory or discriminatory practices. National CAPACD, in partnership with the UCLA Asian American Studies Center and UCLA Center for Neighborhood Knowledge, was able to leverage HMDA lending data and the Census Bureau's American Community Survey (ACS) data for insights into the state of housing for low-income AAPIs since the Great Recession in seven high-cost housing markets and shows the importance of culturally competent housing counseling services for low-income communities of color.[25]

Hate Crimes, Discrimination and Criminal Justice

The major advocacy priorities AA and NHPI communities for improved data collection and disaggregation are around hate crimes and bias incidents, employment discrimination, and incarceration.

Since the backlash on Muslim and South Asian communities post 9-11, organizations such as the Sikh Coalition, Sikh American Legal Defense and Education Fund (SALDEF), South Asian Americans Leading Together (SAALT) and others have push the federal government to collect more detailed data on bias incidents and employment discrimination for South Asian, Muslim and Sikh communities. The key point of contention is the lack of disaggregated data on religious discrimination. In the Department of Justice's 2016 report, Combating Religious Discrimination Today, roundtable participants from various religious communities recommended the following to improve data on justice issues:

1. More clear communication regarding what constitutes a hate crime and how to report incidents.
2. Improve data collection on religious discrimination in the workplace to address the problems of underreporting.[26]

To address the data gap, community organizations have taken it upon themselves to create databases to track incidents. SAALT released a report in 2001 that documented media reports of bias incidents across the country against South Asian, Muslim and Sikh communities post 9-11.[27] SALDEF in their 2020 National Sikh American Survey asked respondents about feelings of acceptance and safety, bullying, and discrimination.[28] Stop AAPI Hate has collected self-reported data from AA and NHPI community members experiences with anti-Asian hate incidents.[29]

On the employment discrimination front, the Ascend Foundation has published two reports, one in 2016[30] and one in 2020[31] that examined EEOC data. Their analysis finds that Asian Americans are overrepresented as employees as professionals but underrepresented in executive leadership positions.

Finally, disaggregated data on prison populations is essential to show that Southeast Asian and Pacific Islander communities are disproportionately impacted by mass incarceration and subsequent mass deportation. Advancing Justice-Asian Law Caucus outlined the issue in a blog post in 2016 and continues to work on the intersectional issues of immigrant rights and criminal justice reform.[32] A convening in June of 2015 entitled AAPIs Behind Bars: Exposing the School to Prison to Deportation Pipeline issued a report that presented the best available data on AA and NHPIs in prison.[33] Challenges to accurate data on the criminal justice system include race data not being based on self-identification and most prison data categorizes AA or NHPI data in an "Other" category along with American Indians, Alaska Natives, and individuals who were multiracial or some other race. The report used local arrest data to show that Southeast Asian and Pacific Islander youth had extremely high arrest rates.

Cross-Sector

The most influential cross-sector areas of advocacy is around the OMB statistical standards on maintaining, collecting, and presenting federal data on race and ethnicity. The AA and NHPI community is keenly aware of the importance of minimum standards for increasing the availability of detailed data for our communities. During the latest review of the standards initiated in 2016, NCAPA, Advancing Justice-AAJC, APIAHF and SEARAC led a nationwide effort to mobilize AA and NHPI community members to submit over 3,600 public comments advocating for more detailed data collection and reporting.[34]

The National Council of Asian Pacific Americans (NCAPA) has also led cross-sectoral efforts to address data equity for AA and NHPI communities. In 2013, NCAPA released a guide for researchers, titled Best Practices: Researching Asian Americans, Native Hawaiians and Pacific Islanders. The guide covered challenges to AA and NHPI data collection, disaggregation, and community involvement. Aimed primarily at researchers in general, the guide has recommendations that should apply to federal statistical agencies, such as creating inclusive advisory committees, disaggregating data where possible and relevant, and working with AA and NHPI communities to fill data gaps. As part of NCAPA's 2020 Policy Platform, data disaggregation was a cornerstone of addressing AA and NHPI visibility. NCAPA recommended that the OMB Race and Ethnic Standards for Federal Statistics and Administrative Reporting should be updated to include provisions for more detailed race and ethnicity data and to require agencies to justify cases where data does not comply with the minimum standards.

Empowering Pacific Islander Communities' (EPIC) Policy Platform for Native Hawaiians and Pacific Islanders in the United States places data needs at the forefront of their platform. To address the data needs of NHPI communities, the platform recommends targeted special population research, oversampling of NHPI communities in surveys, or pooling of survey data. In addition, EPIC recommends better tracking how many federal research grants end up addressing NHPI issues and how many NHPIs participate in federal programs.[35] To address the challenge of access to data and visibility of NHPI communities, EPIC released a report in 2014 called Native Hawaiian and Pacific Islander Community of Contrasts in partnership with Asian Americans Advancing Justice Los Angeles. The report was created with the intention to serve as an additional tool for the NHPI community and others who seek to better understand and serve this diverse community.[36]

One of the challenges of data collection, analysis, and dissemination for Native Hawaiian and Pacific Islanders population is that for national surveys both population groups are such a small proportion of the total population. So it becomes difficult or costly to produce a statistically valid sample design at the national level while accommodating the need for statistically stable estimates for NHPI communities. While there are various methodologies that can address the issue, such as oversampling or pooling of data, some NHPI advocacy groups have focused on state and local efforts in geographic regions where NHPI communities make up a large share of the population. For example, Center for Native Hawaiian Advancement (CNHA) and other Native Hawaiian advocacy groups have focused on getting the state and local government in Hawaii to collect and analyze disaggregated data for Pacific Islander groups to help better understand the impact of the COVID-19 pandemic and better tailor services to those populations. The concentration of Pacific Islander populations in certain areas may make it easier to collect sufficient sample sizes at the state or local scale. Guidance from federal statistical agencies on how to collect, analyze and disseminate disaggregated data and funding for local pilot programs may help jumpstart state and local efforts to disaggregate data and also generate lessons that can be applied to the federal level.

PRIOR INTERAGENCY GOVERNMENT EFFORTS

President Clinton established the first White House Initiative on Asian Americans and Pacific Islanders (WHIAAPI) and President's Advisory Commission on Asian Americans and Pacific Islanders in 1999. An Interagency Working Group (IWG) of 32 federal departments and agencies was created to draft an integrated plan to address the unmet needs of AAs and NHPIs. The Commission released a landmark report in January 2001, *A People Looking Forward: Action for Access and Partnerships in the 21st Century*. The report laid out five cross cutting priorities, one of which was to "Improve Data Collection, Analysis, and Dissemination for Asian Americans and Pacific Islanders," recognizing that data drives implementation of all federal programs. The lack of data often results in the exclusion of AAs and NHPIs from those programs. The Commission report recommended full implementation of the 1997 changes to the OMB data standards, encouraging statistical agencies to go beyond the OMB standards through committing new resources or developing new sampling, analytical or other methods, and building partnerships with community-based partners and experts on AA and NHPI research.[37]

After President Bush shifted the focus of WHIAAPI to business and economic development and moved the initiative to the Department of Commerce,[38] President Obama brought WHIAAPI to the Department of Education and refocused the Initiative on five "cross-cutting priorities: improving data collection, analysis and dissemination of AAPI-specific information; ensuring linguistic and culturally competent access to Federal programs and services; protecting civil rights and equal opportunity; promoting and increasing Federal employment among AAPIs; and increasing outreach and access to Federal grant opportunities and other programs."[39]

WHIAAPI's first report under the Obama Administration was *Winning the Future: A Roadmap for the Asian American and Pacific Islander Community*. The report, released in 2011, outlined the plans for 21 federal agencies to address AA and NHPI community needs in the five priority areas. Ten of the agencies committed to improving data for AA and NHPI communities.[40]

In 2012, OMB released a statistical working paper, *Federal Agency Approaches to Providing Statistical Information on Detailed Asian and Native Hawaiian and Other Pacific Islander Groups*. The paper highlights work by federal agencies such as the Census Bureau, and the Departments of Health and Human Services (HHS), and Labor to expand race and ethnic categories for data collection and to provide more detailed statistics for AAs and NHPIs and other small groups through increasing sample sizes, oversampling small groups, and pooling data across time.[41]

WHIAAPI and CARE co-hosted two iCount: Equity Through Representation Symposiums in 2013 and 2015. Each two-day symposium highlighted the need for disaggregated data for AA and NHPI students to reveal educational disparities among AA and NHPI subgroups. Breakout sessions sought to generate best practices to implement data disaggregation systematically.

In 2014, *Building the American Mosaic: A Report from the President's Advisory Commission on Asian Americans and Pacific Islanders* highlighted data equity efforts among federal agencies. These included the Department of Labor's analysis of disaggregated data from the Current Population Survey; HHS expanding the race and ethnicity standards for federal health surveys beyond the minimum OMB standards, oversampling of Asian Americans in health surveys, and fielding the first ever Native Hawaiian and Pacific Islander National Health Interview Survey (NHPI NHIS); and the Department of Education's Request for Information (RFI) about best practices in the collection and utilization of disaggregated data on AAPI students.[42]

Under the Trump administration, WHIAAPI was returned to the Department of Commerce to again focus on businesses and economic development. WHIAAPI and the President's Advisory Commission on Asian Americans and Pacific Islanders issued a report in 2020, *Advancing Economic Empowerment for Asian Americans and Pacific Islanders*. The report was released in the context of the growing COVID-19 pandemic and made specific recommendations to expand national surveys to measure the economic and social impact of the pandemic, increase tracking of bias and hate crimes against AAs and NHPIs, and for disaggregating Asian ethnicity and oversampling AAs and NHPIs in surveys.[43]

CURRENT STATE OF DATA EQUITY AT FEDERAL AGENCIES

This section seeks to set a baseline of the current status of data equity for a set of federal agencies that cover priority issues for the AA and NHPI communities. This snapshot is not exhaustive and is meant to provide AA and NHPI advocates background information to engage with the federal agencies as they build out their data equity initiatives. This report relies on publicly available information, including such sources such as:

- Technical documentation of various surveys outline the type of race and ethnicity data captured and how they are captured.
- Federal register notices for new statistical or data standards as well as call for public comment were also Methods and sources
- The newly issued Data Equity Plans for key agencies as requested by the Equitable Data Working Group
- Reports that specifically address data disaggregation or data equity for AA and NHPI communities by a federal agency

Past administrations focused on data equity and disaggregation on a department or agency level. The current push for data equity is taking a "whole-of-government" approach, looking for opportunities at statistical agencies to go beyond coordinating standards and to begin to look at combining data sets and leveraging underutilized data. Much of the advocacy work has similarly been siloed around issue areas and individual departments and agencies. There needs to be a more coordinated approach to advocating for data equity in this policy environment.

The focus of the Biden administration on a "whole-of-government" approach to data and racial equity presents a unique opportunity to put into place the systemic policy changes and the staff and policy infrastructure for data equity while there is political will to drive the process. Given uncertainties about the priority of future administrations, it is imperative for federal agencies, community and research partners to work collaboratively and create innovative and lasting changes in the data collection, analysis, and dissemination systems at the federal level and to integrate the values and principles of data equity into those operations.

INTERAGENCY EFFORTS

As with prior presidential administrations, the Biden administration has approached data equity through interagency efforts that have variously served to inspire, guide, and coordinate the activities and initiatives of several individual agencies.

Equitable Data Working Group and WHIAANHPI

Early in President Biden's administration, two executive orders firmly established data equity for AAs and NHPIs as a priority for the administration. The first Executive Order on advancing racial equity and supporting underserved communities, as one of its actions, established the Equitable Data Working Group as part of a "whole of government" approach to advancing racial equity.[44]

The administration also re-established WHIAAPI, renaming the Initiative to the White House Initiative on Asian Americans, Native Hawaiians, and Pacific Islanders (WHIAANHPI) and returning the Initiative to its first home of HHS. The Executive Order also included the appointment of an AAPI senior liaison within the White House and the re-establishment of the President's Advisory Commission on Asian Americans, Native Hawaiians, and Pacific Islanders.[45]

As data equity has become a top priority for the Biden administration, it has produced a steady stream of reports on data equity including:

1. *Presidential COVID-19 Health Equity Task Force Final Report and Recommendations*: This report includes a "Data, Analytics, and Research" section that recommends standardizing demographic and socioeconomic categories in data, including data disaggregation and collaboration among Federal agencies and stakeholders to collect and disaggregate data on AAs and NHPIs for measuring the socioeconomic and health impacts of the pandemic and behavioral health.[46]
2. *Study to Identify Methods to Assess Equity: Report to the President*: This study from OMB summarizes the frameworks and actions taken by different federal agencies in order to assess equity. It recommends data disaggregation as a critical component of equity assessment, noting that many federal agencies currently lack the expertise to make use of and disaggregate data.[47]
3. *A Vision for Equitable Data - Recommendations from the Equitable Data Working Group:* This report from the Equitable Data Working Group identified key practices for achieving equitable data.[48]

A. *Make disaggregated data the norm while protecting privacy*

Under this recommendation falls the Administration’s commitment to revise the standards for maintaining, collecting, and presenting federal data on race and ethnicity taking into account the need for disaggregated data for underserved communities and researchers. OMB is already working on updated guidance to clarify what levels of disaggregated data are already allowable under the current standards. It is vital to encourage federal agencies to go beyond the minimum OMB standards and work with community partners and researchers to identify the AA and NHPI groups that are most in need of disaggregated data. In addition, the Administration will invest in existing surveys to expand sample sizes in order to create disaggregated statistics and also look for alternative ways to create disaggregated estimates, such as multiyear datasets and leveraging administrative data, to create small population estimates in topics of interest, particularly for NHPI communities. All of these methods will increase availability of stable and usable statistics to describe all small populations, especially for the emerging AA and NHPI populations.

B. Catalyze existing federal infrastructure to leverage underused data

The President’s FY 2023 budget request is funding the Census Bureau to study the options for linking demographic data that the Census Bureau collects with the administrative data from social safety net and business assistance programs to understand how to improve equity impact for those programs. Administrative data has some potential benefits from survey data for AA and NHPI populations. For example, many Asian immigrants have a difficult time navigating the public benefit system and rely on community-based organizations to help them. So for survey questions, they may not be providing the most accurate information on which program they receive benefits from. The administrative data for the social benefit agencies, if it can be tied to demographic data from the Census Bureau, provides potentially more accurate information on program participation and also may reduce report burden on individuals.

C. Build capacity for robust equity assessments for policy making and program implementation

The FY2023 budget request will build staff capacity for data equity work to support the evidence-based policies consistent with the Evidence

Act. The Administration will also leverage American Rescue Plan (ARP) funds to support state, local, territorial, and Tribal data infrastructure to allow for more disaggregated data collection. The potential for the Administration to fund pilot projects will provide opportunities to demonstrate best practices for implementing data disaggregation. In partnership with community partners and researchers, the projects could also be designed to address major priorities in AA and NHPI communities.

D. Galvanize diverse partnerships across levels of government and the research community

The Administration will prioritize building collaborations among federal, state, local, territorial and Tribal governments to share data to better evaluate social safety net programs. Best practices on how to protect the data and how to ensure that the collection of the data does not discourage program participation. The Administration will also seek to create grants to support research by historically underrepresented scholars to help build research capacity to address data equity., including those at Historically Black Colleges and Universities and other Minority-Serving Institutions.

E. Be accountable to the American public

The Administration has committed to increased transparency and accountability on the progress to data equity. This will take the form of community engagement, reports and studies to measure progress toward initiative goals, and building data tools (such as dashboards, query systems, and data visualizations) that are user-friendly, easy to understand, and accessible and meaningful to communities. The recommendations include funding for the Census Bureau to create and host data equity tools in partnership with other agencies and stakeholders.

Office of Management and Budget

The most recent review of the 1997 Standards for Maintaining, Collecting, and Presenting Federal Data on Race and Ethnicity occurred in September 2016 when the OMB published a Federal Register notice asking for comments in four areas:

1. Whether race and ethnicity data should be collected in a separate question format or a combined question format;
2. The creation of a Middle Eastern and North African race category;

3. Clarifying the minimum reporting categories; and
4. Changing the terminology used for race and ethnicity categories to reflect the growing and changing diversity of our country.[49]

Many of these recommendations were based on extensive research and community outreach by the U.S. Census Bureau and other federal agencies under the Obama administration to greater accuracy and usefulness in the collection of race and ethnicity data.

An interim report from the Federal Interagency Working Groups for Research on Race and Ethnicity was issued in April 2017, along with a request for comments.[50] However, the Trump administration took no further action on the topic via OMB and, consequently, the 2020 Census did not incorporate any of the recommended changes. The Biden Administration has announced plans to revisit the OMB standards, and this move is supported by a coalition of dozens of community organizations and civil rights coalitions who signed and submitted a joint letter to OMB in March 2022, urging the agency to "to take swift action to revive the revision of the federal data standards" in order to "enhance the quality of data used by scores of decision-makers in the public and private sector."[51]

CENSUS BUREAU

As the largest federal statistical agency, the Census Bureau is a key innovator in the methods of collecting race and ethnic questions and is the gold standard on collecting and producing data for AA and NHPI communities. Because the decennial census underlies all federal surveys particularly in weighting of survey data, the Census Bureau's question design for race and ethnicity are often adopted by other agencies for their own surveys.

The Census Bureau has also recognized the importance of engaging communities and other stakeholders in the entire data production process. For example, in both the 2010 and 2020 Censuses, the Census Bureau created a vast network of partners to encourage the public to participate in the Census, including partnerships with community-based organizations, local businesses and associations, and other groups who had a stake in obtaining an accurate count.[52] After the completion of the 2020 Census, several community organizations, researchers, and private foundations advocated for the preservation and continuation of these tribal, state, regional, and local partnerships, and to make the community partnership programs evergreen rather than be subject to a period of boom-and-bust cycles coinciding with each decennial census.

In its May 2021 meeting, the Census National Advisory Committee passed a recommendation to create such an evergreen community partnership specialist program, in line with advocacy efforts by entities such as Census Counts, the Census Funders Initiative, and Census Legacies. In October 2021, the Census Bureau accepted the recommendation,[53] and has since created the Office of Strategic Alliances to help maintain and build community and stakeholder partnerships on an evergreen basis.[54]

Design and Development

The Census Bureau has done extensive research and testing of various formats for questions on race and ethnicity. These included testing of alternative question formats during the 2010 Census and the 2015 National Content Test. These tests looked at the impact on response rates and consistency of answers for combined versus separate questions on race and ethnicity, the inclusion of a separate Middle Eastern or North African category, and different instruction wording or question terminology. The research informed the OMB's Federal Register Notice in 2016 calling for comments on the Standards for Maintaining, Collecting, and Presenting Federal Data on Race and Ethnicity. While ultimately the federal government did not move forward in adopting new standards for race and ethnicity data, the Census Bureau did make modifications to their 2020 Census race and ethnic questions while still conforming to the 1997 OMB standards.

The U.S. Census Bureau's scientific advisory committee advises the Bureau on demographic, economic, and statistical research design and implementation as well as other technical and operational matters.[55] Similarly, the Census Bureau's national advisory committee advises on matters pertaining to historically undercounted populations, including communities of color, immigrant communities, and those experiencing language and other barriers. Both advisory committees provide opportunities for external stakeholders and experts to weigh in on changes to data collection on race and ethnicity.[56] Public comments are accepted during these advisory committee meetings and are treated as part of the public record.

The Census Bureau has embarked on a transformation and modernization process that seeks to incorporate new methods and sources of data to improve data quality, and to use an equity lens to incorporate alternative perspectives and diverse voices. The Census Bureau intends to address racial equity by improving the quality and utility of the data it produces; increase engagement with stakeholder, especially for underserved communities; and build a culture of documentation and evaluation to learn and share best practices internally and with the wider statistical community.[57]

Compilation, Processing, and Analysis

Also for the 2020 Census, the Census Bureau expanded coding of race and ethnicity variables to include categories that reflect changing demographics and immigration patterns of the country and allowing for capturing up to 200 characters in the 2020 Census (up from 30 characters in the 2010 Census) for all race and ethnic write-in responses and increased the number of categories coded for each write-in area from 2 codes to 6 codes. The code lists used to process the 2020 Census data, and future Census Bureau surveys, were developed based on the results from testing as well as stakeholder engagement. Through this process, the Census Bureau expanded the number of unique codes for detailed Asian groups from 32 unique codes in 2010 to 63 unique codes in 2020. Some of those new codes include Central Asians (individuals who identify as Afghan, Kazakh, Kyrgyz, Tajik, Turkmen, and Uzbek). For the 2010 Census, there was no explicit code for Central Asians, while Afghans were classified as White. For Native Hawaiian and Pacific Islanders, the Census Bureau increased the number of unique codes from 29 in the 2010 Census to 51 unique codes in the 2020 Census. For both censuses there were 3 unique codes for Native Hawaiians (Native Hawaiian, Hawaiian, and Part Hawaiian).

An area the Census Bureau needs to improve their engagement with stakeholders is in regards to communicating about the new privacy methodology they have implemented for the 2020 Census data products. The data user community has major concerns about the impact of differential privacy on the accuracy and timeliness of the 2020 Census data products, particularly for detailed race and ethnic origin data. The Census Bureau National Advisory Committee issued a series of recommendations to improve the Census Bureau's messaging around differential privacy. The recommendations primarily center around making sure that communications to the general public on differential privacy be accessible and understandable and that the impacts of differential privacy on the accuracy and usability of the 2020 Census data be clearly stated.[58]

Dissemination and engagement

Data access and dissemination remain an area for improvement for the Census Bureau. While data is readily available, the means of access have substantial barriers of entry for non-expert users. The Census Bureau does have staff dedicated to providing both in-person and virtual training to use the various platforms for data dissemination that the Bureau has created.[59] The Census Bureau has also undertaken pilot projects to create more integrated and user-friendly data dissemination tools. For example the Census Bureau has created My Community Explorer using ArcGIS Online. The tool pulls from a broad range of social, economic, race, ethnicity, business, and community resiliency data to provide a one-stop tool to examine statistics for any county in the country. The new initiatives to improve data access emphasize place and neighborhood, which tend to work for communities of color that are highly concentrated or segregated by geography. For AA and NHPI communities, which tend to be more dispersed, the Census Bureau also needs to prioritize data tools at higher levels of geography, including at the national and state level. The community-friendly tools that aggregate data across different tables and sources of information will need to be disaggregated by race and ethnicity in order to be meaningful and useful for AA and NHPI communities.[60]

The Census Bureau has increased investment in community partnership programs for each decennial census, having seen the value in these partnerships to increase participation in the census in communities at risk for undercounts. In previous censuses, the Bureau would let these partnerships go into hibernation. Realizing that having to rebuild these partnership programs from scratch every decade was inefficient, the Census Bureau has decided to invest in maintaining the community relationships from the 2020 Census outreach effort by establishing an Office of Strategic Alliances. The Office has set the following goals for itself:

- Engage with external entities to help promote education and respondent participation in the decennial census, economic census, census of governments, and other demographic and economic surveys.
- Engage with internal stakeholders who manage relationships with the Census Bureau's partners, external stakeholders, and customers to leverage those relationships to meet the objectives of the strategic plan and the needs of program areas.
- Engage with external entities to leverage knowledge and data assets in the modernization of Census Bureau data products, collection, acquisition, and dissemination.
- Engage with external entities to seek feedback on their data needs and identify data gaps to solve challenges related to their businesses, organizations, or communities.

The Census Bureau also engages data users through the State Data Center network that engages with state and local government data users and the Census Information Center (CIC) network that aims to promote the use of Census Bureau data products and services among underserved communities, such as communities of color, rural communities, senior citizens, and children. There are currently 10 Asian American-serving CICs and one Native Hawaiian-serving CIC. The CICs provide vital feedback on Census data products and tools and provide examples of how Census Bureau data is used to help the communities they serve. The CICs also promote data accessibility and training to their communities.[61]

HEALTH AND HUMAN SERVICES

Health disparities and access to disaggregated health data have been two primary drivers in the push for data equity for AA and NHPI communities. Through persistent advocacy efforts, both the National Health Interview Survey (NHIS) and the National Health and Nutrition Examination Survey (NHANES) now oversample Asians, the NHIS since 2006 and the NHANES since 2011. [62]For Native Hawaiians and Pacific Islanders, the National Center for Health Statistics (NCHS) conducted the first ever Native Hawaiian and Pacific Islander National Health Interview Survey (NHPI NHIS), a survey of 3,000 NHPI households using the 2014 NHIS survey instrument. Public use data from this survey was released in March 2017.[63]

For the NHIS, public data only reports Asian American estimates, while estimates for AA and NHPI subgroups and Native Hawaiian and Pacific Islander in aggregate were only available in the restricted use files due to confidentiality concerns. No NHPI subgroup data is collected in NHIS. For NHANES, only Asian subgroup data is collected, not Native Hawaiian and Pacific Islander subgroup data. For public data products, only Asian aggregated data is reported. Native Hawaiian and Pacific Islander data is not available separately in NHANES data releases.

The Office of Minority Health at HHS compiled and periodically updates a Compendium of Federal Datasets Addressing Health Disparities. The compendium sets out to "provide a one-stop shop for understanding the landscape of federal datasets related to health equity, and ultimately, can help to shape and inform the development of effective programs, policies, and practices."[64]

BUREAU OF LABOR STATISTICS

The Bureau of Labor Statistics (BLS) is charged with producing the data the government needs to monitor labor markets, price changes, working conditions, and labor force productivity in the U.S. The BLS's primary data source is the Current Population Survey (CPS), which is administered by the Census Bureau. In the past, the Department of Labor has leveraged the CPS to highlight challenges faced by Asian American labor force during and after the Great Recession of 2008. A series of reports in 2011, 2014, and 2016 showed an evolution in analysis from only focusing on Asian Americans in aggregate in the 2011 report, to expanding the analysis to detailed Asian ethnic groups and including analysis of the impact of the Great Recession on Native Hawaiians and Pacific Islanders in the 2014 and 2016 reports. Both the 2014 and 2016 reports show the importance of access by researchers to microdata. Regression analysis of CPS microdata was able to show that AA and NHPI workers who had similar characteristics, such as age, gender, marital status, education, and citizenship, and similar jobs earned less than non-Hispanic White workers. AA and NHPI workers also had higher unemployment rates than non-Hispanic workers with similar characteristics.

The Department of Labor's Equity Action Plan outlines a number of data equity-related priorities.[65]

- "Understanding—and improving—the equity data we collect: Advancing equity requires data in order to assess the needs of underserved populations, the scope of existing programs, and the impacts of potential interventions. Last year, DOL conducted an inventory of the equity-oriented data collected by agencies to better understand where there are gaps in necessary data and opportunities for addressing those gaps. One issue identified by this inventory involves missing demographic data for program participants, including employment and training programs, which makes it more difficult to assess whether those programs are reaching our nation's workers. ETA thus launched an analysis to better understand the extent of missing demographic data, its impact on interpreting program data, and options for improving data quality. Lessons from this project are being applied to other programs (including new grant initiatives, within the bounds of federal nondiscrimination law), to expand the collection of demographic data and improve its quality, and to strengthen analyses of equitable access to programs and services."
- "Lack of disaggregated data on program access by demographic characteristics prevents regular equity tracking that could promote accountability and inform changes to program laws and administration"
- "Create new indicators of program access and barriers to identify equity gaps using UI program data, including key measures like application, recipiency, denial, and timeliness rates broken out by demographic groups (especially race, ethnicity, education, age, gender, disability status, geographic area, and language proficiency)"

DEPARTMENT OF JUSTICE

With an increase in incidents and coverage of anti-Asian bias incidents and hate crimes since 2020, issues related to reporting, categorizing, and sharing of anti-Asian hate crime statistics have come to the fore. The Department of Justice (DOJ) has directed the Federal Bureau of Investigation to update their Crime Data Explorer web tool to spotlight anti-Asian hate crimes and provide scenario-based training in their data collection training manual for state and local partners to improve the collection of anti-Asian hate crimes data. [66]

On May 20, 2022, the Department of Justice released a special report, Raising Awareness of Hate Crimes and Hate Incidents During the COVID-19 Pandemic.[67] The report cited FBI Hate Crimes Statistics showing an increase in reported hate crimes against Asians/Asian Americans, Native Hawaiians, Pacific Islanders, and Black communities. The report also cited Stop AAPI Hate's efforts to document hate crimes and incidents. The report also found serious underreporting and nonreporting of hate crimes by local law enforcement agencies to the FBI's Uniform Crime Reporting (UCR) program. DOJ's National Crime Victims Survey also shows that about 42 percent of violent hate crimes were not reported to law enforcement. The report makes a series of recommendations aimed at building awareness about hate crimes, working with communities to address hate crimes issues, and creating opportunities to build alliances and understanding across all communities.

To address these issues around underreporting and , the DOJ FY 2023 Budget asks include investments in the volume, quality, and analysis of data collected by the National Incident-Based Reporting System, the successor system to the previous Summary Reporting System used by the UCR program, and improving the National Crime Victimization Survey to improve coverage of historically underserved communities.

Anti-Asian hate crimes are not the only criminal justice data set for which data disaggregation helps to provide higher quality information about community experiences. Surveys conducted by the Bureau of Justice Statistics include questions on race and ethnicity detailing statistics related to crime and prisoner populations, with separate categories for Asian and Native Hawaiian and Pacific Islander. Most statistical reports from the Bureau, however, continue to combine AAs and NHPIs into one reporting category rather than the two separate categories of Asian only and Native Hawaiian and Pacific Islander only. Lack of data on AAs and NHPIs in criminal justice statistics is one of the reasons why these communities have been left out of the criminal justice debate, despite indications that incarceration rates are increasing for AAs and NHPIs, particularly for Southeast Asians and Pacific Islanders.[68]

DOJ will also seek to develop findings and recommendations for improved data collection and equity performance metrics and reporting by grant recipients, including establishing criteria by which the Department and its grant-making offices can hold themselves accountable and measure success for improving equity through DOJ programs. This will include, but is not limited to, improved Title VI and Safe Streets Act data collection.[69]

DEPARTMENT OF EDUCATION

In May of 2012, the Department of Education issued a Request for Information (RFI) on data disaggregation for AA and NHPI students and use cases for planning and programming.[70] This RFI was aimed at collecting best practices and policies for state and local education agencies, schools, and higher education to overcome challenges in collecting and disseminating AA and NHPI subgroup data. The RFI was not aimed at changing Federal educational data reporting requirements.

Separate statistical standards for the National Center for Education Statistics (NCES) were also revised in 2012. These standards are designed to guide the NCES staff and contractors in the design and implementation of data collection, analysis and dissemination activities. These standards adhere to the 1997 OMB standards with Asians in a separate category from Native Hawaiians and Pacific Islanders, but, where sample size makes it possible, allow for the collection of additional AA and NHPI subgroup data.

National Forum on Education Statistics issues a *Forum Guide to Collecting and Using Disaggregated Data on Racial/Ethnic Subgroups* to inform state and local policymakers about what data disaggregation is, how it benefits schools to collect and analyze this data, and best practices to implement when adopting data disaggregation to existing data collection processes.[71]

The Department of Education regularly conducts the Civil Rights Data Collection(CRDC). The CRDC collects data on student enrollment and educational programs and services by race and ethnicity, sex, limited English proficiency, and disability. The CRDC only began to collect Asian student data separately from Native Hawaiian and Pacific Islander students in the 2011-12 school year, and detailed AA and NHPI categories are yet to be collected. The data is used by the Department of Education Office for Civil Rights to enforce the civil rights laws and by other education policymakers and researchers.[72]

The 2022 Agency Equity Plan has outlined a plan to build an Equity Dashboard populated with metrics recommended by the National Academies of Sciences report, *Monitoring Educational Equity*.[73]

HOUSING AND URBAN DEVELOPMENT (HUD)

HUD's Equity Action Plan focuses on bringing an equity lens to procurement, fair housing and civil rights resources, homeownership, and homelessness. Data plays a critical role in tracking and evaluating the implementation of the Equity Action Plan, but no specific data equity issues for AA and NHPI were identified in the plan.

To comply with a 2009 Congressional mandate to assess Native American housing needs, HUD undertook a study of the housing needs of Native Hawaiians living in Hawaii. The report found a significant need for affordable housing and less crowded housing by Native Hawaiians, especially by those on the waitlist for homestead leases on Hawaiian homelands.[74]

One area of innovation that HUD researchers are contributing is merging two different datasets to create more detailed characteristic data. The CoC Analysis Tool: Race and Ethnicity combines ACS characteristics data with Point-In-Time Count data to help identify possible racial disparities in homelessness in Continuums of Care areas. Unfortunately the tool is not yet able to provide detailed AA and NHPI group estimates.[75] HUD also put out a guide titled COVID-19 Homeless System Response: Data & Equity: Using the Data You Have to help service providers leverage data to identify disparities and achieve more equitable outcomes.[76]

CONSUMER FINANCIAL PROTECTION BUREAU

The Consumer Financial Protection Bureau (CFPB)'s collection of Home Mortgage Disclosure Act (HMDA) data may also serve as an excellent model for federal agencies in implementing disaggregated data practices. HMDA data have included detailed race and ethnicity categories starting with the 2018 data.

HMDA data in 2018 began allowing for the collection of applicant and co-applicant information for detailed Asian, Native Hawaiian and Pacific Islander groups. Up to five race categories and five Hispanic/Latino categories could be collected for the applicant and the co-applicant. Write-in options for both race and Hispanic categories were available. However, the option of self-reporting race at an aggregated level is also possible, Observed data collection either by visual observation or surname identification, were also allowed in cases where the applicants did not self-identify. CFPB's own analysis of the HMDA data showed a wide variation among Asian and NHPI subgroups in terms of credit scores, incomes, combined-loan-to-value ratios and debt-to-income ratios, making it clear that aggregated data hides existing disparate outcomes in housing markets for AA and NHPI communities.

SOCIAL SECURITY ADMINISTRATION

The collection of race and ethnicity data from Social Security applications has always been voluntary because the data was not essential to the administration of the program. However, changes over the years reduced the utility of the race and ethnicity data collected through Social Security applications. In 1980, the SS-5 application forms began to indicate that race and ethnicity responses were voluntary. In 1986, the Tax Reform Act of 1986 required taxpayers claiming children as dependents to obtain a Social Security number (SSN) for each child aged 5 or older. Currently, nearly all applications are collected electronically either at birth or upon entry into the United States. For both application methods, race or ethnicity is not collected by SSA, due to the information not being essential to the administration of the program and restrictions on data sharing. Instead, the SSA researchers rely on using SSN as a record link to connect administrative and survey data to obtain race and ethnicity data for program evaluation. SSA works primarily with the Current Population Survey, the American Community Survey, the Survey of Income and Program Participation and the University of Michigan's Health and Retirement Study.[77]

Challenges remain with the analysis and dissemination of data on AAs and NHPIs from the SSA. A quick overview of the SSA's Research, Statistics & Policy Analysis web site shows many instances where tables with published data on race and ethnicity do not include data on AAs and NHPIs or the data is aggregated together, contrary to the 1997 OMB standards. With the rapid growth in Asian American seniors, it is essential that disaggregated data be collected and reported. The growth in the Asian American senior population will further overwhelm any Native Hawaiian and Pacific Islander data if aggregated data continues. In addition, disaggregated data will help refine any analyses due to the different immigrant waves and socioeconomic experiences among Asian American communities.

EQUAL EMPLOYMENT OPPORTUNITY COMMISSION

The Equal Employment Opportunity Commission (EEOC) collects workforce data from employers. Reporting by employers include separate categories for "Asian" and "Native Hawaiian or Other Pacific Islander" in compliance with the OMB statistical standard. In addition, the EEOC also expanded the number of AA and NHPI national origin groups collected in their charge data to 12 categories: Cambodian, Chinese, Filipino, Hmong, Indian, Japanese, Korean, Laotian, Pakistani, Thai, Taiwanese, and Vietnamese.

The EEOC provides key data to the public on employment statistics, complaints of employment discrimination, and enforcement, including charge data collected from people alleging they have been discriminated against by a private, state, or local employer.

EEO-1 Data is most easily accessed from the EEOC Explore Tool and the EEO-1 Public Use File.[78] The tool is relatively new and only has data from Fiscal Year 2014 – 2018. The EEOC is working to add more data to the website.

Federal sector data are most easily found in the federal sector annual reports. The reports, especially the workforce tables, provide disaggregated data about Asians and Native Hawaiians/Pacific Islanders.[79]

Public access to charge data is less straightforward. The EEOC itself has published disaggregated charge data of AA and NHPI in two recent data highlights: The Continuing Impact of Pay Discrimination in the United States[80] and Sexual Harassment in Our Nation's Workplaces.[81]

While not statistical data, the EEOC also periodically publishes selected cases lists including one on Asians and Pacific Islanders and another for the Muslim, Sikh, Arab, Middle Eastern and South Asian Communities.[82]

RECOMMENDATIONS AND NEXT STEPS

Asian American, Native Hawaiian, and Pacific Islander (AA and NHPI) communities have long relied on timely and accurate data and research to ensure that public and private programs are adequately addressing community needs. The Biden administration has shown a strong commitment to advancing racial equity through improved research and data collections across federal agencies, and this has included the establishment of the Equitable Data Working Group as part of a "whole of government" approach to advancing racial equity.

In April 2022, the Equitable Data Working Group released a report with its initial set of findings and recommendations for action, which we have summarized earlier in this report. Many of these recommendations are in line with AAPI Data's framework to achieve large-scale impact called DNA: Data, Narrative, Action.[83] As the Equitable Data Working Group report notes, improvements in data standards are necessary to achieve data equity, but are not sufficient to do so by themselves. Actions are needed, including increased investments in innovative methods to collect and analyze data pertaining to smaller populations who have been historically underserved, increased support for scholars who study marginalized populations, and improvements in the ways that data are shared back with communities.

When it comes to building better data dashboards, queries, and visualizations, we see a lot of room for improvement for federal agencies. For example, the April 2022 report of the Equitable Data Working Group points to the U.S. Census Bureau's Community Resilience Estimates for Equity as "an easily understood metric for how vulnerable every neighborhood in the United States is to the impacts of disasters, including COVID-19."[84] Our review and assessment of the linked data tool, however, indicates that most community members as well as policy makers and other decision makers would find the volume of data provided to be non intuitive, complicated, and confusing.

We recommend that federal agencies could learn from best practices in data accessibility from private-sector organizations, many of whom have produced user-friendly, interactive data dashboards on topics such as the New York Times dashboard on COVID-19 case rates and the AARP's Livability Index that enables comparisons across geographic areas and "deeper dives" into particular indicators. Creating a pipeline of data reporting and visualization talent could help federal agencies build the kind of innovative capacity they need in order to make data more accessible and useful.

Finally, several tools such as Community Resilience Estimates for Equity provide place-based measures of community vulnerability that summarize across racial and ethnic groups in a particular geographic area rather than providing race-specific measures of vulnerability for communities in that area. While this kind of race-specific measure of vulnerability may not be possible for small geographic areas due to sample size and data privacy concerns, federal agencies should implement data tools that can be disaggregated by race and ethnicity at levels of geography with sufficiently large populations, including at the level of metropolitan area, state, and nation.

In addition to actions, which can take the forms of improvements in government policies, practices, and investments by government agencies and programs, it is also vital for federal government agencies to consider the role of community narrative in shaping federal data equity strategies and priorities. By building stronger relationships with community organizations and recognizing their subject matter expertise through oral histories and lived experiences, federal agencies can help ensure that their data and research are seen as meaningful and legitimate among a range of stakeholders, including historically marginalized populations. Some aspects of narrative can be subsumed under the rubric of data, with smaller-scale qualitative data collections that can be used as exploratory or explanatory research in conjunction with larger-scale data collections. More expansively, however, narratives can be critical in shaping the ways that data collections are designed and understood, and the ways that data products are marketed, made accessible, and rendered meaningful to historically marginalized communities.

Additional recommendations on advancing data equity come from the September 2021 NCAPA coalition letter that was developed in partnership with community-engaged researchers. These include:

1. Creating additional case studies and pilot research and implementation programs by the Equitable Data Working Group that are specific to AA and NHPI communities and that can offer insights that can inform the work of various federal agencies;[85]
2. Updating the federal minimum standard for data collection across all relevant agencies that expands upon the categories used in the 2020 Census and American Community Survey, so as to include smaller Asian American, Native Hawaiian, and Pacific Islander populations;
3. Creating pilot program(s) or incentivize agencies to expand their current data collection categories for AA and NHPIs beyond the newly created federal minimum standard;

4. Ensuring adequate discretionary funding to all federal agencies to meet new data equity standards and requirements;
5. Committing the Domestic Policy Council to submit an annual public report regarding federal agencies' data practices and progress federal agencies are making towards the disaggregation of AA and NHPI data into recommended expanded categories;
6. Ensuring the inclusion of community and scientific expert voices, in all stages of federal statistical data collection, including its design and development, collection, compilation, processing, analysis, dissemination, and preservation; and
7. Creating and supporting a scientific advisory committee and a community advisory committee on data equity, similar to the structure adopted by the U.S. Census Bureau, with significant representation by Asian Americans, Native Hawaiians, and Pacific Islanders.

To these recommendations, we add two more that have emerged from community concerns about delays associated with the release of detailed origin data from the 2020 Census:[86]

8. Prioritizing timeliness between completion of data collection and reporting data back to community members; and
9. After the dissemination and outreach phase associated with data products, engaging with community members and researchers on evaluation and changes to data criteria and data systems.

For over two decades, the top priority of AA and NHPI communities with respect to data equity has been on data disaggregation, meaning the production of detailed origin/ethnicity data. Moving forward, it is clear that our communities' agenda with respect to data equity can be characterized as "disaggregation plus," meaning that improved federal standards for data collection remain a high priority, but the focus has expanded to include other important factors such as timeliness, accessibility, human-centered design, community inclusion, and federal agency recognition of subject matter and population expertise among community organizations and researchers alike.

TERMINOLOGY AND GLOSSARY

Research pertaining to federal agencies, data collections, racial equity, and communities of color often involves the use of specialized terms and acronyms. In some instances, there are also multiple and alternative terms that are used to describe racial and detailed origin populations as well as concepts, measures, and indicators related to various outcomes and processes. Below, we provide a description of terms used frequently in this report.

FEDERAL AGENCIES

OSTP - Office of Science and Technology Policy, part of the Executive Office of the President, advises the President "on the scientific, engineering, and technological aspects of the economy, national security, homeland security, health, foreign relations, and the environment." (Source: Office of Science and Technology Policy (White House) https://www.whitehouse.gov/ostp/)

OMB - Office of Management and Budget, part of the Executive Office of the President, is responsible for developing the federal budget, managing work across federal agencies, and coordinating and reviewing all significant federal regulations. (Source: Office of Management and Budget (White House) https://www.whitehouse.gov/omb/)

COMMUNITY ORGANIZATIONS

NCAPA - The National Council of Asian Pacific Americans

APIAHF - Asian and Pacific Islander American Health Forum

CNHA - Council for Native Hawaiian Advancement

EPIC - Empowering Pacific Islander Communities

National CAPACD - National Coalition for Asian Pacific American Community Development

SAALT - South Asian Americans Leading Together

SALDEF - Sikh American Legal Defense and Education Fund

SEARAC - Southeast Asia Resource Action Center

RACE AND ETHNICITY CATEGORIES[87]

American Indian or Alaska Native – A person having origins in any of the original peoples of North and South America (including Central America) and who maintains tribal affiliation or community attachment.

Asian – A person having origins in any of the original peoples of the Far East, Southeast Asia, or the Indian subcontinent including, for example, Cambodia, China, India, Japan, Korea, Malaysia, Pakistan, the Philippine Islands, Thailand, and Vietnam.

Black or African American – A person having origins in any of the Black racial groups of Africa.

Hispanic or Latino – A person of Cuban, Mexican, Puerto Rican, Cuban, South or Central American, or other Spanish culture or origin, regardless of race.

Native Hawaiian or Other Pacific Islander – A person having origins in any of the original peoples of Hawaii, Guam, Samoa, or other Pacific Islands.

White – A person having origins in any of the original peoples of Europe, the Middle East, or North Africa.

Asian American - Term used by community organizations, researchers, journalists, and public agencies to refer to residents of the United States who self-identify as Asian with respect to race or as one of the detailed Asian racial categories. Asian American should not be hyphenated.

Native Hawaiian or Pacific Islander or NHPI - Alternative term for the racial category of Native Hawaiian or Other Pacific Islander as currently maintained by the 1997 OMB standards.

AA and NHPI - Acronym that recognizes the fact that Asian American and NHPI are separate racial categories per the 1997 OMB standards.

AAPI - Asian American and Pacific Islander. Term has less common usage today, given that it does not explicitly mention Native Hawaiian as part of the NHPI racial category.

API - Asian Pacific Islander. Term in infrequent use today, given that Asian American is the preferred term to refer to residents of the United States who self-identify as Asian or as one of the detailed Asian racial categories.

APA - Asian Pacific American. Legacy term that is used by several organizations founded prior to the 1997 OMB standards on race and ethnicity.

APIA - Asian and Pacific Islander American. Legacy term that is used by several organizations founded prior to the 1997 OMB standards on race and ethnicity

ENDNOTES

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[1] Neil G. Ruiz, "Key Facts about the U.S. H-1B Visa Program," *Pew Research Center* (blog), April 27, 2017, https://www.pewresearch.org/fact-tank/2017/04/27/key-facts-about-the-u-s-h-1b-visa-program/

[2] We are grateful to Empowering Pacific Islander Communities (EPIC) for their thorough explanation of the web of relationships involving the United States and Pacific Islander communities https://www.empoweredpi.org/our-community

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ACKNOWLEDGMENTS

We are grateful for the assistance and advice of a number of the individuals and organizations listed below, and we look forward to working in partnership with a number of federal agencies to continue the important work ahead, to embed and advance data equity as a set of policies, practices, norms, and investments in as many agencies and programs as possible.

Julie Ajinkya, APIA Scholars

Terry Ao Minnis, Asian Americans Advancing Justice | AAJC

Daisy Kim, Asian and Pacific Islander American Health Forum (APIAHF)

Kham Moua, Southeast Asia Resource Action Center (SEARAC)

Gregg Orton, National Council of Asian Pacific Americans (NCAPA)

Ninez Ponce, UCLA Center for Health Policy Research

Tavae Samuelu, Empowering Pacific Islander Communities (EPIC)

Emma Shainwald, National Council of Asian Pacific Americans (NCAPA)

Sina Uipi, Empowering Pacific Islander Communities (EPIC)

Akil Vohra, Asian American LEAD

We are grateful to the Blue Shield of California Foundation, Henry Luce Foundation, Hewlett Foundation, Skoll Foundation, and Wallace H. Coulter Foundation for their financial support of AAPI Data and making reports like this possible. AAPI Data bears sole responsibility for any errors of fact or interpretation contained in this report.

AMERICAN EDUCATIONAL RESEARCH ASSOCIATION
FOUNDED 1916

October 3, 2022

Denice Ross
U.S. Chief Data Scientist
NSTC Subcommittee on Equitable Data
Office of Science and Technology Policy
[redacted]Building

Submitted via email [redacted]

Re: 87 FR 54269 - Request for Information; Equitable Data Engagement and Accountability

Dear Ms. Ross,

On behalf of the American Educational Research Association (AERA), thank you for the opportunity to provide feedback to the Request for Information (RFI) on Equitable Data Engagement and Accountability.

AERA is the major national scientific association of 24,000 faculty, researchers, graduate students, and other distinguished professionals dedicated to advancing knowledge about education, encouraging scholarly inquiry related to education, and promoting the use of research to improve education and serve the public good. In their work, many of AERA's members address persistent inequities in educational systems and seek to understand family, community, and economic structures that contribute to inequities. In working toward creating more equitable and inclusive educational systems, our members rely on federal data sets, including those collected by the National Center for Education Statistics (NCES) and the National Center for Science and Engineering Statistics (NCSES), and receive research grants from federal agencies, including the Institute of Education Sciences (IES) and the National Science Foundation (NSF).

We appreciate the work of the Equitable Data Working Group that resulted in the recommendations in the report, A Vision for Equitable Data. We look forward to working with the NSTC Subcommittee on Equitable Data in implementing the vision for data disaggregation, access, and accountability articulated in the report. In this response, we are focusing our remarks primarily on NCES, because of its long-term engagement in data innovation, access, and use and the potential of this agency for further advancement of OSTP's equity agenda.

We are responding to questions 1-4 and 7 in the RFI.

1. What are examples of successful collaborations involving equitable data between the Federal government and (a) Tribal, territorial, local, and State governments, or (b) local communities?

The National Academies of Science, Engineering, and Medicine provided recommendations to establish a system of indicators to better understand and combat inequity in the United States' education system in the 2019 report, Monitoring Educational Equity.[i] NCES is currently developing an equity dashboard that will implement many of the recommendations from this report.

As the subcommittee considers how best to address the report's broader implications (e.g., with states), we can point to a few examples of ongoing collaborations across the federal government and state and local governments:

- The National Center for Education Statistics (NCES) has provided funding and technical assistance for the Statewide Longitudinal Data Systems (SLDS) program dating back to the first awards in (FY 2006) to 14 states. During the FY 2019 grant cycle, states had the option of addressing equity in education as a priority in their data systems, with an additional option to test a school-level poverty measure as an alternative to free-and-reduced-price lunch eligibility. State education officials have partnered with NCES, participate in in conferences to share best practices, and develop resources shared across states on data governance, access, and interoperability.
- In administering the National Assessment of Educational Progress (NAEP), NCES works closely with state assessment coordinators and local coordinators who represent districts participating in the Trial Urban District Assessment (TUDA). These partnerships help in building trust and implementing feedback from state and district officials for NCES to ensure a representative sample for NAEP subject and Long-Term Trend assessments.
- Recent efforts to provide real-time data, particularly the Census Household Pulse Survey and the NCES School Pulse Panel, have engaged local stakeholders and provided timely information on the impact of the COVID-19 pandemic on individuals and schools.
- NCES and the Census Bureau are also working with states on reporting school-level finance data. This collaborative process has informed the refinement of data collection practices that will serve as a resource for states as the pilot School-Level Finance Survey transitions to a mandatory collection to align with the Civil Rights Data Collection (CRDC).

2. Among examples of existing Federal collaborations with (a) Tribal, territorial, local, and State governments or (b) local communities involving equitable data, what lessons or best practices have been learned from such collaborations?

In collaborating with state and local stakeholders on activities involving equitable data, federal agencies need to build trust and collective support for shared goals. This can be done through building connections through existing networks; engendering mutual support across states, districts, and local communities; and ensuring that local needs are being met.

To highlight one example highlighted in question 1, in a report detailing the progress of piloting the School-Level Finance Survey, NCES identified several challenges in testing the data collection: clearly communicating the importance of collecting data, lack of procedures for school-level reporting, and state legal requirements.[ii] Providing training and technical assistance and adjusting to local context is key to the success of collaborations involving federal agencies and state, local, and community stakeholders.

3. What resources, programs, training, or other tools can facilitate increased data sharing between different levels of government (Tribal, territorial, local, State, or Federal) related to equitable data?

We strongly support recent efforts to make data more accessible for use in policymaking and in research. The Foundations of Evidence-based Policymaking Act (Evidence Act) and the authorization of the National Secure Data Service (NSDS) in the CHIPS and Science Act have been important steps to facilitate linkages across data in the federal government that are frequently siloed. As the implementation of the Evidence Act and the development of the NSDS continue, we encourage the Office of Science and Technology Policy (OSTP) and the Office of the Chief Statistician to provide guidance for linking data within the NSDS to facilitate access to disaggregated data while also maintaining privacy and confidentiality.[iii]

4. What resources, programs, training, or other tools can expand opportunities for historically underrepresented scholars and research institutions to access and use equitable data across levels of government?

We applaud OSTP for expanding public access to research and data resulting from federal funding immediately upon publication in the memorandum, Ensuring Free, Immediate, and Equitable Access to Federally Funded Research. This is an important step that reaffirms the administration's commitment to scientific integrity and open science. This is one avenue that will also be helpful in increasing opportunities for historically underrepresented scholars to examine equitable data in their work.

Federal agencies can take several additional steps to expand access to and use of equitable data, including in partnership with state and local agencies:

- <u>Expanding grant opportunities for research use of data</u>. One example of this ongoing work is the Using Longitudinal Data to Support State Education Policymaking research grant program that IES launched in FY 2021. This grant program develops partnerships between state departments of education and researchers to examine state data to improve educational outcomes.
- <u>Building infrastructure to support research and data capacity within emerging research institutions</u>. We appreciate the inclusion of the new NSF program, Growing Research Access for Nationally Transformative Equity and Diversity (GRANTED), as an example of this work in the Equitable Data Working Group

report. Programs like GRANTED and NSF INCLUDES, and ongoing activities seeking to broaden the institutions receiving IES research grants[iv] are especially important in expanding access to equitable data.

- Building on the momentum of the OSTP memo, promoting the use of trusted data repositories and encouraging partnerships between agencies and existing repositories.[v] IES, NSF, and the National Institutes of Health have all provided guidance for developing data management plans that include details on how data from research grants will be stored. Federal agencies have also provided data sets for open, public access through data.gov. As important as this resource is, more can be done to provide information on restricted-use access to data, including survey data and administrative data for research use, and to expand policies and best practices for sharing data while preserving privacy and confidentiality. Along with the NSTC May 2022 report, *Desirable Characteristics of Data Repositories for Federally Funded Research,* IES recently released a guide to sharing data for education researchers that could be an example for additional guidance related to equitable data.[vi]
- Developing policies that can further facilitate research using equitable data by historically underrepresented researchers and institutions of federal research grants. These activities could include providing funding for course buyout and supporting training programs that engage emerging research institutions as lead partners with research-intensive universities in research that incorporates equitable data. It also could and should include supplemental funding as incentives to cultivate systemic change—ranging from postdoctoral positions for underrepresented early career scholars to collaborative partnerships with minority serving institutions.

7. In which agencies, programs, regions, or communities are there unmet needs, broken processes, or problems related to participation and accountability that could be remedied through stronger collaborations and transparency around equitable data?

We encourage OSTP and the NSTC Subcommittee on Equitable Data to reaffirm the role that federal statistical agencies have in collecting and reporting equitable data. Most relevant for education research, we call attention to the need for sufficient funding and staff for NCES, particularly for two of its key programs that produce equitable data.

NCES Longitudinal Studies

NCES longitudinal studies have been important for understanding contextual factors that administrative data may not capture and are of particular value for education researchers and policymakers. As an example, NCES recently released data from the Baccalaureate and Beyond survey highlighting the experiences of 2015-16 college graduates during the COVID-19 pandemic. As one key finding, Black graduates who received federal student loans on average owed more than 103 percent of the original amount they borrowed, compared to 73 percent owed by White graduates.[vii]

With the disruption and resulting impact that the COVID-19 pandemic has had across educational systems, students, the educator workforce, and communities, NCES longitudinal studies are even more essential for understanding the long-term effects and potential disparities on academic and non-academic outcomes. Robust resources and staff are essential for NCES to maintain these important equitable data indicators.

Statewide Longitudinal Data Systems

As important as administrative data systems have been to be able to examine intertwined aspects of equity among education, justice, health, and additional services, the SLDS program in particular has remained constrained. The SLDS program funded 28 states during the FY 2019 competition, with an average grant award of $3.3 million. Despite the number of states that received grants, 16 SLDS grant applications from states were not funded as part of the FY 2019 grants. In addition, due to essentially frozen funding for SLDS and the focus on one priority area (a decrease from two in prior years), the maximum amount for the grants awarded during this most recent cycle was lower than in previous competitions.

The research use of these systems has the potential to detail disparities that can inform policy solutions within state and local agencies. We strongly encourage increases into the investment for SLDS to allow NCES to continue to support current grants to state agencies on its current four-year cycle and to compete “off-cycle” grants that would address emerging equity issues. Increasing funding for SLDS also would expand the capacity and infrastructure for states and school districts to collect and report equitable data.

Thank you once again for the opportunity respond to this request. Please do not hesitate to call upon AERA if we can provide additional to help inform the work of the NSTC Subcommittee on Equitable Data.

Sincerely,

[redacted]

Felice J. Levine, PhD

[redacted]

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[iii] AERA previously commented on the Advisory Committee on Data for Evidence-Building that may also be a resource for the NSTC Subcommittee on Equitable Data in this area: https://www.aera.net/Portals/38/AERA%20Comment%20EAB-2021-001%20Data%20Evidence%20Building_FINAL.pdf

[iv] Throughout 2022, IES held DEIA Virtual Listening Sessions focused on broadening participation and diversity, equity, inclusion, and accessibility in education research. These sessions also highlighted data needs. https://ies.ed.gov/funding/listeningsessions.asp

[v] AERA previously commented on the OSTP call on trusted data repositories: https://www.aera.net/Portals/38/AERA%20Comments_OSTP%20RFC%20Draft%20Desirable%20Characteristics%20of%20Repositories_03-17-20_FINAL_v2.pdf.

[vi] Neild, R. C., Robinson, D., & Agufa, J. (2022). Sharing Study Data: A Guide for Education Researchers. (NCEE 2022-004). Washington, DC: U.S. Department of Education, Institute of Education Sciences, National Center for Education Evaluation and Regional Assistance. Retrieved from http://ies.ed.gov/ncee.

[vii] Henderson, M., Drummond, M., Thomsen, E., Yates, S., and Cooney, J. (2022). Baccalaureate and Beyond (B&B:16/20): A First Look at the 2020 Employment and Education Experiences of 2015–16 College Graduates (NCES 2022-241). U.S. Department of Education. Washington, DC: National Center for Education Statistics. Retrieved from https://nces.ed.gov/pubsearch/pubsinfo.asp?pubid=2022241.

AMERICAN
PSYCHOLOGICAL
ASSOCIATION
SERVICES, INC.

October 3, 2022October 3, 2022

NSTC Subcommittee on Equitable Data
Office of Science and Technology Policy
[redacted] Building
Washington, DC 20504

RE: OSTP Engagement and Accountability RFI

Dear Ms. Ross,

The American Psychological Association (APA) appreciates the opportunity to comment on the Office of Science and Technology Policy (OSTP), Subcommittee on Equitable Data of the National Science and Technology Council request for information. This request represents a step in the right direction towards ensuring that stakeholders across disciplines are represented in future efforts to collect, use, and distribute equitable data.

APA is the largest scientific and professional organization representing psychology in the U.S., numbering over 133,000 researchers, educators, clinicians, consultants, and students. For decades, psychologists have a played vital role in the development and use of equitable data. These contributions have been essential to the current standards of data collect. We offer the following comments in response to the RFI to ensure future policy changes to data collect, storage, and use is equitable and representative of underserved communities.

Data Collection Practices

Data is foundational to achieving any population-based behavioral health or health equity goal imaginable, as well as ensuring civil rights compliance by covered entities. Better national standards and uniform data collection practices could have an outsized impact on efforts to narrow health disparities. Yet complete data collection remains largely unavailable for many populations at greater risk of discrimination in healthcare settings and insurance coverage. Cross-agency data-sharing, analysis and reporting is essential to ensure adequate representation of underserved communities. Information sharing can aid efforts to better understand the nexus between social determinants of health, civil rights compliance, and health equity.

We recognize the important role demographic data plays in addressing discrimination and health disparities. At minimum, future policies rule should require disaggregated race, ethnicity, and disability data collection and reporting. The collecting agency or entity should consult with these groups on effective strategies for ensuring the availability and dissemination of data that is crucially needed to protect civil rights and achieve health equity. One important example is the gaps in data that exist for Asian American and Pacific Islander and Native American communities, partially due to historical aggregation of unique groups into larger umbrella terms that fail to properly represent their diversity. Similarly, people of Middle Eastern and North African descent are largely left out from federal data sets.

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Improve Data Availability

Barriers to data exist across society, including within government. The ability for researchers, policymakers, and the public to access relevant and useful information is often hindered by a lack of transparency or availability. Communities are often unaware of what data government collects and possesses. This hinders research and informed policymaking, including by individuals seeking to highlight data inequities or disparities across underserved populations. Transparency around data collection, increasing availability and uniformity would help to ease the burden on researchers and allow for more information to be gleamed from data currently collected.

In addition, data, especially that collected by government, should be made available to the extent possible to enable its use by outside entities. Increased availability of disaggregated, anonymized data is essential to enabling more research into underserved communities. The government should work to centralize and publicize current data resources.

APA has joined other likeminded organizations in signing onto the Transparency and Openness Promotion (TOP) Guidelines, a set of standards aimed at making research data and processes more open by default. The TOP guidelines offer several recommendations on open research data and availability that would assist government in improving data access.

Improve Planning and Cross-Agency Collaboration.

Agencies should continue to strengthen coordination with state and local public authorities to collect, disaggregate and report data as it relates to the hardest-hit populations, to address current disparities more effectively. This includes authorizing grants to state, local and territorial governments to support the modernization of data collection methods and infrastructure and disseminating that data to all relevant stakeholders. Information will guide the actions federal agencies can implement to address social determinants of health leading to poorer health outcomes among certain populations. To promote synergies within federal agencies as it relates to the health of our population, APA recommends the following steps: 1) integrate more behavioral analysis into national response efforts, including consideration of findings from the Behavioral Risk Factor Surveillance Survey, the Youth Risk Behavior Survey and other population-based survey findings, and 2) foster collaboration with health equity offices across government, along with federal agencies responsible for safety net programs, to mitigate underlying social determinants of health responsible health inequities and improve population health.

The Role of Technology

Address the unique role of technology and barriers to using technology. Many populations have unique issues. For example, older adults can use and benefit from technology. Some older adults may be unfamiliar with the technology and/or have functional or physical impairments that may require more training and support in the use of technology. The variation in tech platforms and uses across institutions is a barrier because consumers have to learn different systems and processes. Standardizing platforms as much as possible will reduce this barrier.[1, 2]

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[1] Kuerbis, A., Mulliken, A., Muench, F., Moore, A. A., & Gardner, D. (2017). Older adults and mobile technology: Factors that enhance and inhibit utilization in the context of behavioral health. Mental Health and Addiction Research. doi: 10.15761/MHAR.1000136

[2] Ma, Q., Chan, A. H., & Teh, P. L. (2021). Insights into older adults' technology acceptance through meta-analysis. International Journal of Human–Computer Interaction, 37(11), 1049-1062

Increase Outreach to Underserved Populations

For the government to truly collect more comprehensive and impactful data on underserved populations, it must seek to meet these communities where they are. Data collection methods should be created with the input of members of target populations to ensure effectiveness of language and collection methods. More effort must be made during the development stage to avoid harm. Research efforts designed at the federal level must translate easily and clearly to data collection efforts at the local level. This will help to increase the likelihood that data collection efforts are successful and equitable goals designed at the federal level are achieved when collecting data at the local level. Also, members of target communities should be employed to aid in the data collection process. Underserved populations may harbor resistance to data collection attempts from outsiders. Seeking to collect this data using members of the target community not only helps to increase effectiveness of collection, but also serves to provide the community with employment and engagement opportunities.

Data and Social Determinants of Health

Improved data collection and research on social determinants of health (SDOH) are two ways of improving alignment across federal agencies to address SDOH in policy and programs. The collection of data relating to SDOH should be consistent across all systems so that all providers, payers, and other stakeholders are collecting and reporting the same types of SDOH data. Another example is improving alignment among federal programs such as Medicaid, CHIP, SNAP, WIC, etc. to effectively address SDOH in a holistic way is measurement and documentation. Measuring SDOH has numerous barriers, including philosophical beliefs on the part of providers that it is not their place to be asking such questions, training barriers in not knowing how or what to ask patients, and practical barriers with challenges in identifying community-based interventions to address SDOH and ensuring patients receive these services once identified. If all third-party payers (Medicare, Medicaid, private insurers, etc.) required the same data to be collected, it would greatly increase provider participation and ease documentation burdens that currently exist. However, without actively addressing the aforementioned barriers to implementation, any efforts are unlikely to be fully successful. These steps, along with greater interoperability across electronic health data systems, would contribute greatly toward helping to align health services with community-based services addressing patients' health and social needs.

APA again thanks you for the opportunity to comment on this policy. If APA can be of any f [redacted] se contact Corbin Evans, Senior Director of Congressional and Federal Relations, a

[redacted]

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October 3, 2022

National Science and Technology Council Subcommittee on Equitable Data
Office of Science and Technology Policy
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RE: Office of Science and Technology Policy's Request for Information on Equitable Data Engagement and Accountability

The American Society for Biochemistry and Molecular Biology is an international nonprofit scientific and educational organization that represents more than 10,000 students, researchers, educators and industry professionals. The ASBMB strongly advocates for strengthening the science, technology, engineering and mathematics workforce, supporting sustainable funding for the American research enterprise, and ensuring diversity, equity and inclusion in STEM.

The White House Office of Science and Technology Policy (OSTP) published a request for information titled "Equitable Data Engagement and Accountability" on Sept. 2 seeking feedback on how federal agencies can better support collaboration with other levels of government, civil society, and the research community regarding the production and use of equitable data.

The ASBMB previously has recommended equitable data practices to the National Institutes of Health and the Department of Education and has compiled the following recommendations in response to the prompts provided in the RFI.

1. **What are *examples of successful collaborations* involving equitable data between the Federal government and (a) Tribal, territorial, local, and State governments, or (b) local communities?**

   No response.

2. **Among examples of existing Federal collaborations with (a) Tribal, territorial, local, and State governments or (b) local communities involving equitable data, *what lessons or best practices have been learned from such collaborations*?**

   No response.

3. **What resources, programs, training, or other tools *can facilitate increased data sharing between different levels of government (Tribal, territorial, local, State, or Federal) related to equitable data*?**

   Include Tribal leaders when looking to provide resources, programs, training, or other tools for Tribal governments.

   Unintended consequences are a frequent outcome when conducting research with Native American tribes due to academic researchers' lack of familiarity with their culture. It is therefore critical that informed consent beyond conventional institutional review board (IRB) review be upheld when collaborating with Tribal Nations by involving not only the community but also permissions from

Tribal leaders. Tribal nations must be given the opportunity to identify any potential adverse outcomes, and the efficacy of avoiding harmful outcomes is dependent on the Tribal leader's understanding of the assumptions and methods of the proposed research. And if a given research project is approved, it is critical that tribes be truly equal partners in study design, data collection, interpretation and publication. The National Science Foundation has strived to be a leading example in engaging and including Tribal nation voices within its community. It hosts an Indigenous STEM Affinity Group within the Inclusion Across the Nation of Communities of Learners of Underrepresented Discoverers in Engineering and Science national network and also has engaged in direct communication with Tribal leaders. As OSTP and other federal agencies outline new strategies for resources, programs, training, or other tools to facilitate increased data sharing with Tribal communities, the voices and opinions of Tribal leaders must be kept at the forefront.

4. **What resources, programs, training, or other tools *can expand opportunities for historically underrepresented scholars and research institutions to access and use equitable data across levels of government*?**

Include minority-serving institutions and emerging research institutions as an institution type in federal agency databases, such as the NIH RePORTER and the National Center for Science and Engineering Statistics surveys.

There is a significant disparity in graduate training diversity grants awarded to minority-serving institutions (MSIs) compared with other types of institutions, such as more established R1 universities. To ensure that funding decisions are equitable, public databases, such as the NIH RePORTER and the NSF Award Search, should include more descriptive categories within institution type, including MSIs and institutional classification (using the Carnegie Classification of Institutions of Higher Education). Even more helpful would be the further categorization of the seven federally recognized types of MSIs that serve distinct populations. Additionally, emerging research institutions (ERIs) should be included as an available institution type according to the definition used in the National Science Foundation for the Future Act.

Research has thoroughly established that MSIs strengthen the U.S. STEM workforce and increase the retention of students from historically marginalized backgrounds. Collecting and making public more detailed data on the institutions receiving federal grants will help hold funding agencies accountable. Agencies must ensure a significant percentage is being given to MSIs that have proved to be effective at retaining researchers from historically marginalized backgrounds.

Modernizing the technology infrastructure at MSIs, ERIs and rural areas.

Without better technology infrastructure, MSIs, emerging research institutions (ERIs) and rural communities will be ill-equipped to access and use equitable data (as defined by the OSTP Equitable Data Working Group in its 2022 report, A Vision for Equitable Data). To conduct research with large datasets, MSIs and ERIs need expanded broadband access and modernized technology to meet hardware, security and infrastructure requirements. In 2020, a nationwide survey demonstrated a strong need for better broadband infrastructure at MSIs. Connectivity, equipment, security and access to technology were cited as most important in supporting the goals and objectives of research programs at MSIs. Data storage, data management and data analytics were also reported as significant. Broadband must also be strengthened and expanded for the 20 to 30 percent of Americans in rural areas and Tribal lands that lack broadband internet to ensure equitable access to data.

Create standards for de-identifying data to support availability of disaggregated datasets.

The needs of historically marginalized populations from intersectional identities are lost when researchers and institutions lack clear standards and procedures for disaggregating data in a manner that is safe and adherent to data privacy. Furthermore, the equitable data must be sufficiently detailed to allow for increased depth of analysis to dissect trends in these smaller subsets or intersectional identities of larger populations. Individuals, organizations and communities then need access to these de-identified datasets to perform and report their own independent analyses. Each of these steps is essential for researchers to access and use data that will further identify and address inequities experienced by historically marginalized populations.

Better practices when collecting data on gender identity and sexual orientation.

The ASBMB has previously recommended that the NIH expand its data collection to include both intersectional identities and institutional classifications to produce more useful data tools. Federal agencies might publish demographic data, such as in the NIH Data Book, but it isn't always consistent in how it describes certain categories and should, in fact, contain additional categories. For example, these resources should not conflate sex and gender. The ASBMB recommends including gender identity and sexual orientation and using standardized language when collecting these data so that the agency will be better positioned to respond to issues facing lesbian, gay, bisexual, transgender or queer (LGBTQIA+) individuals.

5. **What resources, programs, training, or tools *can increase opportunities for community-based organizations to use equitable data to hold government accountable to the American public*?**

No response.

6. **What resources, programs, training, or tools *can make equitable data more accessible and useable* for members of the public?**

Require Federal agencies to publish a public report presenting relevant trends in their data.

Members of the public often do not have much experience with data analytics. If the public had access to summary reports from federal science agencies every few years that explained relevant trends in their data on a reoccurring basis, it would increase access, comprehension and allow the public to utilize the equitable data that is collected and provided by federal agencies. Importantly, these reports should be written in lay terms given that over half of the U.S. population reads at below a sixth grade level. The ASBMB recommends that OSTP require federal science agencies to generate, publish and distribute such reports to make equitable data more accessible and usable for members of the public.

Provide web-based embedded data analysis tools and methods within the database that are intuitive, thorough and robust.

Embedded data-visualization tools make it easier for the public to investigate and understand trends when using available databases. Without these tools, only those with knowledge of third-party data analytic software and programs can make the most of the public data. The NSF's National Center for Science and Engineering Statistics provides many tools, although the breadth of data that can be examined in the tools is sometimes limited. Federal agencies should ensure table and figures can be exported for use in studies and reports.

7. **In which agencies, programs, regions, or communities *are there unmet needs, broken processes, or problems related to participation and accountability* that could be remedied through stronger collaborations and transparency around equitable data?**

Enhance and standardize data collection on individuals with disabilities.

There are many limitations to collecting and reporting data on individuals with disabilities. Many of the limitations are highlighted in the National Center for Science and Engineering Statistics technical notes, including variable definitions of a disability, self-reporting nature of surveys, and inconsistent institutional records. Inequitable data and a lack of consistency in the way this information is provided and reported significantly hinders equity for disabled persons. The ASBMB recommends the OSTP take steps to further standardize data collection and reporting practices regarding the disability status of individuals in science and higher education.

Streamline and harmonize institutional review board (IRB) policies and permissions when collecting and reporting human research data.

IRBs are responsible for protecting the welfare, rights and privacy of human subjects during research activities, but their decisions are becoming increasingly inconsistent both within and across IRBs. These inconsistencies as well as the time-consuming and potentially costly process of getting IRB approval are barriers to equitable data. The ASBMB recommends the OSTP implement a toolkit for IRBs to regulate and better operationalize the ethical decision-making process. With a more structured toolkit, IRB decision-making will become more standardized to facilitate more timely, consistent and equitable scientific data collection from human subjects.

Include and empower members from underrepresented groups to be the leaders and researchers of the projects involving their communities.

As explained in our response to Question 3, it is critical to involve the communities that are part of a given research study. This recommendation extends beyond the Tribal community and should be applied to all historically marginalized populations. The scientific community must address the cultural barriers in academia that lead to strained relationships between universities and their local communities. A 2017 report suggested that future collaborations between universities and community leaders include more transformative discussions on race, power and privilege as well as encouraging universities to undergo intra-organizational changes.

The ASBMB has previously recommended the Department of Education and the National Institutes of Health support transparency and equity of federal data in several capacities. Below is a list of our prior recommendations regarding data equity and transparency that have yet to be implemented to the best of our knowledge.

The ASBMB encouraged the Department of Education to report the diversity of their reviewers.

The ASBMB recommended that the department research the diversity of its peer reviewers and conduct outreach to underserved institutions to facilitate grant-writing workshops. Currently, there is no public data on the diversity of peer reviewers. As the department collects data from grantees to fulfill the Executive Order to "assess whether underserved communities and their members face systemic barriers in accessing benefits and opportunities available pursuant to those policies and programs", we recommended the department also conduct research on the type of institutions and demographics of peer reviewers to determine which groups are underrepresented in peer review. Moreover, to support transparency, we asked that the department publish a report on its findings to the equity dashboard.

The ASBMB recommended the NIH consolidate and publish their data on DEAI-related activities.

Given that the agency has eight diversity offices, we recommended that the NIH house all data produced by culture and climate surveys and by all of its other DEAI initiatives in a public, centralized database. Publishing all information in one location (such as COSWD) will make it easier for the STEM community and the public to keep track of and evaluate the outcomes of the agency's DEAI-related activities. The NIH must be transparent if it is to be perceived as a leader in DEAI in STEM.

The ASBMB urged the NIH to add sexual orientation to the demographics of the NIH Scientific Workforce Recruitment Tool.

The ASBMB urged the NIH to include collecting data to better understand the barriers to inclusion for LGBTQIA+ scientists in the scientific workforce diversity plan by adding sexual orientation to the demographics of the NIH Scientific Workforce Recruitment Tool. LGBTQIA+ scientists are more likely to experience harassment and career obstacles than their non-LGBTQIA+ colleagues. As it currently stands, there is only one large-scale study about the experiences of LGBTQIA+ scientists, indicating that the research community needs to conduct more research to better understand the barriers LGBTQIA+ scientists face. The NIH, as the research agency leader, should initiate these research projects to better understand how they can support this community.

The ASBMB endorsed the LGBTQ Data Inclusion Act that, if passed, would require federal agencies to improve their survey demographics by including sexual orientation and gender identity as a voluntary option.

Federal agencies must be more vigilant and inclusive of the identities and unique struggles that face the LGBTQIA+ community. The ASBMB has endorsed the LGBTQ Data Inclusion Act that, if passed, would require federal agencies to improve their survey demographics by including sexual orientation and gender identity as a voluntary option. With better and more equitable data on gender identities and sexual orientation in combination with other metrics, advocates and agencies can identify and better tackle issues within the LGBTQIA+ community such as job security, sexual harassment and less adequate resources in the workplace.

The ASBMB supported establishing an NIH administrative data enclave.

There has been an increasing demand for access to sensitive information collected via the grants process. Such data includes information on peer review outcomes, progress reports, as well as, demographic information such as age range, sex/gender, race and ethnicity of individuals listed in NIH grant applications, etc. To address this demand, the NIH is considering making sensitive data available by establishing a data enclave. The research that will be made possible by the proposed data enclave will provide the opportunity for independent analyses of the NIH funding process, holding NIH accountable to taxpayers and the public. Analyses could be paired with the history of publicly-stated NIH funding policies and programs to provide a view of the consequences, intended or unintended, of how changes in NIH policies and funding levels have affected the landscape of NIH-funded research and the biomedical research enterprise. Armed with these new analyses, the NIH would be in an improved position to make further course corrections and adjustments that increase the efficiency of funding policies and programs to ensure the long-term viability of a robust biomedical research enterprise.

The ASBMB recommends that NIH and other federal science agencies establish a data enclave that provides equitable, transparent and accessible data on how taxpayer's dollars fund scientific research.

For further questions or discussion, please contact Sarina Neote, Director of Public Affairs, at [redacted]

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October 3, 2022

ATTN: National Science and Technology Council Subcommittee on Equitable Data
White House Office of Science and Technology Policy
Eisenhower Executive Office Building
[redacted]
Washington, D.C. 20504
Submitted by email to [redacted]

Re: Request for Information; Equitable Data Engagement and Accountability

Dear Director Nelson:

Thank you for the opportunity to respond to the Office of the Science and Technology Policy's Request for Information on Equitable Data Engagement and Accountability.

Benefits Data Trust (BDT) is a national nonprofit that improves health and financial security by harnessing the power of data, technology, and policy to provide dignified and equitable access to assistance. Together with a national network of government agencies and partners, we efficiently connect people today to programs that pay for food, healthcare, and more while helping to modernize benefits access for tomorrow. Since 2005, BDT has assisted people in submitting over one million public benefits applications and secured more than $9 billion in benefits for households across the country, helping to reduce hunger and poverty and build pathways to economic mobility.

We bring more than 15 years of experience in using data and technology to target outreach and awareness campaigns to connect people to essential benefits and services such as the Supplemental Nutrition Assistance Program (SNAP), the Special Supplemental Nutrition Program for Women, Infants, and Children (WIC) and Medicaid, informing public policy strategies, and incorporating human-centered design to ensure services are informed by – and responsive to – clients' needs. We welcome the opportunity to be part of the conversation improving access to public benefits.

In our response, we address federal actions that can promote access to public benefits, including (1) Providing permission and guidance to states in leveraging data to engage in cross-program outreach and enrollment; (2) Providing resources for states to easily verify eligibility data; and (3) Supporting health care plans and providers with access to information about enrollment in public benefits. Such actions have the power to ease access to benefits and reduce the frustration of individuals seeking assistance.

Thank you for your consideration.

Rachel Gershon, Senior Policy Manager, [redacted]

Public benefits like SNAP, WIC, and Medicaid are powerful tools to address personal deprivation, strengthen the economy, and encourage economic growth. Assistance reduces hunger, lifts people out of poverty, and substantially decreases mortality rates.[1] And yet, for years, public benefits policy has prioritized preventing fraud and abuse over promoting efficiency, effectiveness, or equity. This has exacerbated rather than reduced racial and other inequities. As a result, benefits are hard to access and use, with more than $80 billion in assistance going untapped annually, and millions of children, older adults, veterans, and families needlessly going hungry.[2] Government agencies collect the same information and documentation repeatedly and enforce archaic rules that prevent eligible people from receiving assistance.

Given advances in data and technology, the Biden administration has the opportunity to leverage equitable data and advance *true* program integrity that prevents fraud and abuse *and* ensures that eligible people receive assistance efficiently and equitably**.** As noted in the White House National Strategy on Hunger, Nutrition, and Health (National Hunger Strategy"), states should engage in "cross-enrollment of eligible people across SNAP, Medicaid, and other federal programs."[3] In order to engage in cross-program outreach and cross-enrollment activities, states and localities have voiced to us a need for guidance. **Notably, coordinated permission and guidance at the federal level regarding how to leverage data (with appropriate consent) would empower states, localities, and community-based organizations to ensure better access to public benefits for their communities.** In addition to building upon the National Hunger Strategy, these recommendations fit well with President Biden's Executive Order on Transforming Federal Customer Experience and Service Delivery to Rebuild Trust in Government, which aims to meet Americans experiencing key life events with equitable access to assistance.

1. What are examples of successful collaborations involving equitable data between the Federal government and (a) Tribal, territorial, local, and State governments, or (b) local communities?

Below are examples of successful collaboration by federal and state government entities to improve access to public benefits.

A. Efforts to leverage data to conduct effective outreach. As more people know about the assistance available to them, more will be able to access them. States and the administration have engaged in innovative ways to let people know which benefits are available to them, especially using enrollment data for benefits with similar eligibility criteria. For example:

- **Using Pell Grant data to increase access to EBB and ACP.** The Education Department informed Pell Grant recipients about the Emergency Broadband Benefit (EBB) and is emailing over six million Pell Grant recipients this award year to let them know that they are eligible for the Affordable Connectivity Program (ACP) and how to sign up.[4]
- **Using other data sources to increase access to ACP.** The Social Security Administration, Department of Education, Department of Veterans Affairs, and Department of Housing and Urban Development are delivering outreach for the ACP.[5]
- **Using SNAP and Medicaid data to increase access to WIC.** BDT partners with several states, using SNAP, Medicaid, and other administrative data to provide data-driven outreach to individuals likely eligible for WIC through text messaging, with evidence of increased WIC certification.[6] Several other state WIC agencies have used existing data to identify individuals likely eligible for WIC, notified those individuals, and helped them apply.[7] The United States Department of Agriculture (USDA) is currently

implementing new WIC funds from the American Rescue Plan to increase outreach efforts, and BDT looks forward to how data-driven outreach can be leveraged.

- **Using Medicaid data to increase access to SNAP.** A peer-reviewed study by economists at the Abdul Latif Jameel Poverty Action Lab and BDT found that targeted outreach and telephonic application assistance *tripled* enrollment in SNAP among Medicaid enrollees aged sixty and older. This intervention was observed to address equity considerations, with increased enrollment for Black individuals, individuals with non-English primary languages, and older adults.[8]
- **Using data to connect students to assistance.** The Department of Education sent a Dear Colleague Letter to all public and private higher education institutions informing them that they can use Free Application for Federal Student Aid (FAFSA®) data to communicate with students about other public benefit programs that they may be eligible for, such as SNAP and ACP. The letter encourages colleges to coordinate with campus stakeholders to inform their campus community of these benefits.[9] And, as announced last week in the National Hunger Strategy, "USDA and [the Department of Education] will establish a Memorandum of Understanding (MOU) to conduct joint outreach to Pell Grant recipients and others to inform them of their potential eligibility for SNAP benefits."[10]

B. Other efforts to facilitate enrollment and maintenance of coverage

- **Using already-verified information to facilitate enrollment in health care assistance programs.** The administration leverages the Federal Data Services Hub to assist states with Medicaid, Advanced Premium Tax Credit, and Basic Health Program eligibility verification via secure, verified information.
- **Using already-verified information to facilitate enrollment in phone and internet assistance.** The administration leverages the National Verifier to assist with Lifeline and ACP eligibility verification via secure, verified information.[11]
- **Engaging in cross-program enrollment.** There are a number of pathways for states to use already-verified information to engage in cross-program enrollment, including *ex parte* renewal, Express Lane eligibility, and the Combined Application Project.[12] The Centers for Medicare and Medicaid Services, in particular, has been leveraging cross-program enrollment to address access in Medicaid (including *ex parte* guidance in anticipation of the end of the Public Health Emergency) and Medicare Savings Programs (with the pending enrollment processes Notice of Proposed Rule-making signaling the use of Low-Income Subsidy information to streamline Medicare Savings Program enrollment).[13] New Mexico just launched a new program to automatically connect eligible families with WIC when they apply for SNAP, Medicaid, or Temporary Assistance for Needy Families (TANF).[14]

C. Efforts to provide the states and the public with up-to-date program information

- **Providing the public up-to-date program information.** The Centers for Medicare and Medicaid Services (CMS) hosts a dynamic set of tools to share waiver and state plan amendments documentation that informs states and the public of current Medicaid policy.[15] USDA offers a website of state-by-state COVID-19 waiver document and waiver approvals for SNAP.[16] Access to data oncurrent program parameters allows researchers, evaluators, and the public to consider how those rules affect access to public benefits for individuals and the equitable administration of those benefits.

2. Among examples of existing Federal collaborations with (a) Tribal, territorial, local, and State governments or (b) local communities involving equitable data, *what lessons or best practices have been learned from such collaborations*?

In the course of using data to engage in application assistance, BDT has a number of lessons learned for using data to ensure equitable access.

A. Use data to engage in a coordinated, comprehensive, "no wrong door" approach to benefits access. In order to ensure that people can effectively get the benefits information they need, it is crucial that state and federal governments offer multiple access points – whether online, over the phone, in-person at government offices, or in-person at sites in the community where people already frequent.

B. Consider how siloed policy and administration at the governmental level can amplify barriers for the individual. For instance, separate applications for different benefits with similar eligibility requirements, requiring submission of the same verifications to different agencies, uncoordinated renewal timelines, and siloed policy, administration, and compliance requirements broadly increase burdens on a population already experiencing chronic scarcity. It also puts pressure on the human services workforce with added complexity.

C. Consider how program integrity standards and program evaluation activities may hamper access initiatives. Initiatives to use data to improve access may run into barriers if incentives are not aligned on the program integrity side of program administration. Current program integrity measures disincentivize administering agencies from pursuing solutions that reduce burdens and barriers to public benefits access, by focusing financial penalties and significant efforts to keeping ineligible people off benefits.

D. Incorporating clear consent language and increasing an individual's ownership of data can help provide guardrails in data-sharing processes. Building in consent for how individuals want their data shared, and how they want to be contacted, can improve systems for maintaining benefits.

E. Include stakeholders who are participants, eligible non-participants, and community-based organizations that involve benefit design, implementation, and evaluation. Persons with lived experience with benefits have access to valuable data about how systems work, and how they can be better designed.

3. What resources, programs, training, or other tools can facilitate increased data sharing between different levels of government (Tribal, territorial, local, State, or Federal) related to equitable data?

Leveraging data to improve access to benefits holds promise, but it can be challenging for state and local governments to understand what is allowed. BDT has published resources to assist with this process, including: (1) A Medicaid churn toolkit for states to engage in data-informed practice to keeping eligible people enrolled[17]; (2) A WIC coverage toolkit for states to leverage data from Medicaid and SNAP to increase enrollment[18]; and (3) A SNAP texting guidebook to help county and state government staff address costly churn by leveraging text messaging.[19]

In addition, last week, the White House Conference on Hunger, Nutrition, and Health announced BDT's commitment to "publish a new toolkit in early 2023 to help states and higher education institutions identify and enroll eligible college students in public benefit programs like SNAP, Medicaid, and the new Affordable Connectivity Program”[20]

7. In which agencies, programs, regions, or communities *are there unmet needs, broken processes, or problems related to participation and accountability* that could be remedied through stronger collaborations and transparency around equitable data?

Please find below our set of recommendations for remedying unmet needs in the public benefits space using stronger collaborations and transparence around equitable data.

A. Make it easier for individuals to understand their public benefit options. Despite meeting the eligibility criteria for multiple public benefit programs, individuals often connect to only a subset of programs for which they are eligible. Cross-benefit outreach and enrollment assistance can be a particularly successful strategy for states to connect individuals with needed benefits. We recommend that the Biden administration build on the National Hunger Strategy to provide funding and guidance to support successful outreach and enrollment activities. In particular, the administration should consider:

- **Publishing guidance for states to feel more comfortable engaging in cross-benefit outreach activities and enrollment activities.** Leveraging data that government agencies already have on hand can unlock opportunities to increase enrollment across benefit programs, but many agencies grapple with data security and privacy concerns that can make them hesitant to take advantage of these opportunities. For example, specific guidance on data-sharing between benefit programs to facilitate outreach and enrollment can help states reach across silos to help eligible individuals access benefits. When states express hesitance for how eligibility could be streamlined across two programs, joint guidance from both federal agencies overseeing those benefits would help spur positive changes.
- **Creating dedicated (or braided) funding that facilitates cross-benefit outreach and enrollment activities.** Even when funding is available to government agencies and community-based organizations to promote benefits access, it is typically focused on one (or just a few) benefits, causing efforts to become siloed. Dedicated and coordinated funding can help state agencies fund cross-benefit outreach.

B. Make it easier to verify eligibility. Verifying documentation is another area where an individual can face major barriers in accessing and maintaining benefits. States and localities have engaged in creative solutions for allowing documents to be uploaded using multiple methods. For example, Minnesota WIC’s policies allow documentation obtained by phone to satisfy income, residence, and identification requirements.[21] The federal government could do more to help states verify eligibility using existing data sources such as the Federal Data Services hub and the National Verifier/Lifeline.

- **Leverage federal data sources to streamline verification processes.** Federal data sources such as the Federal Data Services Hub and the National Verifier should be expanded to help states more easily verify documents and reduce the frustration of applying for and maintaining benefits.[22] They offer secure, verified information that states can use. We can improve the system by allowing more benefits to utilize these tools. For example, state agencies can use the Federal Data Services Hub to verify Medicaid eligibility but are not allowed to use that same information to verify SNAP eligibility. States should be allowed to leverage the Federal Data Services Hub to verify eligibility. The National Verifier could be leveraged to expand beyond its existing programs to reduce the burden of multiple verifications on states and individuals.

C. Support health care plans and providers with access to information about enrollment in public benefits. In our work with health plans, we hear that they often lack sufficient and timely access to data on what public benefits their members are not enrolled in. Sharing such information (with the member's consent) can improve population health and promote health equity. For example:

- Knowledge of a member's enrollment status in public benefits is helpful for determining opportunities to connect that member with assistance.
- Information about upcoming renewal requirements can be helpful in reminding members to keep their contact information up to date with state systems and offering targeted assistance for people who need help renewing their benefit.
- Knowing which members have been recently disenrolled from public benefits can help plans and providers identify who is at risk of losing access to basic assistance.

We are glad to see that the Office of the National Coordinator for Health Information Technology (ONC) and its partners are working on making social drivers of health needs and interventions part of a standardized and well-adopted part of Health Information Systems, including electronic health records. We are also glad to see the Trusted Exchange Framework Common Agreement (TEFCA) includes government benefits as a data element that can be shared and look forward to its implementation and further opportunities to guide the process.

We recommend that, in the process of including public benefits information into health information systems, care is taken to consider which information would be most helpful for plans and providers. For example, data on upcoming renewals and recent dis-enrollments may be particularly helpful for identifying members with application assistance needs. Routinely updating information is also important, as members can come on and off public benefits frequently.

D. Research. Understanding the power of public benefits, and the best way to improve them, relies on research. We recommend that the administration consider:

- Encouraging states to publish data that can be used to analyze how well a benefit is taken up among eligible individuals, including numbers of applications, denial rates, denial reasons, disenrollment rates, and disenrollment reasons, disaggregated by demographic factors important for equity.
- Funding research to understand (1) issues related to equity and access to public benefits; and (2) the relationship of public benefits to economic, health, and education (especially higher education) outcomes.
- Funding quantitative, qualitative, and mixed-methods research that includes individuals with lived experience in research design and planning.
- Providing guidance to states regarding engaging in equity research, including considerations for disaggregating data, defining equity, and measuring equity.

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[1] Brian P Lee, Jennifer L Dodge, and Noral A. Terrault. Medicaid Expansion and Variability in Mortality in the USA: A National, Observational Cohort Study. The Lancet Public Health 7:1 (December 2, 2021) (Linking Medicaid expansion to decreased mortality). Signe-Mary McKernan, Caroline Ratcliffe, and Breno Braga. The Effect of the US Safety Net on Material Hardship Over Two Decades. Journal of Public Economics 197 (May 2021) (Increased participation in TANF, SNAP, Medicaid, and the Children's Health Insurance Program (CHIP) decreases hunger and other material hardship).

[2] The figure is based on BDT estimates of the dollar amount of benefits that eligible individuals are not enrolled in based on the most recent government data publicly available.

[3] White House. Biden-Harris Administration National Strategy on Hunger, Nutrition, and Health (September 2022)

[4] U.S. Department of Education. Department of Education Launches Outreach Campaign to Millions of K-12 Students and Federal Pell Grant Recipients Now Eligible for Monthly Discounts on Broadband Internet Service (May 12, 2021). White House. Fact Sheet: Vice President Harris Marks Important New Milestone in Administration's Efforts to Cut Costs for American Families (July 21, 2022). The White House. Biden-Harris Administration Making "Back to School" Drive to Help Students and Families Get Free High-Speed Internet (September 15, 2022).

[5] White House. Fact Sheet: Vice President Harris Marks Important New Milestone in Administration's Efforts to Cut Costs for American Families (July 21, 2022).

[6] Maneely, J. and Neuberger, Z. Benefits Data Trust and Center on Budget and Policy Priorities. Using Data Matching and Targeted Outreach to Enroll Families with Young Children in WIC (2022).

[7] Center on Budget and Policy Priorities and Benefits Data Trust. Assessing Your WIC Certification Practices (2022).

[8] Amy Finkelstein and Matthew J. Notowidigdo. Take-Up and Targeting: Experimental Evidence from SNAP. The Quarterly Journal of Economics. 134(3):1505-1556 (August 2019)

[9] United States Department of Education. Biden-Harris Administration Takes Action to Support Students' Basic Needs and Mitigate the Spread of COVID-19 at Colleges and Universities (January 20, 2022)

[10] White House. Biden-Harris Administration National Strategy on Hunger, Nutrition, and Health (September 2022)

[11] For more information on the federal data services hub and the national verifier, see Sonal Ambegaokar, Zoë Neuberger, and Dorothy Rosenbaum. Opportunities to Streamline Enrollment Across Public Benefit Programs. Center on Budget and Policy Priorities and Social Interest Solutions (November 2, 2017)

[12] see Sonal Ambegaokar, Zoë Neuberger, and Dorothy Rosenbaum. Opportunities to Streamline Enrollment Across Public Benefit Programs. Center on Budget and Policy Priorities and Social Interest Solutions (November 2, 2017)

[13] Centers for Medicare and Medicaid. State Health Official Letter RE: Promoting Continuity of Coverage and Distributing Eligibility and Enrollment Workload in Medicaid, the Children's Health Insurance Program (CHIP), and Basic Health Program (BHP) Upon Conclusion of the COVID-19 Public Health Emergency (March 3, 2022); Centers for Medicare and Medicaid. Fact Sheet: Streamlining Eligibility & Enrollment Notice of Proposed Rulemaking (August 31, 2022).

[14] New Mexico first in nation to connect Human Services Department and Department of Health WIC services to combat child hunger (June 9, 2022)

[15] See CMS Waiver List and Medicaid State Plan Amendments

[16] See SNAP: COVID-19 Waivers by State

[17] Jamila McLean, BDT. Medicaid Churn Toolkit.

[18] Center on Budget and Policy Priorities and Benefits Data Trust. Increasing WIC Coverage Through Cross-Program Data Matching and Targeted Outreach (2022)

[19] Katie Sullivan, Sara Soka, and Keith Barnes. Using Text Message Outreach to Reduce SNAP Churn (2021)

[20] The Biden-Harris Administration Announces More than $8 Billion in New Commitments as Part of Call to Action for White House Conference on Hunger, Nutrition, and Health (September 28, 2022)

[21] Center on Budget and Policy Priorities and Benefits Data Trust. Assessing Your WIC Certification Practices (2022).

To: **Office of Science and Technology Policy (OSTP)**

From: **Casey Family Programs**

Re: **Request for Information: Equitable Data Engagement and Accountability**

Date: **October 3, 2022**

Thank you for the opportunity to provide comments in response to the Office of Science and Technology Policy's (OSTP) request for information around the production and use of equitable data.

Casey Family Programs (Casey) was founded in 1966 and is the nation's largest operating foundation focused on providing, improving, and ultimately preventing the need for foster care. We provide strategic consultation, technical assistance, data analysis, and independent research on child welfare policies and practices to improve outcomes for children and families. Casey also works directly with children and families in our field offices across the country to develop and demonstrate effective, practical solutions to safely reduce the need for foster care, improve well-being, and secure safe and lifelong families for every single child in our care. Casey's perspectives are informed by our own experiences working with child welfare agencies in all 50 states, the District of Columbia, Puerto Rico, the U.S. Virgin Islands, and with 16 American Indian tribal nations.

Background

All families deserve to be valued, respected, and honored, and children should be with their families whenever possible. The federal government has an important role and opportunity to identify and address policy and practice barriers that contribute to disparate outcomes and inequities across child welfare involved populations and the collection, production, and use of equitable data is a key tool in this process. Currently, there are significant gaps in what we know about children and families involved in the child welfare system, including Latinx, Black/African American, LGBTQ+ and American Indian and Alaska Native children and families, which impacts our ability to support all children, youth, and families. Based on what Casey has learned from our work to improve outcomes for children, youth, families, and communities across the country, we offer the following comments and considerations in response to the questions posed.

1. What are *examples of successful collaborations* involving equitable data between the Federal government and (a) Tribal, territorial, local, and State governments, or (b) local communities?

Two examples of successful collaborations in which Casey participates are:
Race Equity Improvement Collaborative. In order to provide and expand opportunities for peer-to-peer learning and sharing of information, Casey Family Programs has been working with 15 state child welfare agencies to advance race equity in child welfare by convening and supporting a race equity improvement collaborative. Members of the collaborative determined that it was

important to create a framework that could guide the work. In creating a framework, the intention of participants was to:

- Establish a clear vision: *Ultimately, we envision a child and family well-being system that is free of structural racism and that benefits all children, families, and communities equitably … and where outcomes for vulnerable children and families can no longer be predicted by race or place.*
- Create a roadmap for the collaborative work going forward.
- Identify goals and objectives, particularly on the use of disaggregated (by race and ethnicity) data to reveal root causes, measure progress and inform decisions.
- Establish a set of values and guiding principles for the collective effort.
- Prepare each jurisdiction to have difficult and uncomfortable conversations through utilization of “agreements” designed to create a healthy environment for the work.
- Offer a glossary of terms designed to create clarity and alignment for the work across the collaborative.

Thriving Families, Safer Children. Casey supports and engages in cross-sector collaboration and the development of aligned goals to help address the conditions and social determinants of health that are negatively impacting outcomes for children and families. A key opportunity for this lies in encouraging states, Tribes, and grantees to coordinate data collection, programs, financing, and information sharing. For example, the U.S. Children’s Bureau, Casey Family Programs, the Annie E. Casey Foundation, and Prevent Child Abuse America launched a first-of-its-kind effort — Thriving Families, Safer Children: A National Commitment to Well-Being[1] —which works across the public, private and philanthropic sectors to assist jurisdictions in developing more just and equitable systems that benefit all children and families and break harmful intergenerational cycles of trauma and poverty. Recently, the Centers for Disease Control joined as a collaborating organization.

2. Among examples of existing Federal collaborations with (a) Tribal, territorial, local, and State governments or (b) local communities involving equitable data, *what lessons or best practices have been learned from such collaborations*?

In order to equitably collect and analyze data, as well as report and disseminate findings, it is critical to involve a diverse set of stakeholders who are representative of a broad cross-section of impacted communities. Stakeholders come with unique perspectives on how to interpret the data, how to best communicate findings to their communities, and to help determine any potential implications the data collected may have in policy and practice. Following are some of the strategies and resources Casey has utilized to ensure more equitable, diverse, and comprehensive stakeholder engagement:

Engage experts with lived experience in an authentic and equitable way. Family Voices United[2] is a collaborative project supported by Casey Family Programs that works closely with partners in multiple states and jurisdictions to elevate the voice and perspective of young people,

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[1] https://www.acf.hhs.gov/media/press/2020/first-its-kind-national-partnership-aims-redesign-child-welfare-child-and-family

[2] https://familyvoicesunited.org/

parents, and kinship caregivers involved with the child welfare system. This partnership developed a *Constituent Voice Assessment Toolkit*[3] with best practice examples for engaging constituents.

Include individuals with lived experience in the Request for Proposals (RFP) review committee. When hiring a research contractor, it is common practice to solicit RFPs. In addition to engaging the community and people with lived experience in co-creating questions, we encourage inclusion of them as equal partners in the decision-making process.

Hire and encourage partners and grantees to hire individuals with lived expertise to ensure the work is centered on youth and family voice in an authentic and meaningful way. For example, there are several Parent Partner[4],[5] and multi-disciplinary parent legal representation programs[6] across the country, for which a growing number of empirical studies reveal the following outcomes:

- Higher rates of reunification for those parents who have participated
- Lower rates of reentry for children involved in the program
- Increased participation in services and court hearings

Authentically and consistently engage youth, parents and families who experienced the child welfare system.[7] Parent engagement and partnership is a critically important tool for keeping children and families safe and is necessary to advance equity and achieve the transformation we need in child welfare. Partnering and co-designing with individuals who have lived expertise in the child welfare system as part of these teams has been an enormous asset to the learning and ultimate progress toward shared goals, including the advancement of equity. Individuals with lived expertise should be engaged at all levels of the system as:

- Experts on what their family needs at the individual case level;
- Peer mentors who offer support and guidance to those trying to navigate the system;
- Consultants who participate in leadership and decision-making on policy development implementation and evaluation; and
- Co-designers and active participants in system transformation.

Invest resources to increase the outreach, communication, and engagement with a broad range of children, youth, parents, and caregivers (including foster and adoptive parents and kinship caregivers) representing different experiences including reunification, foster care placement, guardianship, and adoption. The following are some populations who should be included as partners in advancing equity and should be at the table in the design of programs to provide supports and services as well as a key partner in working to assess equity:

- Fathers and paternal family members who are all too often discounted;[8]
- Black youth, families, and community leaders;
- Native American and Alaska Native youth, families, and community leaders;
- Latinx youth, families, and community leaders;

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[3] https://familyvoicesunited.org/voices/constituent-voice-assessment
[4] https://www.casey.org/parent-partner-program/
[5] https://www.casey.org/Appendix-A-Research-Parent-Partner-Programs/
[6] https://cfrny.org/wp-content/uploads/2021/03/Effects-of-an-interdisciplinary-approach-to-parental-representation-in-child.pdf
[7] https://www.casey.org/constituency-engagement/
[8] https://www.casey.org/engaging-fathers-prevention/

- Alumni of foster care;
- Parents who are currently and formerly involved in the child welfare system;
- Relative/kinship caregivers formally and informally caring for children;
- Youth and caregivers who identify as LGBTQ+2S, people with disabilities, or immigrants;
- Pregnant/expecting and parenting youth in foster care; and
- Youth who have experienced trafficking while in foster care and their caregivers.

Additional resources to engage those with lived experience in the child welfare system:

- To learn more about examples and strategies to prioritize constituent voice see *How Can We Prioritize Constituent Voice and Choice?*[9]
- *Birthparent National Network*[10] has developed a briefing series *What Parents Say About…*[11]

3. What resources, programs, training, or other tools *can facilitate increased data sharing between different levels of government (Tribal, territorial, local, State, or Federal) related to equitable data*?

The following recommendations address two specific opportunities for increased data sharing: **The federal rules on funding for Comprehensive Child Welfare Information System (CCWIS)** development discourage child welfare agencies from partnering and sharing system data with outside private agencies and courts. This impacts their ability to educated and collaborate with innovative agencies focused on addressing inequalities in certain communities and populations. Investigating how to provide greater flexibilities to child welfare agencies to facilitate data sharing across systems could help to address inequities and reduce negative outcomes for overrepresented populations in the child protection system.

We encourage the development of strategies to **enhance cooperation and collaboration between states and Tribes as contemplated by the Indian Child Welfare Act**, which is an important mechanism for addressing disparities faced by American Indian and Alaska Native children. Specifically, the Federal Adoption and Foster Care Analysis and Reporting System[12] (AFCARS) currently does not collect data on American Indian and Alaska Native children and Indian Child Welfare Act (ICWA) compliance. We encourage the development of a process on how to report this data equitably and inclusively through AFCARS.[13]

6. What resources, programs, training, or tools *can make equitable data more accessible and useable* for members of the public?

The Center for the Study of Social Policy (CSSP), in partnership with Casey Family Programs, created a series of resources entitled, *Our Identities, Ourselves*, to share best practices for collecting more nuanced and accurate data about race, ethnicity, and other demographic

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[9] https://www.casey.org/constituent-voice-choice/
[10] https://ctfalliance.org/partnering-with-parents/bpnn/
[11] https://ctfalliance.org/partnering-with-parents/bpnn/
[12] https://www.acf.hhs.gov/cb/data-research/adoption-fostercare
[13] https://www.acf.hhs.gov/cb/monitoring/child-family-services-reviews

information including sexual orientation, gender identity and expression, national origin, language spoken, disability, religion, and tribal affiliation in child welfare agencies nationwide. These tools are intended to assist caseworkers and service providers in asking youth and families about their racial and ethnic identities in more accurate, inclusive, and affirming ways, and to guide system leaders and data administrators in how to better report and incorporate that information to support them. The series includes:

- *Our Identities, Ourselves: A Guide to Anti-Racist Data Collection for System Leaders and Data Administrators* – Guiding principles and best practices for applying an anti-racist and equity focused lens to data collection, analysis, usage and reporting within child welfare systems.[14]
- *Our Identities, Ourselves: A Guide to Anti-Racist Data Collection for Case Workers and Other Frontline Staff* – A tool for case workers and frontline staff in collecting demographic data from young people and families.[15]
- *Our Identities, Ourselves: Rights Guide for Young People and Families* – A guide for young people and families in understanding their rights when asked questions about their identities.[16]
- *Our Identities, Ourselves: An Anti-Racist Review on Collecting Accurate Data on Race and Ethnicity*[17]

7. In which agencies, programs, regions, or communities *are there unmet needs, broken processes, or problems related to participation and accountability* that could be remedied through stronger collaborations and transparency around equitable data?

Currently, the data and method for collection varies across programs and child welfare agencies, including the type of data and the options given to individuals to self-report, resulting in some significant gaps in data collection and reporting. For example, AFCARS collects data in a number of demographic areas including race, ethnicity, age, gender, and number of placements, but does not collect data on sexual orientation or gender identity. Additionally, most data collected by state child welfare agencies does not further disaggregate race/ethnicity to identify locally relevant groups and subpopulations that could be misclassified under the standard minimum categories.

While there are some significant gaps in what data are currently collected, following is what we do know. Despite reductions in the number of Black children in foster care over the past few years, in many communities they continue to be disproportionally overrepresented, making up almost one-quarter of children in care, but only 14% of the general population.[18] For some communities, this kind of disparity exists at every decision point within the child protection system. In many

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[14] https://cssp.org/resource/our-identities-ourselves-a-guide-to-anti-racist-data-collection-for-system-leaders-and-data-administrators/

[15] https://cssp.org/resource/our-identities-ourselves-a-guide-to-anti-racist-data-collection-for-case-workers-and-other-frontline-staff/

[16] https://cssp.org/resource/our-identities-ourselves-rights-guide-for-young-people-and-families/

[17] https://cssp.org/resource/our-identities-ourselves/

[18] Children's Bureau, Administration On Children, Youth And Families, Administration For Children And Families, U. S. Department Of Health And Human Services (2020). *AFCARS Foster Care File, 6-month periods (FY2015B - 2020A)* [Dataset]. National Data Archive on Child Abuse and Neglect. https://doi.org/10.34681/rf96-fh32

communities, Black children are four times more likely than non-Black children to be removed from their homes,[19] and are more likely than their white peers to experience negative outcomes, including a greater likelihood of being reported or having a substantiated report of maltreatment, longer lengths of time spent in foster care, less stability of placement and lower rates of reunification.[20]

American Indian and Alaska Native children continue to be removed from their homes at three times the rate of non-Native children. For Native children who are adopted, 56% are placed with non-relatives, outside of their communities and culture. American Indian and Alaska Native children are overrepresented in the child welfare system in 17 states, and Black children in 40 states.[21]

For Latinx families and children, the national data do not reflect disparities in rates of removal, though we know from our work at the community level that disparities exist in some cities and counties.[22] We also do not collect national data on youth who identify as lesbian, gay, bisexual, transgender, queer or questioning and two-spirit (LGBTQ+2S), but we have some data from smaller studies that show as many as one in three youth in foster care identify as LGBTQ+2S or gender nonconforming,[23] LGBTQ+2S youth are 3.8 times more likely to experience childhood sexual abuse, 1.2 times more likely to be physically abused by a caregiver, and nearly 2.5 times more likely to enter foster care than their heterosexual peers.[24]

Advancing equity and supporting underserved communities impacted by the child welfare system is complex and requires comprehensive systems focused strategies – of which data collection and analysis is a critical component. But while data is critical to informing equitable solutions, it is important to note that for some communities, excessive data collection can feel like surveillance and intrusion, not a mechanism for providing better assistance. Being clear and intentional about when, where, and why certain data will be collected and how the data will be used can help build rapport and trust.

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[19] Children's Bureau, Administration On Children, Youth And Families, Administration For Children And Families, U. S. Department Of Health And Human Services (2020). *AFCARS Foster Care File, 6-month periods (FY2015B - 2020A)*

- [20] Pryce, J., Lee, W., Crowe, E., Park, D., McCarthy, M., & Owens, G. (2018). A case study in public child welfare: County-level practices that address racial disparity in foster care placement. *Journal of Public Child Welfare*, 13(1), 35-59.
- Boyd, R. (2014). African American disproportionality and disparity in child welfare: Toward a comprehensive conceptual framework. *Children and Youth Services Review*, 37, 15-27.
- Dettlaff, A. J., Weber, K., Pendleton, M., Boyd, R., Bettencourt, B., and Burton, L. (2020). It is not a broken system, it is a system that needs to be broken: The upEND movement to abolish the child welfare system. *Journal of Public Child Welfare,* 14(5), 500-517.

[21] U.S. Department of Health and Human Services, Administration for Children and Families, Children's Bureau. (n.d.). Child Population Data. Retrieved from https://cwoutcomes.acf.hhs.gov/cwodatasite/population/index.

[22] Children's Bureau, Administration On Children, Youth And Families, Administration For Children And Families, U. S. Department Of HHS (2020). *AFCARS Foster Care File, 6-month periods (FY2015B - 2020A)*

[23] https://youth.gov/youth-topics/lgbtq-youth/child-welfare

[24] https://www.casey.org/lgbtq-programming/

Based on what we know through our work, we make the following recommendations to address current gaps in data collection and unmet needs of child welfare involved children, youth, and families:

- Collect and report out on community indicators, such as the social determinants of health, to obtain an aggregate understanding of how communities are faring.
- Disaggregate and analyze administrative data by race/ethnicity, geography, gender and gender identify, sexual orientation, socioeconomic status, and other indicators at the federal, state, local and Tribal level to ensure targeted solutions address disparities.
- Update data systems move beyond broad classifications to more accurately capture race and ethnicity. Allow racial and ethnic identity information to be updated over time.[25]
- Data should be collected on primary language spoken, country of origin, and Tribal affiliation to provide the opportunity to clearly see the experiences of subpopulations.
- Identify populations and geographic areas that have increased service/support needs and who, because of these needs, may be at increased risk of child welfare involvement.
- Identify equitable and inclusive ways to collect data on American Indian/Alaska Native children, in compliance with, and in the spirit of, the Indian Child Welfare Act (ICWA).[26]
- Train staff/caseworkers so they are better equipped to ask children and families about their background rather than assume designations (often incorrectly) based on appearance, language spoken, or other characteristics.[27]
- Embed an equity lens in all data gathering, research, evaluation, and assessment activities**.** Engage experts to help identify and address issues, provide training, and cultivate pipelines for hiring staff with a broad array of experiences. More specifically:
  - Form a diverse research team that includes community members and individuals with lived experience as thought partners and co-developers.
  - Include representatives of the target population of individuals who are being examined.
  - Conduct an impact analysis to mitigate harm – including examination of data collection methods to highlight areas that may do harm, such as increased “surveillance” of particular communities.
  - Develop and use strengths-based assessments (focusing on resiliency and protective factors), which can lead to improved outcomes in supporting families and promoting timely permanency.
  - Utilize the community-based participatory research (CBPR), “a collaborative process that equitably involves all partners in the research process and recognizes the unique strengths that each brings.”[28]

Casey Family Programs appreciates the opportunity to provide comments on this RFI. If you have questi [redacted] formation, please contact Christine Calpin, Managing Director, Public Policy [redacted]

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[25] https://www.casey.org/data-and-equity/
[26] https://www.acf.hhs.gov/cb/monitoring/child-family-services-reviews
[27] https://www.casey.org/data-and-equity/
[28] http://www.2040partnersforhealth.org/Programs/CBPR

CCD
Consortium for Constituents
with Disabilities

October 3, 2022

The White House
Office of Science and Technology Policy (OSTP)
Subcommittee on Equitable Data, National Science and Technology Council

Re: RFI Equitable Data Engagement and Accountability

Dear Subcommittee Members,

The Consortium for Constituents with Disabilities (CCD) is the largest coalition of national organizations working together to advocate for Federal public policy that ensures the self-determination, independence, empowerment, integration, and inclusion of children and adults with disabilities in all aspects of a society free from racism, ableism, sexism, and xenophobia, as well as LGBTQ+ based discrimination and religious intolerance. The CCD Housing Task Force works to ensure that all people with disabilities have safe, stable, accessible, affordable, integrated housing that enables people to live in communities of their choosing, with full access to home and community-based services and supports. Thank you for this opportunity to submit information on the need for more equitable data engagement and accountability as part of the implementation of President Biden's Executive Order on Advancing Racial Equity and Support for Underserved Communities Through the Federal Government.

The main question we will answer is:

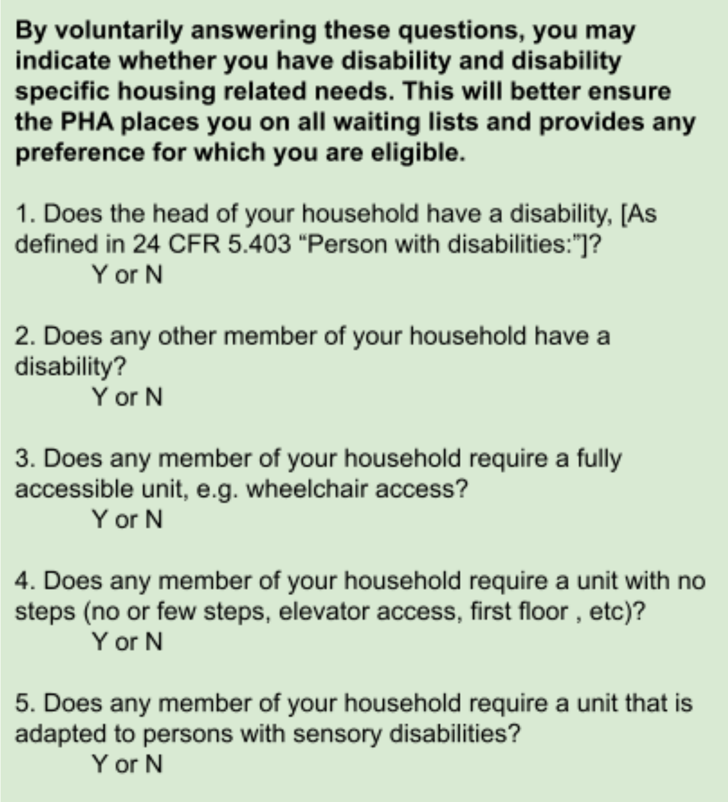
#7 In which agencies, programs, regions, or communities *are there unmet needs, broken processes, or problems related to participation and accountability* that could be remedied through stronger collaborations and transparency around equitable data?

Current data research fails to quantify, capture, and validate the need for disability-forward housing and how the lack of affordable, accessible, and inclusive housing affects the lives of disabled people and their families. Current data research fails to quantify, capture, and validate the need for disability-forward housing and how the lack of affordable, accessible, and inclusive housing affects the lives of disabled people and their families. The gaps in data apply to disabled people living in all places and arrangements, but the gaps are most acute for people with disabilities living in all types of institutions and those unhoused.

Beyond the very limited information collected by the Census, there is no national data source that looks at the population of people living in institutional settings. There are a lot of estimates, but no data set captures the demographics and needs of this left-out population, including but not limited to their needs related to housing. As the federal government continues to de-invest in institutional settings, in part due to explicit policy mandates, we must be able to draw on up-to-date data of this population to ensure that our community-based housing and services infrastructures are responsive and equitable in policy and practice. Federal agencies should explore collaborative ways to collect data on this population.

Moreover, to effectively capture data on the disabled population, there should be alignment across all federal data sets, including how disability is defined and asked about. Currently, this is not the case which creates substantial inconsistencies and gaps in understanding the fullest needs and demographics of people with disabilities. Moreover, disability experience is rarely asked about in optional demographic questionnaires offered by federal agencies.

We want to ensure that people with disabilities have the opportunity to be identified as such to ensure that they are connected to the appropriate programs without delay. This should include a choice to self-disclose disability in any demographic information requested from them. For example, within the Department of Housing & Urban Development (HUD), the public housing authorities only ask about disability regarding mobility or sensory units. These are important questions, but only a small percentage of disabled people need those specific types of units. Failure to identify the greater group of households with disabilities inhibits timely connection with housing supports that should be available to this broader group. We have encouraged HUD to urge PHAs to employ a questionnaire like the one here to ensure that households with people with disabilities are identified on a more comprehensive basis.



By voluntarily answering these questions, you may indicate whether you have disability and disability specific housing related needs. This will better ensure the PHA places you on all waiting lists and provides any preference for which you are eligible.

1. Does the head of your household have a disability, [As defined in 24 CFR 5.403 “Person with disabilities:”]?
   Y or N

2. Does any other member of your household have a disability?
   Y or N

3. Does any member of your household require a fully accessible unit, e.g. wheelchair access?
   Y or N

4. Does any member of your household require a unit with no steps (no or few steps, elevator access, first floor , etc)?
   Y or N

5. Does any member of your household require a unit that is adapted to persons with sensory disabilities?
   Y or N

Despite this recommendation, there continues to be broad pushback on embedding disability-related questions into broader demographic data collection. It is important to ensure that questions are voluntary, but without disability-inclusive data collection, the diverse needs of the disabled population will not be captured.

Additionally, it is critical to solve for the data gaps of people who receive non-institutional services and those who need services but who have no access to services. This is particularly significant because there are proven racial gaps in who accesses and doesn't access home and community-based services. Federal agencies must provide more guidance and accountability measures for when and how this data is collected and include questions relating to housing-related needs.

Overall, any of these efforts to increase data equity should be co-created and informed by the communities that the data is focused on. Thank you for the opportunity to comment on the White House's efforts to increase equitable data engagement and accountability.

Sincerely,

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Center for the Study of Social Policy
Ideas into Action

October 3, 2022

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Re: Equitable Data Engagement and Accountability (*87 FR 54269*)
Submitted via email to [redacted]

The Center for the Study of Social Policy (CSSP) is pleased to provide information regarding Equitable Data Engagement and Accountability (*87 FR 54269*). CSSP is a nonpartisan, national policy organization recognized for its leadership in shaping policy, reforming public systems, and building the capacity of communities with a focus on promoting racial equity and securing equal opportunities and better futures for children, youth, and families. For over 40 years, CSSP has partnered with federal and state government agencies and provided technical assistance and analysis on a broad set of policies affecting children and families including family economic security, child welfare, and health. We work with public systems and community organizations to identify internal barriers to equity (e.g. where policies implicitly or explicitly exclude families of color, how systems and organizations ensure accountability to equitable policies and practice, etc.) and develop and implement strategies – *including equitable data practices* – to address these concerns.

Core to advancing equity is undoing systemic and institutional racism embedded throughout and within our governing policies and the data practices stemming from them. In our work, CSSP has outlined four principles for anti-racist policymaking: ensuring that policies (1) redress past injustices, (2) meet the needs of children and families of color, (3) support the whole family, and (4) serve all children and families in need.[1] Leveraging nuanced, accurate, and affirming data is crucial to advancing policies that ensure children, youth, and families of all races, ethnicities, and income levels have access to public benefits and supports they need to thrive.

We were pleased to see President Biden's E.O. 13985 on advancing equity, the Office of Management and Budget's respective Request for Information (*86 FR 24029*), and the Vision for Equitable Data issued in April 2022. From our work, and as noted in our response to *86 FR 24029*,[2] equity requires authentic, consistent, and sustained engagement with children, youth, families, and communities as experts in both their needs and the government policies and services with which they interact. An equitable data infrastructure is one that prioritizes the voices and experiences of those who are interacting with public programs and systems and recognizes, addresses, and continuously assesses the inequities built into data development practices.

Our comments are based on our policy and technical assistance experience with governments and communities on areas impacting families including child welfare, early childhood, health (including healthy development of LGBTQ+[3] youth), economic security, and immigration. They include information, resources, and recommendations specific to

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[1] Minoff, E. et al. "Principles for Anti-Racist Policymaking." *CSSP*, 2020. http://bit.ly/Anti-Racist-Policymaking.
[2] "Public Comment OMB-2021-0005-0086." *CSSP*, July 2, 2021. https://www.regulations.gov/comment/OMB-2021-0005-0086.
[3] LGBTQ+ is used in this report to refer to lesbian, gay, bisexual, transgender, and queer individuals; the plus symbol is included to recognize those for whom these labels do not accurately describe their sexual orientation or gender identity such as two spirit, gender expansive, and gender nonbinary individuals.

agencies, programs, regions, or communities in which there are unmet needs, broken processes, or problems related to participation and accountability that could be remedied through stronger collaborations and transparency around equitable data (Q7). We focus especially on data practices related to policies and programs under the purview of the U.S. Department of Health and Human Services (HHS) Administration for Children and Families (ACF) and the Internal Revenue Service (IRS). Specifically, we focus on data practices to address:

1. The impact of broken processes in data collection, analysis, and use in child welfare systems that fail to meet the needs of children and families by hiding or exacerbating disparities based on race, ethnicity, tribal affiliation, sexual orientation, and gender identity and expression;
2. Unmet needs of communities of color due to the exclusion of culturally responsive programs and services in the Title IV-E Prevention Services Clearinghouse based on inequitable criteria on evidence and data; and,
3. Incomplete participation in and uptake of benefits administered through the tax system by communities of color and those with very low-income, for whom there is a lack of data available to outreach partners.

1. Broken processes in data collection, analysis, and use in child welfare systems and a lack of accountability to equitable data practices exacerbate disparities for children and families of color and LGBTQ+ children.

Equitable data collection can improve the accountability of child welfare systems by ensuring full visibility and inclusion of all groups and identities served. Based on our work with child welfare systems across the country, CSSP has developed principles of equitable data collection that can help to ensure full visibility and inclusion of all groups and identities of all people served by the child welfare system.[4] Equity requires an examination of power regarding who makes decisions that impact people's lives. In the case of child welfare, equitable data collection, reporting, and analysis requires that individuals who are impacted by the system are engaged in the process of determining what data is collected, how data is collected, and what decisions are made with the data collected and analyzed.[5]

Equitable data collection prioritizes self-identification and self-reported data, to ensure that people self-identify their own demographic information, and can change their information over time (e.g. gender identity).[6] For self-identification to be best facilitated, categories of race and ethnic identity should be co-designed with the youth and families whose data are being collected, and the process to collect the information should integrate the input, opinions, and feedback of community members. Further, data systems should be accessible to youth and families to see what information has been provided and update if necessary.

Beyond changing data collection fields, comprehensive training for frontline staff is crucial to data collection and analysis processes,[7] so that staff understand the value of collecting self-identified data and can communicate that importance to respondents in order for them to give informed consent and understand their data privacy rights and confidentiality laws. Training can also mitigate fears about which questions to ask and how to handle evolving terms. By shifting their role from "expert" to "learner," caseworkers center child and family as experts in their own identity.

Effective continuous quality improvement processes for using data are crucial to ensuring systems do not harm children and families of color. Collecting disaggregated data and developing systems to house this data in ways that are transparent to families are necessary but insufficient to advance equity. Researchers clearly state that "disaggregating race data does not, by itself, create equitable outcomes, just as reporting transparent disaggregated data does not, by itself, create targeted strategies to address disparity and disproportionality."[8] Through our work in child welfare systems, we have often seen jurisdictions fall short in using data to advance equity because they either do not believe they have enough data, their data system is outdated so data collection is manual and burdensome, or they stop after they have disaggregated the data by race. When and how data are used is as important as how and what data are collected. When communities are not involved in the analysis, we have seen misinterpreted data and,

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[4] Jawetz, A., Mishraky-Javier, L., Hand, R. "Our Identities, Ourselves: An Anti-Racist Review on Collecting Accurate Data on Race and Ethnicity." *CSSP*, September 2021. https://cssp.org/resource/our-identities-ourselves.

[5] Children's Bureau. "CFSR Technical Bulletin 13." *U.S. DHHS, ACF*, August 6, 2021. https://www.acf.hhs.gov/sites/default/files/documents/cb/cfsr-technical-bulletin-13.pdf.

[6] Child Welfare Information Gateway. "Child Welfare Practice to Address Racial Disproportionality and Disparity." *U.S. Department of Health and Human Services, Administration for Children and Families*, 2021. https://www.childwelfare.gov/pubs/issue-briefs/racial-disproportionality/.

[7] Cuccaro-Alamin, S., et al. (2017). "Risk Assessment and Decision Making in Child Protective Services: Predictive Risk Modeling in Context." *Children and Youth Services Review* 79: 291–298. https://doi.org/10.1016/j.childyouth.2017.06.027.

[8] Jawetz, A., Mishraky-Javier, L., Hand, R. "Our Identities, Ourselves." *CSSP*, September 2021. https://cssp.org/resource/our-identities-ourselves.

consequently, inadequate solutions developed to address perceived problems rather than the actual experiences of children and families in the community. For example, in one jurisdiction, data about service utilization was misinterpreted by system administrators who concluded the service was not needed in the community. However, the community quickly corrected the error in their analysis: the service was desperately needed but was not being provided accessibly (i.e. the office was inaccessible by public transportation and only offered during standard work hours). **States need clear and considerable technical assistance and guidance to be aware of and prevent the use of data to harm families and communities**, especially as changes to data practices are made.

There are some examples of jurisdictions that have begun to implement these promising practices. The Washington State Department of Children, Youth, and Families (DCYF) issued a report to build a common understanding of race and ethnicity data, including the intended uses of race and ethnicity data; standard and summarize race/ethnicity data collection and reporting practices; and understand their implications for aligned data systems, cross program analyses, and reporting. The report is also meant to identify racial and ethnic disproportionality and disparity across DCYF programs and their related outcomes, and use this information as a starting point for ongoing improvements in measuring, tracking, and reporting on racial/ethnic equity, and understanding what drives differences in experiences and outcomes between racial/ethnic groups.[9] For more information on state and local data collection efforts on race and ethnicity and community-based participatory research within public health, see *Counting a Diverse Nation*.[10]

Equitable data practices can improve outcomes for LGBTQ+ and Indigenous youth involved with child welfare. Child welfare systems must have data to support their well-being (including through the development and implementation of prevention services), reduce the reliance on congregate care, and improve recruitment and retention of foster parents. Without understanding the reasons for entry into care – e.g. how many children enter foster care due to parent child conflict related to the child's sexual orientation, gender identity and expression (SOGIE) – child welfare systems will not be able to design prevention services to meet the needs of these young people. Furthermore, if child welfare systems are unable to disaggregate well-being and permanency outcomes including the reason for entry into care, placement type, length of stay in foster care, permanency goal, or receipt of health care, states' ability to make data-driven investments that reduce the costs associated with placement in foster care while maximizing opportunities to promote the well-being of children and families will be hindered.

The Adoption and Foster Care Analysis and Reporting System (AFCARS) represents a critical mechanism and opportunity to promote equitable data collection through what is included in AFCARS and guidance from the federal government as to how to collect the required data. In 2016, the Children's Bureau issued a final rule on collecting data through AFCARS on sexual orientation of child welfare-involved youth 14 and older, but this rule was rescinded from taking effect in May 2020.[11] This decision is particularly harmful to LGBTQ+ and Indigenous youth as a lack of information about their experiences impacts the development and implementation of targeted solutions. Adding data elements regarding sexual orientation and related to American Indian/Alaska Native (AI/AN) children in out-of-home placement and barriers to permanency support child welfare's ability to meet their well-being and permanency needs.[12] Specifically, collecting data on SOGIE of youth in foster care as well as foster and adoptive parents and guardians is crucial for the child welfare system to be able to make decisions in the best interest of LGBTQ+ youth in care. Many state systems underestimate the number of LGBTQ+ youth in care and their disparate experiences, including higher numbers of placement changes, lower rates of permanency, and high rates of placement in congregate care settings.[13]

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[9] Cummings, K., et al. "Using Data in DCYF to Advance Racial Equity." *Washington State Department of Children, Youth, and Families – Office of Innovation, Alignment, and Accountability*, 2021. www.dcyf.wa.gov/sites/default/files/pdf/reports/OIAAEquityData2021.pdf.

[10] Rubin, V., et al. "Counting a Diverse Nation: Disaggregating Data on Race and Ethnicity to Advance a Culture of Health." *Policy Link*, 2018. https://www.policylink.org/resources-tools/counting-a-diverse-nation.

[11] U. S. Government Accountability Office. "Foster Care: Further Assistance From HHS Would Be Helpful in Supporting Youth's LGBTQ+ Identities and Religious Beliefs." April 2022. https://www.gao.gov/products/gao-22-104688; Medina, C., et al. "Improving the Lives and Rights of LGBTQ People in America: A Road Map for the Biden Administration." *Center for American Progress*, January 12, 2021. https://www.americanprogress.org/article/improving-lives-rights-lgbtq-people-america/.

[12] CSSP addressed the 2016 rule in its comments on the 2018 ANPRM regarding the proposal to streamline AFCARS data collections, NPRM regarding the proposed delay for compliance and effective date for the AFCARS 2016 Final Rule (*83 FR 11450*), NPRM for the 2016 Final Rule (*81 FR 90524*), SNPRM for AFCARS data elements related to ICWA (*81 FR20283*). See: "SNPRM – Proposed AFCARS data elements relate to the ICWA of 1978." *CSSP,* May 9, 2016. https://www.regulations.gov/comment/ACF-2015-0001-0151; "NPRM – Regarding proposed changes to AFCARS." *CSSP,* April 10, 2015. https://www.regulations.gov/comment/ACF-2015-0001-0096.

[13] Martin, M., Down, L., and Erney, R. "Out of the Shadows: Supporting LGBTQ youth in child welfare through cross-system collaboration." *CSSP,* 2016. https://cssp.org/resource/out-of-the-shadows/.

Having accurate data on AI/AN children is also crucial to keeping families together, respecting the unique needs of Native children and tribal communities, and respecting the intent of the Indian Child Welfare Act (ICWA) which applies to children who are eligible for tribal membership. Data collection on the experiences of Native children is a prerequisite to understanding the inequities they face broadly and agency failures in implementing and enforcing ICWA, and designing effective responses toward racial equity in child welfare. Without collecting these data, Native children will continue to be harmed through longer stays in foster care and being disconnected from their tribal communities.[14] However, data collection strategies for Native children must be created in collaboration with Native communities and led by Native leaders, to ensure that data sovereignty is respected, and data collected or shared by tribal leaders are not misused.[15] (For data sharing to be possible, state and federal governments must begin to build trust to address the history of oppression of Native communities by these governments.) The 2016 Final Rule includes the first federal data elements that can provide detailed information on ICWA implementation, allowing tribes, states and federal agencies to improve understanding of the trends in out-of-home placement and barriers to permanency for AI/AN children.

Some child welfare jurisdictions have taken steps to collect SOGIE data. CSSP provided technical assistance through the getREAL initiative[16] to the Allegheny County Department of Human Services (DHS) in Pennsylvania as they worked to better support LGBTQ+ youth. This work included updating the case management system to include the collection of SOGIE data, conducting extensive training on data collection for staff, and appointing a staff person to be responsible for providing coaching and monitoring data collection.[17] As part of a pilot program, they also field tested the "Guidelines for Managing Information Related to the Sexual Orientation and Gender Identity and Expression of Children in Child Welfare Systems."[18] As a result of the expanded data collection and using the data to drive practice, DHS improved practice to support the healthy sexual and identity development of youth, including developing cultural shifts within the Office of Children, Youth, and Families (CYF) so that SOGIE is recognized and discussed; beginning efforts to collect SOGIE data; improvements in CYF and DHS infrastructure to support SOGIE of children, youth, and families served; innovation and adaptation in other areas of practice to support assessment and services related to SOGIE; and developing strong ties with community-based organizations supporting LGBTQ+ children, youth, and families.

Resources to support implementation of equitable data practices

- CSSP and Casey Family Programs (CFP) have established a Learning Community of child welfare agencies to support implementation of equitable data collection principles. This community, and others like it, are necessary supports for states working through developing and implementing equitable data practices. The federal government should consider how to support states in engaging and learning together, including by redefining federal demographic data categories with input from those impacted by data collection efforts.
- CSSP and CFP developed a guide to share best practices for collecting data about race, ethnicity, and other demographic information including SOGIE, national origin, language spoken, disability, religion, and tribal affiliation in child welfare agencies nationwide.[19] This guide is a critical resource for the federal government and states working to implement equitable data practices. Examples of recommendations from this resource include:
    - Provide options for those who identify as "multiracial" to select a specific combination that resonate and an open-ended option so that respondents can include identities that may be missing.
    - Include race and ethnicity options within a single question to allow for a more accurate selection by individuals who do not make a clear distinction in self-identity between the two categories.
    - Tribal affiliation should include a list of all federal- and state- recognized tribes with a write-in option for First Nations or other affiliations not listed.[20]

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[14] Meltzer, J. "Every Child Counts: Trump Administration Undermines Child Welfare's Ability to Serve All Children Well through Final AFCARS Rule." *CSSP*, May 12, 2020. https://cssp.org/about-us/connect/press-room/child-welfare-afcars-rule/.

[15] To maintain tribal sovereignty, the Urban Indian Health Institute recommends that data about specific tribes should not be reported without a specific data agreement or memorandum of understanding from the relevant tribe.

[16] See: https://cssp.org/our-work/project/getreal/.

[17] Weber, K. and Bettencourt, B. "Progress Towards Building an Affirming and Supportive Child Welfare System: getREAL in Allegheny County." *CSSP,* 2019. https://cssp.org/resource/getreal-in-allegheny-county.

[18] Wilber, S. "Guidelines for Managing Information Related to the Sexual Orientation and Gender Identity and Expression of Children in Child Welfare Systems." *Putting Pride Into Practice Project, Family Builders by Adoption*, 2013. https://cssp.org/resource/guidelines-for-managing-information-related-to-the-sexual-orientation-gender-identity-and-expression-of-children-in-child-welfare-systems/.

[19] "Our Identities, Ourselves: A Guide to Anti-Racist Data Collection for: System Leaders and Data Administrators." *CSSP*, September 2021. https://cssp.org/wp-content/uploads/2021/09/Our-Identities-Ourselves-Guide-for-System-Administrators-FINAL.pdf. See also: Jawetz, A., Mishraky-Javier, L., Hand, R. "Our Identities, Ourselves." *CSSP*, September 2021. https://cssp.org/resource/our-identities-ourselves.

[20] See Footnote 15.

- Through CSSP's getREAL initiative, Family Builders by Adoption led the development of "Guidelines for Managing Information Related to the Sexual Orientation and Gender Identity and Expression of Children in Child Welfare Systems."[21] This resource provides important guidance for collecting SOGIE data for all children and youth in care.

2. There are unmet needs of communities of color that are due to exclusion of culturally responsive programs and services in the Title IV-E Prevention Services Clearinghouse based on inequitable criteria on evidence and data

Children, youth, and families of color and other populations marginalized by systemic racism and institutional policies are harmed when inequitable data analysis methods are applied. In child welfare, a clear example of the application of inequitable data analysis methods is within the criteria established by the Title IV-E Prevention Services Clearinghouse to determine whether a program is "evidence-based." As CSSP made clear in its responses to *86 FR 37332* (2021) on the Clearinghouse Handbook of Standards and Procedures[22] and *83 FR 29122* (2018) on initial criteria and potential programs and services to be considered for systematic review, a broad range of programs in the Clearinghouse would provide states, territories, and tribes the flexibility to identify and implement a continuum of programs that meet the unique needs of each family that may come to the attention of child welfare and prevent entry into foster care. However, the current criteria required by the Clearinghouse limit the range of effective programs available and exclude prevention programs known to work for communities of color and others marginalized by public policies and institutional practices in two ways:

- First, the criteria incentivize a "one-size-fits-all" approach to programs and services and fail to recognize different ways of knowing such as qualitative research methodology;[23] exclude research and evaluation methodologies that are effective for small sample sizes; ignore subgroup analyses that can identify effectiveness within subgroups rather than across; fail to facilitate evaluation of programs for populations with multiple barriers rather than just one; rely heavily on methodologies which favor experimental settings to determine program validity rather than results with populations in non-experimental settings;[24] and require control-group methodologies, including randomized control trials (RCTs) and quasi-experimental group designs, which may be inappropriate for small, high priority populations for pragmatic, cultural, or ethical reasons.[25]
- Second, the criteria define evidence requirements so narrowly that programs and services developed by and for communities of color and other populations facing the greatest inequities are simply excluded from the Clearinghouse. The majority of studies comparing culturally adapted programs and un-adapted programs show that culturally adapted programs result in better outcomes for youth and families.[26] But even modest cultural adaptations must undergo new evaluations that are expensive and time consuming and require capacity and evaluation infrastructure that are not attainable for small programs without additional resources and support.

These narrow criteria exacerbate the gap in "evidence-based programs" that meet the needs of communities of color.[27] Despite recognition by the Children's Bureau of the importance of cultural adaptations in services and programs, the restrictive, current allowable flexibility does not promote equitable adaptations.[28] To address this gap, Clearinghouse criteria must be responsive to realistic conditions, respect different ways of gaining information about impact in

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[21] Wilber, S. "Guidelines for Managing Information Related to the Sexual Orientation and Gender Identity and Expression of Children in Child Welfare Systems." *Putting Pride Into Practice Project, Family Builders by Adoption*, 2013. https://cssp.org/resource/guidelines-for-managing-information-related-to-the-sexual-orientation-gender-identity-and-expression-of-children-in-child-welfare-systems/.

[22] A version of these comments may be found here: CSSP, et al. "Letter to Associate Commissioner Schomburg." August 23, 2021. https://www.childrensdefense.org/wp-content/uploads/2021/08/Letter-on-Title-IV-E-Clearinghouse-Criteria.pdf.

[23] Brown, K. S., et al. "Confronting Structural Racism in Research and Policy Analysis." *Urban Institute*, 2019. https://www.urban.org/sites/default/files/publication/99852/confronting_structural_racism_in_research_and_policy_analysis_0.pdf.

[24] Petr, C. and Walter, U. (2009). "Evidence-based practice: A critical reflection." *European Journal of Social Work* 12(2): 221-232. https://www.tandfonline.com/doi/abs/10.1080/13691450802567523; Webb, S.A. (2001). "Some considerations on the validity of evidence-based practice in social work." *British Journal of Social Work* 31(1): 57-79. https://academic.oup.com/bjsw/article-abstract/31/1/57/1654601.

[25] Gray, M., Plath, D., and Webb, S. (2009). *Evidence-based Social Work: A critical stance.* Routledge; Pawson, R. & Tilley, N. (1997). An introduction to scientific realist evaluation. In E. Chelimsky and W. R. Shadish (Eds.). *Evaluation for the 21st century: A handbook* (pp. 405–418). Sage. https://doi.org/10.4135/9781483348896.n29.

[26] Domenech-Rodríguez, M., Baumann, A., and Schwartz, L. (2011). "Cultural adaptation of an evidence-based intervention: from theory to practice in a Latino/a community context." *American Journal of Community Psychology* 3(47): 170-186. 10.1007/s10464-010-9371-4; Garcia, A. R., et al. (2019). "Mitigating barriers to implementing evidence-based interventions in child welfare: Lessons learned from scholars and agency directors." *Children and Youth Services Review* 100: 313–331. https://doi.org/10.1016/j.childyouth.2019.03.005; Hurlburt, M., et al. (2014). "Interagency collaborative team model for capacity building to scale-up evidence-based practice." *Children and Youth Services Review* 39: 160–168. 10.1016/j.childyouth.2013.10.005; Kumpfer, K. L., et al. (2002). "Cultural sensitivity and adaptation in family-based prevention interventions." *Prevention Science* 3: 241–246. 10.1023/a:1019902902119.

[27] Whitesell, N. "Evidence and Equity: Challenges for Research Design." *Office of Planning, Research, and Evaluation, The Administration for Children and Families*, November 2017. https://www.acf.hhs.gov/opre/report/evidence-and-equity-challenges-research-design.

[28] Administration for Children and Families. "Allowable flexibilities related to adaptations of evidence-based programs in the title IV-E prevention services program for tribal communities." *U.S. Department of Health and Human Services*, January 13, 2021. https://www.acf.hhs.gov/sites/default/files/documents/cb/im2104.pdf.

communities, prioritize innovations developed by communities based on existing need and agency, and revolve around common design elements rather than rigid adherence to model fidelity. Centering equity in the development of knowledge requires valuing the perspectives and knowledge of people most affected by the root causes of inequity and by the proposed solutions; understanding and articulating the structural, systemic, cultural, and historical factors at the root of the inequities; and supporting variations, not "'what works' on average, for some individuals, somewhere."[29]

Resources and recommendations to promote equitable data analysis

- OPRE has argued that effective approaches to ensuring programs and services adequately serve communities of color include engaging community partners in research, prioritizing rigor over rigidity, acknowledging challenges to community-based interventions, and utilizing innovative research designs. The approaches have been affirmed by, among others, a 2017 OPRE convening of experts, which featured the importance of rigorous alternatives to RCTs.[30]
- Revise the Clearinghouse criteria to allow for adaptations for all programs with small sample sizes and subgroup analysis and the disaggregation of data by gender, race, and ethnicity. The criteria should also promote opportunities to (1) improve how disaggregated data about race and ethnicity are collected, understood, and managed; (2) integrate community voices into the research design process; (3) develop sources for high-quality, widely available survey data that represent key dimensions of the intersection of gender, race, ethnicity, and health and wellbeing; (4) use data analysis to assess the impact of work on reducing racial disparities for communities served; and (5) measure improvements using baseline data to see if program solutions are in fact having a positive impact for communities of color. Criteria should be revised to allow for local implementation to adapt and learn through continuous quality improvement based on outcomes defined by the community, a practice foundational to data- and evidence-informed decision making.
- To support building the evidence for programs developed by and within communities of color, HHS should create and fund a national resource center dedicated to funding the development, adaptation, and learning around culturally responsive programs and services, including cultural-adaptations and programs and services created by communities of color and historically marginalized and inadequately served communities. This center should also focus on supporting evaluators of color who bring personal and lived experience, cultural and historical knowledge, and community trust and relationships to evaluations.[31]

3. <u>There is incomplete participation in and uptake of benefits administered through the tax system by communities of color and those with very low-income, for whom there is a lack of data available to outreach partners.</u>

Using data to develop outreach strategies to address inequities in access to supports, including the Child Tax Credit (CTC), is critical to advancing racial equity,[32] by ensuring that families who are not otherwise connected to systems, programs, and services have what they need to thrive. For example, Code for America (CFA) has found that robust data shared by the IRS on low-income families claiming refundable tax credits like the CTC and Earned Income Tax Credit can help target outreach efforts, help outreach campaigns create momentum toward shared goals, empower advocates and agency leadership to identify and prioritize bottlenecks in user experience, and make it possible for outside actors to assist clients with tax issues.[33] Non-filers are disproportionately Black and Hispanic families, who have lower-incomes due to historic and ongoing racism in public policies and the labor market[34] – highlighting the opportunity to use data to advance equity. Specifically, targeted data can help outreach partners identify where to target outreach efforts and

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[29] Farrow, F. and Morrison, S. "Placing Equity Concerns at the Center of Knowledge development." *CSSP*, 2019. https://cssp.org/wp-content/uploads/2019/05/Putting-Equity-at-the-Center-of-Knowledge-Development.pdf.

[30] Malin, J. & Deterding, N. "Building Strong Evidence in Challenging Contexts: Alternatives to Traditional Randomized Controlled Trials." *OPRE, ACF*, November 2017. https://www.acf.hhs.gov/opre/report/building-strong-evidence-challenging-contexts-alternatives-traditional-randomized.

[31] Lo, F. and Espiritu, R. "Evaluation is So White: Systemic Wrongs Reinforced by Common Practices and How to Start Righting Them." *Funder & Evaluator Affinity Network*, 2021. https://fdnweb.org/fean/files/2021/01/Evaluators-of-Color_FEAN-Call-to-Action-Series_1.19.2021.pdf.

[32] CSSP is the co-chair of the Automatic Benefit for Children (ABC) Coalition, a diverse, intersectional group of national, state, and grassroots organizations committed to advancing a child allowance that benefits all families who need it. A fundamental part of our work has been to ensure that the 2021 expanded CTC reaches the families with children who most need it, by building communications channels between federal and local partners and sharing best practices from partners who conduct outreach to help individuals who typically do not have tax obligations sign up for the advanced CTC in 2021 and the full or second-half in 2022. See: https://www.abccoalition.org/.

[33] Zucker, G. "Data to improve administration of refundable tax credits." *Code for America*, March 14, 2022. codeforamerica.org/tax-data-memo.

[34] Collyer, S., Harris, D., Wimer, C. "Left Behind: The One-Third of Children in Families Who Earn Too Little to Get the Full Child Tax Credit." *Columbia University, Center on Poverty and Social Policy Brief* 3(6), May 13, 2019. https://static1.squarespace.com/static/610831a16c95260dbd68934a/t/61154a19cce7cb59f8660690/1628785178307/Who-Is-Left-Behind-in-the-Federal-CTC-CPSP-2019.pdf; Minoff, E., et al. "The Lasting Legacy of Exclusion: How the Law that Brought Us Temporary Assistance for Needy Families Excluded Immigrant Families & Institutionalized Racism in our Social Support System." *CSSP and Georgetown Center on Poverty and Inequality Economic Security & Opportunity Initiative*, August 2021. https://cssp.org/resource/the-lasting-legacy-of-exclusion/.

what kind of organizations can help reach families based on who they already serve. Ensuring that the IRS makes data available to outreach partners is key to improving take up of this and future refundable tax credits.

Recommendations to promote equitable data sharing

- CSSP supports CFA's recommendations that the IRS share (1) regularly updated statistics on eligible households who have not filed, by state, county, and/or zip code, (2) demographic and geographic trends of non-filers to help target outreach efforts, (3) identified non-filer microdata to allow for direct outreach from state and local governments, (4) real-time return processing data, to understand the experience of low-income taxpayers awaiting refunds, (5) numbers and types of returns filed by low-income households, to understand which methods of filing returns are working best for low-income families and what issues low-income taxpayers are facing, and (7) data on any advance payments, reporting and corrections, rejections and resolutions, and online tool usage.[35]
- The IRS should share data for families who claimed the CTC using the non-filer portal, disaggregated by number of children in each family, zip code, family relationship to children, age of children, whether filers had SSNs or ITINs, household filing status, portal language used, whether they were previously known to the IRS (e.g. through health insurance), and method of receipt for the CTC payments. This data will assist local, state, and community partners in identifying disparities that exist and understand successes and limitations of current methods of outreach.

Conclusion

Across federal and state agencies, data practices that advance equity are critical to ensuring policy is implemented in ways that meet the needs of those most often excluded from supports. When collected, analyzed, and reported with collaboration from the community, data are a powerful means to understand and develop solutions to address deep challenges experienced by children, families, and communities. However, when data are gathered through biased data systems and analyzed outside of the historical understanding of the racist roots of policies, it can result is extremely harmful circumstances for children and families. Specifically, efforts to streamline decision-making by using data to drive decisions can be extremely harmful and exploitative, especially when used in algorithms or interpreted without a historical framework or context for surrounding circumstances. For example, predictive risk modeling in child welfare[36] often uses administrative data embedded with biases in risk factors associated with child maltreatment, which can lead to false-positive screenings that perpetuate racial disparities in child welfare by increasing unnecessary system involvement.[37] Biased data, methodologically unsound algorithms, ineffective or biased staff training on risk modeling tools, and ahistorical analysis can result in more children, families, and communities being surveilled and policed.[38]

Jurisdictions need adequate staffing, resources, and capacity to develop and implement equitable data practices. This is a primary lesson learned from an existing Federal collaboration (Q2) through the National Resource Center for Infant Toddler Court Teams. Many jurisdictions are overburdened and understaffed and need support from the federal government (1) to build internal capacity to both design and implement equitable data practices, (2) for ongoing reassurance that information being gathered is of long-term value, and (3) to finance redesign of their data systems. While some support is available to states through CCWIS redesign, not all jurisdictions have been able to access it.

The information shared within these comments only touch the surface of the issues and I am more than happy to provide additional information. If you have any questions, please do not hesitate to contact me at [redacted]

Sincerel

[redacted]

Megan Martin
Executive Vice President, Director of Public Policy, Center for the Study of Social Policy

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[35] Zucker, G. "Data to improve administration of refundable tax credits." *Code for America*, March 14, 2022. codeforamerica.org/tax-data-memo.

[36] Sacher, S. (2022). "Risking Children: The Implications of Predictive Risk Analytics Across Child Protection and Policing for Vulnerable and Marginalized Children." *Human Rights Law Review* 22(1). https://doi.org/10.1093/hrlr/ngab028; Feely, M. and Bosk, E.A. (2021). "That Which Is Essential Has Been Made Invisible: The Need to Bring a Structural Risk Perspective to Reduce Racial Disproportionality in Child Welfare." *Race and Social Problems* 13(1): 49-62. https://doi.org/10.1007/s12552-021-09313-8.

[37] Capatosto, K. "Foretelling the Future: A Critical Perspective on the Use of Predictive Analytics in Child Welfare." *Kirwan Institute for the Study of Race and Ethnicity at The Ohio State University*, 2017. https://kirwaninstitute.osu.edu/sites/default/files/2017-05//ki-predictive-analytics.pdf/.

[38] Lanier, P., et al. (2020). "Preventing Infant Maltreatment with Predictive Analytics." *Journal of Family Violence* 35(1):1–13. https://doi.org/10.1007/s10896-019-00074-y.

Child TRENDS®

October 3, 2022

Denice Ross
U.S. Chief Data Scientist
Office of Science and Technology Policy
White House

Dear Ms. Ross,

Child Trends is a highly respected, nonpartisan research organization focused exclusively on improving the lives and prospects of children, youth, and their families. For more than 40 years, decision makers have relied on our rigorous research, unbiased analyses, and clear communication to improve public policies and interventions that serve children and families. Our researchers have a deep bench of experience advancing the equitable collection, analysis, use, and communication of data across sectors that support children and families.

On September 2, 2022, the Office of Science and Technology Policy (OSTP) published a request for information "on how Federal agencies can better support collaboration with other levels of government, civil society, and the research community around the production and use of equitable data." Below, we provide our perspectives on four of the specific questions posed by OSTP:

Question 4. What resources, programs, training, or other tools can expand opportunities for historically underrepresented scholars and research institutions to access and use equitable data across levels of government?

Child Trends recommends greater investment in federal research initiatives, with a focus on specific populations and capacity building in the research field, to close gaps in opportunities for historically underrepresented scholars and research institutions in accessing and using equitable data. The National Research Center for Hispanic Children & Families ("Hispanic Center") bridges such a gap in data access by providing opportunities for scholars who focus on Hispanic populations to have access to federally funded data and professional development experiences.[1] The Hispanic Center is led by Child Trends—in collaboration with Duke University, the University of Maryland, College Park, and the University of North Carolina, Greensboro—and is funded by the Office of Planning, Research and Evaluation at the U.S. Department of Health and Human Services' Administration for Children and Families. The Hispanic Center's research scholars' program has afforded graduate students and early career scholars access to federally funded data and opportunities to publish accessible research briefs that focus on Hispanic children's and families' experiences with federally funded programs.[2] The

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[1] About Us. Hispanic Research Center. (2021, November 29). Retrieved September 26, 2022, from https://www.hispanicresearchcenter.org/about-us/

[2] Research Scholars Program. Hispanic Research Center. (2021, November 2). Retrieved September 26, 2022, from https://www.hispanicresearchcenter.org/emerging-scholars/research-scholars-program/

Hispanic Center has also provided training opportunities for early career scholars—including those at Hispanic Serving Institutions and those from historically underrepresented groups—to use data across various government agencies and engage in professional development that bridges the gap in access to resources.

Question 5. What resources, programs, training, or tools can increase opportunities for community-based organizations to use equitable data to hold government accountable to the American public?

Child Trends recommends federal capacity-building initiatives that advise community organizations on using data to hold the federal government accountable. Data may not be a leading priority for community organizations working to provide for the immediate needs of their communities; rather, these organizations must prioritize addressing those needs. For this reason, federal efforts should build accountability mechanisms that reduce the guesswork and time burden for community organizations. For example, this synergy between community organizations and the federal government has been developed successfully through the National Center on Parent, Family, and Community Engagement (“Family Engagement Center") out of the Office of Head Start. Locally operated Head Start programs and staff can engage with the Family Engagement Center to use their own data sources and those offered by the Office of Head Start to improve family outreach, recruitment, attendance, and well-being.[3]

Question 6. What resources, programs, training, or tools can make equitable data more accessible and useable for members of the public?

Child Trends recommends that federal agencies develop tailored data products and dissemination strategies for different audiences. The federal government has many data sources—including the National Survey for Early Care and Education, The American Community Survey, Decennial Census, Common Core Data, etc.—that are publicly available. For these sources, the equity challenge is not the availability of data, but how these data are shared with the public. An equitable dissemination process includes the following steps: 1) Understanding the data needs of various populations in the United States (e.g., underrepresented populations, grassroots advocates, communities with a history of disinvestment, disabled individuals, etc.), 2) ensuring that data are presented in plain language and in the target audiences’ various native languages, 3) sharing data in concise formats accessible to non-researchers, and 4) using multiple outlets (e.g., social media, websites (e.g., federal websites, state government websites, local government websites, etc.), and news mediums) and trusted information brokers (e.g., membership associations, community organizations, community outreach organizations, etc.) to ensure that information reaches the right hands.

Child Trends also recommends greater use of data visualization and maps as strategies to make federal data both more equitable and more accessible. It can be far simpler to understand primary findings in data by looking at a bar graph, for example, than by reviewing a large data table. In this way, data visualization can make data more equitable for people without the advanced training required to understand more complex presentations of data. Maps, as a form of data visualization, can also increase public use of data—for example, by people who may be interested in better understanding the areas in which they and their families live. For example, the use of maps to show COVID-19 case rates and

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[3] National Center on Parent, Family, and Community Engagement (NCPFCE). ECLKC. (2022, June 8). Retrieved September 26, 2022, from https://eclkc.ohs.acf.hhs.gov/about-us/article/national-center-parent-family-community-engagement-ncpfce

hospitalizations during the ongoing pandemic helped people make informed decisions about their activities and masking. Tableau and PolicyMap are two tools that support data visualizations and mapping and have free versions accessible to the public, and both tools (especially PolicyMap) have pre-loaded federal data.[4,5]

Child Trends further recommends a multi-pronged public education effort to help the broad public—from public officials to families and parents—understand how federal surveys and other data collection and reporting advance equity. National surveys such as the Youth Risk Behavior Surveillance System (YRBSS) play an important role in promoting health equity, particularly for LGBTQ+ (lesbian, gay, bisexual, transgender, and queer/questioning) youth and youth of color. In 2016, Wyoming ended its participation in the YRBSS, expressing concerns about some of the questions, especially those related to students' sexual history. More recently, Florida withdrew its participation from the YRBSS,[6] and state leaders engaged in Child Trends projects have noted greater pushback from communities about the survey. Some pushback seems to be driven by misinformation that asking certain questions will affect students' behavior and/or identity. Research shows that actively presenting correct information and sharing it broadly can prevent and reduce the spread of misinformation.[7] Families and community members are equally important as stakeholders in data as researchers and policymakers; however, they may need information presented in clearer, more simple formats, and disseminated through different mediums, relative to researchers and policymakers. Proactively addressing families' and community members' questions and concerns can build support for the continuation of important data sources.

<u>Question 7. In which agencies, programs, regions, or communities are there unmet needs, broken processes, or problems related to participation and accountability that could be remedied through stronger collaborations and transparency around equitable data?</u>

Child Trends supports health care data being transparent and accessible to improve accountability. Child Trends is often asked by states and counties, nonprofit organizations, and government offices how to access Medicaid data. Medicaid covers roughly 70 percent of Black births in the United States, so access to these data is critical for research, advocacy, and accountability for the egregious health disparities experienced by Black birthing people and their infants.[8] Accessing Medicaid data varies state by state, can be a long and arduous process, and can be cost-prohibitive if seeking access to data from more than one state. Further, the complexity and nuance in these data require advanced skills and analytical tools for use. The federal Medicaid data available online are helpful but are limited to

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[4] Tableau. (n.d.). Retrieved September 26, 2022, from https://www.tableau.com/

[5] Home. PolicyMap. (2022, May 9). Retrieved September 26, 2022, from https://www.policymap.com/

[6] Blad, E. (2022, May 6). Some states back away from a major student well-being survey. why, and what it could mean. Education Week. Retrieved September 26, 2022, from https://www.edweek.org/leadership/some-states-back-away-from-a-major-student-well-being-survey-why-and-what-it-could-mean/2022/05

[7] Flynn, T. (2020, September 16). 10 ways to combat misinformation: A behavioral insights approach. Institute for Public Relations. Retrieved September 26, 2022, from https://instituteforpr.org/10-ways-to-combat-misinformation/

[8] Solomon, J., (2021, July 26). Closing the coverage gap would improve Black Maternal Health. Center on Budget and Policy Priorities. Retrieved September 26, 2022, from https://www.cbpp.org/research/health/closing-the-coverage-gap-would-improve-black-maternal-health

individual states' levels and not disaggregated by race/ethnicity—limiting their utility for equitable research.[9]

Child Trends supports strengthening collaboration between systems specifically at transition points to better meet the needs of children and youth who face challenges accessing services. Young people engaged with multiple systems (e.g., those who interface with the child welfare and/or juvenile justice systems, in addition to the education and health systems) have unique needs that would benefit from coordination across services. As a technical assistance provider for the National Technical Assistance Center for the Education of Neglected or Delinquent Children and Youth (NDTAC), we have found that gathering education data on youth served in juvenile correction and detention facilities is a challenging process. The transition from the education system to the juvenile justice system (and vice versa) presents a vulnerable point in time for sharing data about students' needs and tracking their progress. Some of these challenges stem from logistics, such as the need to coordinate across geographic locations (e.g., a student may go to a juvenile facility outside of their school district) and have adequate staff to manage these transition points.

Child Trends recommends federal collaboration with state and local child support agencies, as well as parents served by such agencies, to reform performance measurement to incorporate more demographic data and a broader range of outcome measures. Federal and state officials have observed the disengagement and nonparticipation of families who are eligible for child support.[10]While performance measures could, in theory, support policy analyses to investigate and address nonparticipation, they are often underutilized due to the limited range of outcome measures and the lack of demographic data needed to understand those measures.[11] Current child support performance measures focus exclusively on parents' financial obligations and largely ignore other ways in which parents stay involved in their child's life and contribute to their well-being. Such measures encourage child support systems to address the financial aspect of family relationships with a goal of enforcement. Together with punitive child support enforcement strategies, such performance measures limit the types of parents that systems can serve.[12] Child support systems also do not collect sufficient demographic data to understand disparities in their performance measures; therefore, these systems cannot form policies and practices based on evidence. For example, racial and ethnic disparities in the labor market[13] may have extended to child support payment outcomes,[14] and child support enforcement measures may have enlarged the effects of such disparities on children. The federal

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[9] Children's Health Care Quality measures. Medicaid. (n.d.). Retrieved September 26, 2022, from https://www.medicaid.gov/medicaid/quality-of-care/performance-measurement/adult-and-child-health-care-quality-measures/childrens-health-care-quality-measures/index.html

[10] Meyer, D. R., Cancian, M., & Chen, Y. (2015). Why are child support orders becoming less likely after divorce?. Deutsches Zentralinstitut für soziale Fragen/DZI. https://doi.org/10.1086/681604; Waller, M. R., & Plotnick, R. (2001). Effective child support policy for low-income families: Evidence from street level research. *Journal of Policy Analysis and Management, 20(1), 89-110*. https://doi.org/10.1002/1520-6688(200124)20:1<89::AID-PAM1005>3.0.CO;2-H

[11] Sorensen, E. (2016). *The child support program is focused on performance*. Office of Child Support Enforcement. https://www.acf.hhs.gov/sites/default/files/documents/ocse/sbtn_csp_focused_on_performance.pdf

[12] Waller, M. R., & Plotnick, R. (2001). Effective child support policy for low-income families: Evidence from street level research. *Journal of Policy Analysis and Management, 20(1), 89-110*. https://doi.org/10.1002/1520-6688(200124)20:1<89::AID-PAM1005>3.0.CO;2-H

[13] U.S. Bureau of Labor Statistics. (n.d.). Civilian unemployment rate. U.S. Bureau of Labor Statistics. Retrieved September 25, 2022, from https://www.bls.gov/charts/employment-situation/civilian-unemployment-rate.htm

[14] Sorensen, E. (2010). Rethinking public policy toward low-income fathers in the child support program. *Journal of Policy Analysis and Management, 29(3),* 604–610. https://doi.org/10.1002/pam.20512

government should form a technical workgroup to develop a broader set of measures for parent involvement, pilot these measures in systems that serve specific populations of interest (e.g., low-income families, families of racial and ethnic minorities, etc.), engage families in the development of measurement, and recommend evidence-based measures to all states. These initiatives should also include assessment, development, and piloting of available demographic data, as well as recommendations of how to use these already available demographic data within systems. To fully capitalize on these efforts to improve measurement, the federal government should provide sufficient trainings and technical assistance to state and local child support agencies to help with (1) collection of data to ensure data quality; (2) policy making around ethics, including limits on data-related burden to families and protections of data confidentiality; and (3) the effective use and analysis of outcome and demographic data to inform policies.

We appreciate the opportunity to provide comments and suggestions regarding *Equitable Data Engagement and Accountability*, and we are happy to expand on any of these points. For any questions regarding this letter, please contact Kristen Harper, vice president for public policy and engagement at Child Trends [redacted]

Sincerely,

/s/

Carol Emig
President
Child Trends

Austin Clyde
Assistant Computational Scientist

Data Science and Learning Division
Argonne National Laboratory
[redacted]

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October 3, 2022

NSTC Subcommittee on Equitable Data
Office of Science and Technology Policy
Building
[redacted] Washington, DC 20504

Re: Request for Information; Equitable Data Engagement and Accountability (87 FR 54269)

Dear Members of the NSTC Subcommittee on Equitable Data,

Thank you for the opportunity to comment on the development of infrastructures and resources for public engagement with equitable and open data. In this comment, we express that meaningful community engagement with equitable data is a necessary condition for the public to hold the government accountable with and for open data. We first address why access and accountability go hand in hand, then we move to answer directly question 6 regarding useability and accessibility and then question 5 regarding accountability. The comments expressed here are my own, developed with Aishani Aatresh, a Fellow of the Harvard Kennedy School's Program on Science, Technology and Society. The comments express here are not necessarily endorsed, nor meant to imply endorsement, by the Harvard Kennedy School, Argonne National Laboratory, or the Department of Energy.

Civic knowledge and public engagement are at an all-time low, according to a 2016 Annenberg Public Policy Center report.[1] We believe that public data, especially those released by local, state, and federal governments, presents a major and unprecedented opportunity for increasing the public's access to civic engagement. Data can be used to identify harms faced by citizens and their communities, understand trends and progressive realization of development and socio-economic goals, and offer a new participatory perspective into government at various levels.

Accessibility and useability are necessary conditions for accountability because accountability is a condition for democratic discourse, at a minimum.[2] Because "*to hold government accountable to the American public*" demands a citizen providing account of the government's actions vis-a-vis data, it also requires citizens to *be able to* develop an account conceptually and practically. This can only be through the kinds of awareness and familiarity that mechanisms of accessibility and usability provide. Otherwise, citizens cannot see how to participate in accountability discourse and make it be responsive their interests—"it is like playing a game whose rules do not make any sense to one."[3] This relationship between access and accountability is currently under development in the European Union. A recent proposal in the EU aims to increase access to civil liability law in artificial intelligence (AI) and data systems cases because the current bar for admission "may make it difficult or prohibitively expensive for victims to identify the liable person and prove the requirements for a successful liability claim" due to specific characteristics of AI and data

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[1] Sarah Shaprio and Catherine Brown, "The State of Civics Education," *Center for American Progress* (blog), February 21, 2018, https://www.americanprogress.org/article/state-civics-education/.

[2] Michael W Dowdle, "Public Accountability: Conceptual, Historical and Epistemic Mappings," *Regulatory Theory: Foundations and Applications*, 2017, 197–215.

[3] Thomas Christiano, *The Constitution of Equality: Democratic Authority and Its Limits* (Oxford ; New York: Oxford University Press, 2008), 62.

systems.[4] Given the limited access citizens currently face, usability and understanding of AI and data systems are prohibitively complex. Accountability suffers as the knowledge-gap between citizens, the government, and technology developers is extremely wide in terms of the technical information available, even if the democratic sensibilities of working towards building representative and usable technologies are not limited to those of experts.

RFI Question 5. What resources, programs, training, or tools can make equitable data more accessible and useable for members of the public?

We address this question with three main points. In summary, accessibility requires a *bi-directional relationship* between the government and community organizations and citizens using the data; this relationship must to provide the necessary equipment (physical and conceptual) for developing an understanding of their usage, and for citizens to co-develop new avenues of usage; and, useability and accessibility require explicit understanding and avenues for institutional responsiveness to the kinds of civic engagement citizens undertake with the data.

First, it is imperative that the resources, programs, and tools developed to increase data's accessibility and usability are understood as a relationship between the government and the citizens and community organizations which aim to use these tools. It is a collective effort undertaken by the government and citizens where understanding is a moving target, not a one-off deposit of some tools without responsive avenues for feedback and development. Technology and data policy are steeped a tradition which follows "a paternalistic, top-down, technocratic approach where the context, values, and agendas of datafication are obscured from the citizen."[5] It communicates to citizens the technocratic, and undemocratic, idea that "modern life is too complicated to be managed by ordinary people" and "only those with specialist knowledge and skills can rise to the task."[6] A unidirectional relationship reduces "citizens and civil society…to passive but demanding 'users' to be served by the public sector" rather than partners and owners of this democratic project.[7] Therefore, access must be developed in conjugation with community stake-holders and citizens, especially if it is for fostering government accountability (question 5).

As citizens and community groups face increasing access to data tools, their conceptual understanding grows. When communities become proficient in accessing and using data tools, the horizon of use cases and activities which can be undertaken with the data also grows. This means that access for who, access for what, and usability for what purpose is a constant moving target. Therefore, the ways in which citizens want to access and use the data moves and if the government cannot be responsive to these shifts, then the government risks alienating citizens from civic engagement further. Quintessential to the ideal of democracy is that decision making "tracks the interests and the ideas of those citizens whom it affects."[8] It is through government responsivity to considered public opinion and through the government fostering the access to the tools for the formation of considered public option, that the complex and dynamic democratic process of civic engagement can function.

Second, equitable data useability requires developing infrastructures for conceptual understanding, computing devices and public computing resources, and community-building for collective understanding and engagement. Usability is the condition of data or code conceptually understandable by the intended audience, physically accessible, and collectively

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[4] Procedure 2022/0303/COD COM (2022) 496: Proposal for a DIRECTIVE OF THE EUROPEAN PARLIAMENT AND OF THE COUNCIL on adapting non-contractual civil liability rules to artificial intelligence (AI Liability Directive). https://ec.europa.eu/info/sites/default/files/1_1_197605_prop_dir_ai_en.pdf

[5] Heather Broomfield and Lisa Reutter, "In Search of the Citizen in the Datafication of Public Administration," *Big Data & Society* 9, no. 1 (January 1, 2022): 20539517221089304, https://doi.org/10.1177/20539517221089302.

[6] Sheila Jasanoff, *The Ethics of Invention: Technology and the Human Future*, First edition, The Norton Global Ethics Series (New York: W.W. Norton & Company, 2016), 19.

[7] Broomfield and Reutter, "In Search of the Citizen in the Datafication of Public Administration."

[8] Philip Pettit, *Republicanism: A Theory of Freedom and Government*, Oxford Political Theory (Oxford : New York: Clarendon Press ; Oxford University Press, 1997), 184.

endorsed. A great challenge in fostering citizen participation in equitable data releases is the development of the conceptual tools for understanding *what are the kinds of questions and concerns one can address through data? What are the methods, tools, and resources a required to answer those questions? And who can help and guide citizens through this process?* Without addressing these questions, datasets will simply not be useable.

For example, many local governments release data sets[9]; however, there are far and few public spaces where one can interact with someone who can share how to interpret data. Traditionally, public libraries and librarians were resources for civic engagement.[10] While traditional high school civics education taught students the conceptual tools for conducting research in these public spaces, no programs currently exist which educate students on the open-data equivalent. But without many libraires prepared to handle data civics due to lacking data-trained staff, lacking computing resources, and lacking data-minded educational programs, education in schools alone is necessary, but not sufficient. In my experience teaching undergraduate computer science at the University of Chicago, students when invited to use public data to answer questions about their local communities were beyond excited and passionate. Because they were in a data-centric course and had access to computing resources, they were empowered to use their own city's data to not only verify of their own suspicions but are able to share this knowledge with their community.

Finally, we have made calls on the scientific community to develop public computing resources as demonstration, education, and activist sites where initiative can be met with the resources needed.[11] Participation relies "on different forms of public demonstration to legitimate their particular epistemologies."[12] Public computing and demonstration are further commitments to developing new modes of algorithmic and data justice, and proposals have been made in a similar vein.[13] It is necessary that resources and tools provide both the conceptual and physical means for using data systems.

Third, resources and tools for access and use of equitable data systems should address communities and collectives rather than individuals. While empowering individuals is an important endeavor, a particular focus should be placed on privileging communities and collective understanding. In this comment, I am mainly addressing uses of government data for the public to gain an understanding of their communities and governance for civic engagement. While democratic engagement can occur at the individual level, true empowerment for underprivileged communities comes through joining the forces of the community through data, building community through data efforts, and leveraging community partners to amplify their voices. The incorporation of algorithmic and data knowledge into civil life opens new modes of collective resistance against oppression. Collective resistance can "enact not only a making-visible of algorithms, but a making-affective of their role in society, providing voices through which their uneven impact can be felt by others."[14]

We provide two examples. The first example regarding the Census Bureau's differential privacy transition is a *negative* of failed public consultation, where accessibility and usability to the public suffered due to lack of a bidirectional communication channel between the public and the data sources. The second example of the COVID-19 Tracking Project is a positive one that

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[9] Beth Simone Noveck, "Rights-Based and Tech-Driven: Open Data, Freedom of Information, and the Future of Government Transparency," *Yale Hum. Rts. & Dev. LJ* 19 (2017): 1.

[10] Rashad Young, "More than Just Books: The Role of Public Libraries in Building Community and Promoting Civic Engagement," *National Civic Review* 101, no. 4 (2012): 30–33; Rachel Scott, "The Role of Public Libraries in Community Building," *Public Library Quarterly* 30, no. 3 (2011): 191–227.

[11] Austin Clyde, "AI for Science and Global Citizens," *Patterns* 3, no. 2 (February 11, 2022): 100446, https://doi.org/10.1016/j.patter.2022.100446.

[12] Sheila Jasanoff, "Restoring Reason: Causal Narratives and Political Culture," in *Organizational Encounters with Risk*, ed. B. Hutter and M. Power (Cambridge University Press, 2005), 228, https://books.google.com/books?id=wIfAU5exEPQC.

[13] Maayan Perel and Niva Elkin-Koren, "Black Box Tinkering: Beyond Disclosure in Algorithmic Enforcement," *Fla. L. Rev.* 69 (2017): 181.

[14] Garfield Benjamin, "Algorithmic Imaginaries and Political Resistance," in *ACM Conference on Fairness, Accountability, and Transparency 2022*, 2022.

demonstrates how data can itself be a source of bidirectionality and create modes of community involvement that counters pressing challenges of our time.

The Census Bureau is tasked with proving a count of everyone in the United States, among others such as protecting the privacy of individuals in their collection. The move to differential privacy for the 2020 data release meant the application of a new mathematical framework which "provable" protects privacy; however, as a result, it introduces targeted amounts of statistical noise into database queries which introduced inconsistencies when looking at aggregate and local data. Previously, noise was also added to the data but in a simplified procedural way outlined in the data releases. The way the noise is added with differential privacy now introduces some unknowability, leading to controversy by researchers and the public—even becoming center in a court case.[15] The sudden introduction of this change lead to controversy and the ‘‘statistical imaginary’ of the data—that the data is truly just a count of people without any inference involved.[16] Researchers now are ”unable to evaluate the quality of the data" as the "introduced technical and procedural uncertainties" are a black-box to them and they were unprepared for the change. This example illustrates a failure of communication, access, and useability due to the lack of public consultation, preparation of the community through engagement and listening, and developing and fostering the epistemic tools to work with the shift.

The COVID-19 Tracking Project was a volunteer initiative launched by employees at *The Atlantic* in an attempt to better compile, interpret, and disseminate information about the pandemic in the United States, particularly given limited information and great uncertainty in the early stages of the outbreak about testing and cases. The Project was also one of the first to focus explicitly on racial data in the pandemic, in addition to the impact on long-term care facilities, bolstered by its entirely volunteer base of hundreds of data-collectors, software developers, writers, designers, and more dedicated to make more legible the impact of COVID-19 — not only in relation to individuals' daily lives, but to enable community efforts to hold leaders to account to *care* for citizens, to shine a light on problems that tend to be shrouded in darkness when looked upon from above, and to offer alternative avenues through which a problem as large and unwieldy as a pandemic could be tackled. It was in bringing together people from across communities to create yet another form of a collective that The COVID-19 Tracking Project was able to reimagine what responsible and usable data might look like as a means to hold power to account; federal data over time improved partially in response to these efforts such that the emergent, urgent need for the project waned over time.[17]

RFI Question 5. What resources, programs, training, or tools can increase opportunities for community-based organizations to use equitable data to hold government accountable to the American public?

Withstanding the theoretical comments from question 6, that accountability requires access, I offer a concrete institutional activity—local government hackathons—that can be supported by OSTP to hold the government accountable by the public through equitable data. The idea of local government hackathons is to host community-sponsored events in public institutions such as libraries and schools where data scientists, librarians, and members of civil organizations educate the community on the tools and resources for using data, share the kinds of questions members can bring to data and computing, and offer assistance and mentorship to citizens desiring to prove cases. Not only does this activity support communities, but it represents a bi-directional relationship between expertise and communities where experts offer their knowledge to the

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[15] https://www.washingtonpost.com/dc-md-va/2021/09/09/alabama-drops-census-lawsuit-privacy/

[16] boyd, danah, & Sarathy, J. (2022). Differential Perspectives: Epistemic Disconnects Surrounding the U.S. Census Bureau's Use of Differential Privacy. Harvard Data Science Review, (Special Issue 2).

[17] The COVID Tracking Project. "About Us." Accessed October 3, 2022. https://covidtracking.com/about.

questions and demands of citizens, and where citizens can be informed of the basic horizon to which they can have questions and demands of.

There is great emancipatory power in data, and in particular the publicity and demonstration aspect of data is extremely exciting. Demonstration is a core way the public accept and come to understand claims. This is particularly true in scientific communities and demonstrated through Professor Sheila Jasanoff's comparative study of the relationship between science and politics across different political communities.[18] Computing offers new avenues for demonstration because data projects can be reproduced, shared, and shown to many parties. While a few community members may suspect that their water quality is less than that of a wealthier neighborhood, statistical analysis which demonstrates this claim in a reproducible way is very strong evidence—evidence which can even be used to meet requirements for engaging in litigation activates which otherwise may have been prohibitively expensive or inaccessible.

To offer a concrete example how computing and data can create narratives demonstrating oppression, we can look to Amazon's attempt at creating a resume screener.[19] Utilizing data from its hiring practices department, Amazon created an algorithm which learned to screen resumes versus paying employees to do the task. A year later, the engineers reportedly noticed something troubling about their engine — it did not accept women's resumes. They examined the algorithm in the following way after a year. They looked at counterfactual cases where resumes would include signifiers common to women, without making gender explicit. For example, the inclusion of Barnard College, an all-women's liberal art college, would cause the algorithm to reject an application that otherwise would be highly desirable. Unlike a bureaucratic equivalent, a human-staffed HR office, the discrimination against women was demonstratable across time, locations, and parties. In fact, the use of data here more explanatory to those facing oppression than a traditional office would be.[20] The algorithm and data exposed itself clearly, showing its own bias printed on a screen through the right research question. Contrast this with people, who work quite hard to hide their implicit biases.

We hope you found these comments helpful and pointed. Many of the points expressed here are active areas of my research, and we are keenly working towards developing local community data hackathons in conjugation with non-profit organizations such as SEED AI. Please do not hesitate to follow up on any points that are not clear or for further information. We look forward to reading new policies and initiatives that come out of this request for information.

[redacted]

Austin Clyde
Assistant Computational Scientist
[redacted]l Laboratory

[redacted]

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[18] Sheila Jasanoff, *Designs on Nature: Science and Democracy in Europe and the United States* (Princeton, N.J: Princeton University Press, 2007).

[19] Jeffrey Dastin, "Amazon Scraps Secret AI Recruiting Tool That Showed Bias against Women," in *Ethics of Data and Analytics* (Auerbach Publications, 2018), 296–99.

[20] Rob Reich, Mehran Sahami, and Jeremy M. Weinstein, *System Error: Where Big Tech Went Wrong and How We Can Reboot*, First edition (New York, NY: Harper, an imprint of HarperCollinsPublishers, 2021), 109.

CLASP
The Center for Law and Social Policy

October 3, 2022

To: Office of Science and Technology Policy

Re: Request for Information on Equitable Data

The Center for Law and Social Policy (CLASP) is a national, nonpartisan, nonprofit organization whose mission is advocating for policies that advance economic and racial justice. Founded more than 50 years ago, CLASP works to develop and implement federal, state, and local policies (in legislation, regulation, and on the ground service delivery) that reduce poverty, improve the lives of people with low incomes, dismantle barriers arising from systemic racism, and create pathways to economic opportunity.

We appreciate the opportunity to comment on equitable data collaboratives. While data collection and other data cycle processes are powerful tools to inform key policy decisions, these data processes were created within the same systems, institutions, and structures that have been shaped by the historic and present impacts of white supremacy culture and systemic racism. This means that each component in the data cycle may collectively and individually reflect and uphold systemic inequities that center on race.

Understanding that the approaches used to gather and analyze data are not inherently neutral, CLASP highlights the importance of widening the scope of approaches and tools used to collect data about issues, which may include both quantitative, qualitative, and mixed-method approaches that include data that may come in non-traditional formats (such as storytelling) to illuminate the lived experiences of disenfranchised communities of color.

We have identified the following best practices for inclusive and equitable data and for incorporating inclusive community engagement frameworks into expanded data strategies:

- Interrogate whose knowledge (i.e., evidence, lived experiences, and perspectives) is considered central to the policymaking and advocacy process, and whose is not.
- Analyze data with the intention of understanding inequities;
- When possible, disaggregate data to honor and unpack the trends and experiences of different groups; when it is not possible, consider whether there are other types of information that can be brought to bear;
- Lead with the voices of those who are impacted in defining the problem, designing the solutions, and during implementation;
- Involve directly impacted people/communities not just as people to survey, but in developing data strategies including constructing survey questions, creating outreach strategies, interpreting and organizing qualitative responses, etc.
- Engage in authentic conversations with directly impacted community members to capture their perspectives;
- Respectfully partner with community-based connectors and organizing entities to build trust and authentic reciprocal relationships; and
- Ensure that the results of research are shared in ways that are accessible to the people it’s about and who

may be impacted by policy based on that research – e.g., findings should be shared through blogs, videos, or interactive websites not just in a long technical paper that may be behind a paywall.

For a deeper discussion of these issues, CLASP recommends our 2021 paper, Shaping Equitable Early Childhood Policy: Incorporating Inclusive Community Engagement Frameworks into Expanded Data Strategies, by Alycia Hardy and Alyssa Fortner. Although this paper was specifically written with regard to early childhood policy, the overall framework and many of the recommendations and resources included are of broader relevance.

Other resources that we have found useful and that we recommend for your consideration:

Data equity framework created by We All Count. This framework breaks down data work into seven stages: funding, motivation, project design, data collection and sourcing, analysis, interpretation, and communication & distribution; and discusses key equity decision points within each of these stages. We All Count also provides training programs and a discussion community.

AAPI Data Equity Project. Data equity is a particular concern for the AANHPI population, because they are often lumped into an "other" category in data analysis. Even when AANHPI is identified as a distinct group, the differences between various ethnic communities within the AANHPI population means that aggregate numbers can be misleading. In particular, we draw attention to the AAPI Data Equity Project's recent report: *2022 AANHPI Roadmap for Data Equity in Federal Agencies (in collaboration with National Council of Asian Pacific Americans)*, which assesses the current state of data equity efforts and includes recommendations for next steps.

Learning and Action in Policy and Partnerships. To strengthen alignment and data sharing among the public health, health care, and social services sectors, the Robert Wood Johnson Foundation is supporting the Learning and Action in Policy and Partnerships (LAPP) national initiative, which is led by Data Across Sectors for Health in partnership with the Center for Health Care Strategies (CHCS). This project has supported 11 partnerships across two funding rounds. A recent report, A Community-Centered Approach to Data Sharing and Policy Change: Lessons for Advancing Health Equity, August 2022, provides lessons from the first round of funded partnerships.

We have also heard very positive things from our partners about the Hartford Data Collaborative (HDC), a network of Hartford area non-profit organizations, government agencies, and philanthropic partners that facilitates data sharing and data integration among its partners.

Thank you for your consideration.

HAC
Housing Assistance Council
We help build homes and communities across rural America.

October 3, 2022

Attn: NSTC Subcommittee on Equitable Data
Office of Science and Technology Policy
Eisenhower Executive Office Building
[redacted] NW
Washington, DC 20504
Via email to [redacted]

Re: Engagement and Accountability RFI

To Whom It May Concern:

The Housing Assistance Council (HAC) appreciates this opportunity to submit comments to the Request for Information on Equitable Data Engagement and Accountability. HAC is a national nonprofit organization that helps build homes and communities across rural America. HAC and our rural stakeholders have relied on data for decades to improve our understanding of rural communities and to inform strategies and solutions for rural America. With over 50 years of experience in affordable housing and rural markets, HAC feels uniquely qualified to comment on this RFI to voice concerns related to rural and housing data.

Quality and accessible data is essential to develop strategies and solutions for some of the most complex challenges experienced by communities – and especially rural areas. But data can also be difficult, and sometimes intimidating. Today, users can be overwhelmed by the sheer amount of data available to them. Data is typically scattered in many disparate locations, and data clearinghouses are often unwieldy and difficult to navigate. The geography and population characteristics of rural communities also add constraints and problems for the quality of data in more sparsely settled areas.

Below are HAC's responses to some of the specific questions in the Request for Information.

4. What policies, resources, programs, training, or other tools can expand opportunities for historically underrepresented scholars and research institutions to access and use equitable data across levels of government?

HAC has identified two specific government resources that could be expanded or improved to provide more equitable data for nonprofit research organizations and the public.

Develop a "reliability index" for Home Mortgage Disclosure Act data

The Home Mortgage Disclosure Act (HMDA) is an invaluable resource for understanding and improving home lending markets across the country. Congress enacted HMDA in 1975 to help inform the public and policymakers of mortgage lending activity, and, in doing so, make it possible to identify communities where access to credit is being denied or discrimination is occurring.[1] With some exceptions, the law mandates that institutions originating home purchase, refinance, and/or home improvement loans must publicly disclose certain information on loan applicants and loan characteristics.

HMDA currently excludes rural activity through some of its reporting exemptions that limit coverage. Reporting exemptions exist for lenders with extremely small assets ($50 million in 2022[2]) and lenders that do not operate a bank office or branch in a Metropolitan Area (as identified by the Office of Management and Budget). As a result, many smaller banks and banks that operate exclusively in rural areas do not report home lending data. This exemption calls into question the thoroughness of HMDA data for some small markets. Recent changes that have exempted even more lenders from reporting have further exacerbated the problem of data coverage, particularly for small rural areas.

A HMDA "Reliability Index,"[3] as presented at a 2021 Tech Sprint[4] hosted by the Consumer Financial Protection Bureau, would provide a classification or typology that estimates the amount of lending activity in a market that is covered by HMDA data. The introduction of a Reliability Index would be helpful for the CFPB and would enhance equity for data users and consumers alike. For example, markets such as the colonias in the U.S.-Mexico border region, where many home purchases involve cash-only transactions that are not covered by HMDA,[5] would be classified as having "limited coverage."

Return rural to the American Housing Survey

The American Housing Survey (AHS),[6] conducted by the Census Bureau for the U.S. Department of Housing and Urban Development (HUD), is one of the richest data sources on housing conditions in the United States. HUD, however, has removed the rural codes from the AHS's Public Use File. The inability to separate rural household data in such an important resource is a glaring equity issue for rural data users and efforts that utilize this data. HAC recommends that HUD work with the Census Bureau to make rural data available to AHS users again.

6. What policies, resources, programs, training, or tools can make equitable data more accessible and useable for members of the public?

Support resources that make data easy to access and use

To help wade through the virtual sea of disparate data, the Housing Assistance Council created a searchable database that combines many separate data sources in one easily accessible place. The Rural Data Portal (ruraldataportal.org) is a simple, easy to use, online resource that provides essential information on the social, economic, and housing characteristics of communities in the United States. The Rural Data Portal provides over 350 data indicators and millions of data points for rural communities across the United States. Most of the information provided comes from HAC tabulations of various public use data sets such as the Decennial Census of Population and Housing, the American Community Survey (ACS), the Bureau of Labor Statistics, Home Mortgage Disclosure Act data, HUD Annual Homeless Assessment Report data, and other programmatic and resource data from an array of federal agencies.

The Rural Data Portal was not built for power or sophisticated data users. Instead, this unique portal was designed to be accessible and useable for local residents and community-based organizations without the complexity and intimidation that data access and manipulation sometimes evokes. HUD provided support to help build the first version of the Rural Data Portal in 2004. As the tool has expanded, so have costs and complexities of data management and presentation. HAC suggests that federal agencies such as HUD and USDA consider supporting the next iteration of a new and improved Rural Data Portal – called Rural Data Central. This dynamic resource, which is now nearly complete, not only addresses serious data gaps and access issues in rural areas, but also helps local community-based organizations and municipalities better strategize, plan, and administer federal resources and programs.

7. In which agencies, programs, regions, or communities are there unmet needs, broken processes, or problems around participation and accountability that could be remedied through stronger collaborations and transparency around equitable data?

Better data is needed to understand a hidden – yet essential – community

Agriculture is a multibillion-dollar industry in the United States and is integral to the health and well-being of the nation. The affordability of fresh and unblemished fruits and vegetables comes, in part, through cheap labor undertaken by farmworkers. While no definitive figures are available, an estimated 2.5 million people work harvesting fields, farms, and orchards in the United States.

Among the poorest groups in the nation, farmworkers earn low wages and experience working conditions that hinder their ability to access affordable, quality housing. Their situation is further exacerbated by legal, cultural, and geographic circumstances that often keep them in the shadows of American society and contributes to their economic marginalization. Additionally, farmworkers in the United States have often been ethnic minorities or immigrants.

Data for farmworkers are generally nonexistent in large-scale surveys and data collection instruments such as the decennial Census or the American Community Survey. The National Agricultural Workers Survey (NAWS),[7] administered by the U.S. Department of Labor, provides some insights into the demographic and employment characteristics of farmworkers in the United States. The NAWS does not, however, provide detailed information about housing quality or conditions. Additionally, the survey excludes farmworkers who are temporarily in the United States with H-2A visas and now account for a large portion of the farm workforce.[8] This means that there are huge gaps in the NAWS dataset. The Housing Assistance

Council recommends that the NAWS survey methodology be amended to include H2-A visa holders.

Additionally, HAC recommends a renewal of public-nonprofit partnership to improve an understanding of farmworker housing conditions. In 2001, HAC conducted a first-of-its-kind survey of national farmworker housing conditions.[9] This survey was conducted in partnership with the U.S. Department of Housing and Urban Development and the U.S. Department of Agriculture. In the more than 20 years since, much has changed in farmworker dynamics, housing situations, and the use of employment visas to secure farm laborers. HAC proposes to renew this national survey with a specific focus on better understanding the changes and implications that the expanded use of H-2A visas has had on the housing and well-being of all farmworkers. Support from HUD and USDA would again be extremely useful.

* * * * *

Thank you for the opportunity to provide input to the Subcommittee on Equitable Data in its efforts to support the identification, production, and use of equitable data. HAC looks forward to working with you to continually improve and enhance data for all communities – urban and rural. Please do not hesitate to contact me if you need additional information or clarification of our comments.

Sincerely,

[redacted]

David Lipsetz
President and Chief Executive Officer

Notes

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[1] Federal Reserve Bank of Boston, Home Mortgage Disclosure Act (HMDA) Data for New England, October 29, 2018, https://www.bostonfed.org/data/data-items/home-mortgage-disclosure-act-hmda-data-for-new-england.aspx.

[2] Home Mortgage Disclosure (Regulation C) Adjustment to Asset-Size Exemption Threshold, Consumer Financial Protection Bureau, Federal Register, December 23, 2021, https://www.federalregister.gov/documents/2021/12/23/2021-27899/home-mortgage-disclosure-regulation-c-adjustment-to-asset-size-exemption-threshold.

[3] R(ural) Five, CFPB HMDA Tech Sprint, March 22-26, 2021, https://www.youtube.com/watch?v=-UaiU-xCyYQ&list=PLrfmdUlWzRF2Tb_28HcbfsDrFr5vLPjP0&index=6.

[4] Home Mortgage Disclosure Act Virtual Tech Sprint, Consumer Financial Protection Bureau, https://www.consumerfinance.gov/rules-policy/innovation/cfpb-tech-sprints/home-mortgage-disclosure-act-tech-sprint/.

[5] Noah J. Durst and Elena J. Cangelosi, “Self-Help Housing and DIY Home Improvements: Evidence from the American Housing Survey,” Housing Studies 36:8 (2021), pp.1231-1249.

[6] U.S. Census Bureau, American Housing Survey (AHS), https://www.census.gov/programs-surveys/ahs.html.

[7] National Agricultural Workers Survey, Employment and Training Administration, U.S. Department of Labor, https://www.dol.gov/agencies/eta/national-agricultural-workers-survey.

[8] Skyler Simnitt and Marcelo Castillo, “Use of H-2A Guest Farm Worker Program More Than Triples in Past Decade,” Amber Waves, Economic Research Service, U.S. Department of Agriculture, September 2, 2021, https://www.ers.usda.gov/amber-waves/2021/september/use-of-h-2a-guest-farm-worker-program-more-than-triples-in-past-decade/.

[9] No Refuge From the Fields: Findings From a Survey of Farmworker Housing Conditions in the United States (Washington, DC: Housing Assistance Council, 2001), https://ruralhome.org/reports/no-refuge-from-the-fields-findings-from-a-survey-of-farmworker-housing-conditions-in-the-united-states/.

September 27, 2022

White House Office of Science and Technology Policy
Attn: NSTC Subcommittee on Equitable Data
Eisenhower Executive Office Building
[redacted]
Washington, DC 20504.

Re: Request for Information; Equitable Data Engagement and Accountability

Comments submitted by:
Brett Williams – Public Policy Analyst
Michigan Developmental Disabilities Council
320 South Walnut Street
Elliott-Larsen Building – Garden Level
Lansing, MI 48933

Michigan Developmental Disabilities Council (MiDDC) greatly appreciates the opportunity to provide comments and feedback on the Request for Information (RFI) regarding Equitable Data Engagement and Accountability. The first point we would like to share is that people with disabilities must be a factor in all data collections. There is an unwavering intersectionality of disability across all other populations; this can not be overlooked.

We agree that “Durable, equitable data infrastructure requires fostering collaborations across all levels of government, as well as with a diverse community of external organizations to advance outcomes for underserved communities.” However, we also note that trusted community-integrated individuals must be included within this position.

We believe that the steps being taken within this RFI are admirable, the challenges faced in collecting equitable data through engagement of socially repressed communities or organizations will not be corrected in short-term efforts. Marginalized populations have experienced centuries of repression, broken promises, segregation, inequitable treatment, lack of resources, implicit and explicit biases, and discrimination from all levels of government. Yes, there has been progress made to restore components of trust, however, there is substantial distrust that still remain today.

The definition provided in this RFI reads “By equitable data, we mean data that allow for rigorous assessment of the extent to which government programs and policies yield consistently fair, just, and impartial treatment of all individuals, including those who have been historically underserved, marginalized, and adversely affected by persistent poverty and inequality.”

Question 2.
Among examples of existing Federal collaborations with (a) Tribal, territorial, local, and State governments or (b) local communities involving equitable data, what lessons or best practices have been learned from such collaborations?

Response (b)
There is little debate that trusted individuals or trusted community organizations/partners with rich connections to a served population is essential to engage in meaningful conversations and create the ability to extract/share significant data. It would be extremely difficult to set a "best practices" threshold due to the incredible uniqueness of each community. What has been learned, is that there is not a specific one-size-fits-all best practice. To narrow this down to a core focus, trust needs to be established long before any "ask" is employed.

Question 5
What resources, programs, training, or tools can increase opportunities for community-based organizations to use equitable data to hold government accountable to the American public?

Response:
The best tools available are truth, and asking the community how they would like to see all levels of the government held accountable. As in the disability community when discussing programs and policies, "Nothing about us without us" is the moniker. We don't know, what we don't know. We must engage the community in designing programs, developing training or tools, and how to best integrate within that particular community. After that component is established, then accurate data may be harvested and utilized effectively to meet the objective of question 5.

Question 6
What resources, programs, training, or tools can make equitable data more accessible and useable for members of the public?
Response:
1. Break data down to a digestible level for non-academics
2. Ensure accessibility means more than just accessing the data, it should meet accessibility standards for people with disabilities
3. Ensure that reports containing data are linguistically and culturally appropriate
4. Ask the communities of fucus how they would like the data categorically organized, most appropriate format, and how they would like it to be shared
5. Never assume that what is produced will meet the needs of the community. You must include that community throughout the entire process from collection to distribution

Question 7
In which agencies, programs, regions, or communities are there unmet needs, broken processes, or problems related to participation and accountability that could be remedied through stronger collaborations and transparency around equitable data?

Response:
Beginning with rectifying past discretions, this will take diligent efforts from all involved parties, those who have experiences in marginalization, discrimination, and segregation as well as representation from ***all levels*** of government. Secondly, this question has been asked and answered for decades (less the equitable data component). The simple answer is, virtually all programs, regions, and low-income communities experience unmet needs, broken promises, and barriers to collaborations. In order to promote stronger collaborations and transparency, we must rebuild the trust between all parties. There is no simple way to accomplish this goal, however, you can never begin a journey without taking that first step.

Sincerely,
Brett Williams
Public Policy Analyst
Michigan Developmental Disabilities Council

Response to Request for Information Equitable Data Engagement and Accountability

Attn: NSTC Subcommittee on Equitable Data, Office of Science and Technology Policy, Eisenhower Executive Office Building, [redacted] Washington, DC 20504.

Name of Organization: Digital Science

- UEI NXUBHKXWVBL4
- CAGE 7SMW9

Name of Digital Science PoC

- Frank Semancik, Program Manager, [redacted]
- Monika Dunbar, Program Manager, [redacted]

—-

Digital Science & Research Solutions, inc. (Digital Science) is interested in working with OSTP to support their data engagement and accountability requirements. Digital Science works with small business partners including HubZONE and SDVOSB small business prime contract holders on the CIO-CS Governmentwide Acquisition Contract as a streamlined option for the US Federal Government to contract with us. Digital Science's ***Figshare*** product offering is the premier generalized data repository serving the United States Federal Government for scientific, technical, research data sharing needs. We are supporting Agencies including the National Institutes of Health (we are featured on nlmdirector.nlm.nih.gov and https://datascience.nih.gov/exploring-generalist-repository-nih-funded-data), USDA, and more. Digital Science's ***Figshare*** is pleased to be able to respond to the following questions:

3. What resources, programs, training, or other tools *can facilitate increased data sharing between different levels of government (Tribal, territorial, local, State, or Federal) related to equitable data* ?

Having a centralized repository for storing and sharing data allows work done by stakeholders at different levels to collaborate on sharing and discovering outputs. Figshare's Projects functionality provides a pathway to collaboration; users can create new projects and access those they've been invited by others to collaborate on. Members of each project can upload files or add text notes, as well as comments. In addition to software functionality that provides different levels of access and sharing between stakeholders, training to use the tools and best practices are key in increasing sharing and usage of equitable data.

To be useful, and improve equitability, data needs to be accompanied by well-described metadata, ideally shared in non-proprietary file formats and shared in a place where researchers and the public alike will be able to easily discover, and interact with data.

One of the community standards that has been developed around best practices for sharing research data, especially publicly funded data, are the FAIR principles. These stand for Findable, Accessible, Interoperable, and Reusable. Figshare as a repository provider, and contributor to community driven efforts such as implementing the FAIR principles, creates case studies (https://figshare.com/collections/figshare_case_studies/3282239) detailing best practices.

Figshare has been working with the Howard Hughes Medical Institute's Janelia Research campus since 2017 to provide repository software to meet their researchers' needs for a system to make data available publicly. Since their launch, they've uploaded over 1,600 items into their repository, all of them Open Access. In 2020, Janelia added the newly-launched Figshare Curation Service to their repository to enhance metadata published alongside Janelia research data, ensuring documentation is as thorough and FAIR as possible. These values are in line with HHMI's commitment to open access and to ensuring public engagement is at the heart of their role in the community. Figshare designed the Figshare Curation Service to provide data sharing guidance and review of submissions by data experts via the Figshare for Institutions infrastructure after completing a repository pilot with the NIH and seeing the significant difference that metadata checks had on the FAIRness of open data.

The Figshare curation team has provided guidance to Janelia researchers on:

- How to organize files into zipped folders, linked files, individual file formats, items, and collections so they could best be reused and cited

- Meaningful titles for datasets and other research outputs

- Descriptions to provide context to the research question and research methods

- Links to other resources including project web pages, visualizations, related publications, GitHub repositories, other datasets or code

- Authorship

- Sharing data in a way that can be managed by research projects in the future and released in future versions

The full case study of how Figshare is helping to improve the quality of how data is being shared is available here: https://figshare.com/articles/online_resource/Janelia_Research_Campus_works_with_Figshare_s_Curation_Service_to_enhance_metadata_for_reuse_and_discoverability/14423639?backTo=/collections/figshare_case_studies/3282239.

Contact Monika Dunbar at [redacted] *to receive a demo of Figshare*

4. What resources, programs, training, or other tools *can expand opportunities for historically underrepresented scholars and research institutions to access and use equitable data across levels of government* ?

Data sharing where the responsibility is on the individual to find funding, navigate finding and using third party repository software, and understanding metadata best practices and licensing options, are barriers to data being shared. This information is gathered directly from researchers, and staff in government, funders, publishers and institutions in Figshare's annual State of Open Data survey and report. Now in its 7th year, the State of Open Data survey has had over 26,000 responses from 192 countries and continues to provide a detailed and sustained insight into the motivations, challenges, perceptions and behaviors of researchers towards open data. This year, the survey received over 5,000 responses and the report which will be published in mid-October will include a piece authored by the NIH Office of Data Science Strategy and Office of Science Policy on their data sharing mandate that comes into effect in 2023. You can read all of the annual reports and access the survey data here: https://figshare.com/collections/State_of_Open_Data/4046897.

If data isn't available in a centralized place with metadata that enhances discoverability, data from and on historically underrepresented scholars is less likely to be found and used. Federal level repositories like The United States Environmental Protection Agency's, fosters sharing and use of data by removing practical barriers such as cost and a lack of knowledge of using repositories to adhere to best practices. As the cost of running the repository is covered by the federal agency, when data and research information is shared on the repository this ensures the end user has free, public access to data. Federally funded research projects should include direct costs for data description, curation, and deposit in trusted repositories, which is what the NIH mandate coming into effect in January 2023 provides for its grantees. In addition, federally funded research training programs should include training on data management and sharing skills and best practices as well as data science for its grantees, to ensure the end results will be made available to the public in the most useful and accessible manner.

6. What resources, programs, training, or tools *can make equitable data more accessible and usable* for members of the public?

Building on our response to question 3, federal funders and agencies have a responsibility to not just publish data, but to publish data in a manner that is useful to end users, including the public. As researchers and data sharers are not always experts in search engine optimization, or conveying their particular research in a manner suitable for the public, having a dedicated research data manager to oversee the publication of data will allow federal agencies to be confident in the quality of the data they're sharing. By combining data proficient repository software with a FAIR data specialist who can check and curate the metadata, the datasets and files are published with metadata that acts as an effective 'shopfront' - clearly explaining to readers and end users what the data is, how it was collected and who funded it, for example. Experts can also provide guidance to those wishing to share data on their options for licensing their content, by choosing open licenses such as those from Creative Commons, barriers to reuse of data are reduced.

By aggregating research data and outputs in a single place like a Figshare repository, federated search and discovery tools can be applied to make navigating a repository easy for anyone with internet access. Any content shared on a Federal Agency's Figshare-powered repository is also mirrored on our generalist repository figshare.com, increasing the reach of any given institutions' output. To search across all of Figshare, go to figshare.com/search.

7. In which agencies, programs, regions, or communities *are there unmet needs, broken processes, or problems related to participation and accountability* that could be remedied through stronger collaborations and transparency around equitable data?

Although funded programs such as the EU Horizon 2020 have been piloting research data sharing policies and best practices for several years now (https://ec.europa.eu/research/participants/docs/h2020-funding-guide/cross-cutting-issues/open-access-data-management/data-management_en.htm), the United States has only seen national or federal level best practice guidance really take shape in 2022, with the announcement of the NIH's data mandate (https://sharing.nih.gov/data-management-and-sharing-policy/about-data-management-and-sharing-policy/data-management-and-sharing-policy-overview#after) and the Office of Science and Technology Policy's memo (https://www.whitehouse.gov/wp-content/uploads/2022/08/08-2022-OSTP-Public-Access-Memo.pdf).

With these new policies coming into action in the coming years in the United States, training people working within communities on data management, sharing, and data science will be an important part of providing adoption capabilities of grantees. Funders and the federal government can provide or fund resources like repositories and data tools at all levels from federal agencies, to state, to regional to meet the needs of researchers with software tools where they are. To increase equity in collecting, managing and sharing data, tools funded at the federal level that are available to smaller communities that they can easily opt into using, rather than having to find or build their own solutions, may help to increase the speed of adoption of sharing data.

The Humanities and Social Sciences (HSS) is often the research discipline that data on equity is conducted within. We know from the State of Open Data, that academics who conduct HSS research are often faced with greater needs that are not met by the current support available to them. Rebecca Grant, Head of Data and Software Publishing at F1000, stated in a recent article (https://blog.f1000.com/2022/09/07/open-data-humanities-and-social-sciences/):

> "there seems to be a general lack of experience in data sharing compared to the life sciences.

> In scientific disciplines, data is the bedrock of research and discovery—it is gathered, stored, and analyzed as part of the scientific process. However, in the humanities, many researchers are unclear on what exactly constitutes “data”. Often, researchers have used or generated data, but don’t immediately recognize it as such.
>
> Humanities scholars often use third-party sources in their research. This can include data generated by others, or provided by cultural heritage institutions, which could lead to copyright issues if the author attempted to re-share it under an open license. Lastly, researchers in the field might not be aware of resources that could facilitate data sharing, such as data repositories.
>
> In the social sciences, the primary challenge is not necessarily identifying the data, but understanding whether it can be shared. Most social sciences researchers work closely with human research participants. It is essential to protect their identity and privacy. Moreover, social science research often involves sensitive topics. In such cases, scholars in the field must get participant consent to share data openly.”

Federal agencies including the Department of Homeland Security and the United States Department of Agriculture look to Figshare because we provide data proficient repository software and because we are thought leaders who contribute to further best practices in the data sharing space. For example, Figshare is contributing to the NIH GREI project (https://datascience.nih.gov/news/nih-office-of-data-science-strategy-announces-new-initiative-to-improve-data-access), to further the creation of best practice across generalist repository software providers. We help federal agencies to ensure that everyone that needs to share data within their organizations can do so in a FAIR, and equitable way.

<u>Acquisition Input:</u>

Digital Science offers the US Federal Government several ways to contract with us. Among them, NIH NITAAC’s CIO-CS Government-Wide Acquisition Contract (GWAC) now offers the Digital Science products and value added services to all Federal Agencies via small business (HUBZone and SDVOSB) prime CIO-CS contract holders. Digital Science supports the US Government’s small businesses goals by working with small business resellers using NITAAC’s streamlined contracting vehicle. Please contact Monika Dunbar [redacted] for more information on procuring Figshare via CIO-CS.

Contact Monika Dunbar at [redacted] to receive a demo of Figshare

The Kelsey

[redacted]
San Francisco, CA 94103
www.thekelsey.org

Re: RFI Equitable Data Engagement and Accountability

October 3, 2022,

The White House
Office of Science and Technology Policy (OSTP)
Subcommittee on Equitable Data, National Science and Technology Council

Dear Subcommittee Members,

Thank you for this opportunity to submit information on the need for more equitable data engagement and accountability as part of the implementation of President Biden's Executive Order on Advancing Racial Equity and Support for Underserved Communities Through the Federal Government. At The Kelsey, we pioneer disability-forward housing solutions that open doors to more affordable homes and opportunities for everyone. We have 240 homes in our pipeline and lead advocacy initiatives to support market conditions to make inclusive housing the norm. Therefore, our comments today will focus on the need for more equitable data related to disability and housing.

The main question we will answer is:

#7 In which agencies, programs, regions, or communities *are there unmet needs, broken processes, or problems related to participation and accountability* that could be remedied through stronger collaborations and transparency around equitable data?

Current data research fails to quantify, capture, and validate the need for disability-forward housing and how the lack of affordable, accessible, and inclusive housing affects the lives of disabled people and their families. The gaps in data apply to disabled people living in all places and arrangements, but the gaps are most acute for people with disabilities living in all types of institutions and those who are unhoused.

Beyond the very limited information collected by the Census, there is no national data source that looks at the population of people living in institutional settings. There are a lot of estimates, but no data set captures the demographics and needs of this left-out population, including but not limited to their needs related to housing. As the federal government continues to de-invest in institutional settings, in part due to explicit policy mandates, we must be able to draw on up-to-date data of this population to ensure that our housing and services infrastructures are responsive and equitable in policy and practice. Federal agencies should explore collaborative ways to collect data on this population. Moreover, to effectively capture data on the entire disabled population, there should be alignment across all federal data sets, including how disability is defined and asked about. Currently, this is not the case which creates substantial inconsistencies and gaps in understanding the fullest needs and demographics of people with disabilities.

Moreover, disability experience is rarely asked about in optional demographic questionnaires offered by federal agencies. This lack of opportunity to self-disclose can often lead to some people with disabilities falling through the cracks, unable to access programs they may qualify for.

For example, public housing authorities only ask about disabilities concerning mobility or sensory units. Those are important questions, but only a percentage of disabled people need those specific types of units. This means that there are people with disabilities who may not need a specific adaptive unit but do qualify for programs for adults with disabilities because they have other disabilities. Therefore, without more inclusive questions about disability, people cannot access programs they qualify for. The Department of Housing & Urban Development (HUD) must implement new practices when collecting demographics and needs-based information. The Kelsey would like to refer the White House to further recommendations sent by the Consortium for Constituents with Disabilities Housing Task Force.

Additionally, it is critical to solve for the data gaps of people who receive non-institutional services and those who need services but who have no access to services. This is particularly significant because there are proven racial gaps in who accesses and doesn't access home and community-based services. Federal agencies must provide more guidance and accountability measures for when and how this data is collected and include questions relating to housing-related needs.

In conclusion, any of these efforts to increase data equity should be co-created and informed by the communities that the data is focused on.

Thank you for the opportunity to submit this letter. If you are interested in connecting further about the data gaps and actions for equitable data collection, specifically at the intersection of housing and disability, please reach out via email: [redacted]

Sincerely,

Allie Cannington
Senior Manager
The Kelsey
[redacted]

DQC
Data Quality Campaign

September 29, 2022

NSCT Subcommittee on Equitable Data
Office of Science and Technology Policy
Executive Office of the President
Eisenhower Executive Office Building
[redacted]
Washington, D.C. 20504

RE: Request for Information on Equitable Data Engagement and Accountability (87 FR 54269)

Dear Members of the Subcommittee:

I am writing on behalf of the Data Quality Campaign (DQC), a nonprofit organization focused on changing the role of data to ensure that it is useful for individuals navigating their pathways through education and into the workforce. We advocate for data policies and practices that will result in better support and services to individuals, particularly policies and practices related to state longitudinal data systems (SLDS)—systems that contain early childhood, K–12, postsecondary, and workforce data.

DQC appreciates the subcommittee for asking these critical questions about the ecosystem necessary to support better data use. From our perspective, SLDS are both a critical foundation for federal data collections and essential to ensuring equitable access, usage, and collaboration across levels of government. As such, we are focusing our comments about the state of the current inter-governmental data sharing ecosystem on questions 1, 3, 6, and 7 in the Request for Information.

1. Examples of successful collaborations between the federal government and (a) tribal, territorial, local, and state governments or (b) local communities involving equitable data?

A number of states and local governments have constructed longitudinal data systems that link data across agencies (e.g., early childhood, K–12 education, postsecondary education, and workforce) and with various federal data sources. Some leading states use these SLDS to understand inequities within their education and workforce programs, help state residents make better informed decisions about their own education and workforce journeys, and direct state resources to address inequities.

- The Kentucky Center for Statistics (KYSTATS) incorporates data from the state Occupational Employment and Wage Statistics program and the Bureau of Labor Statistics to produce employment and wage estimates that are available for students, graduates, and job seekers through the KYSTATS Career Explorer. Kentuckians can search by desired salary, major or certification, or skills and abilities, providing accessible and equitable data to empower individuals in making career and education decisions.

- Allegheny County (PA) Data Warehouse is an integrated data system incorporating 21 categories of data at the local, state, and federal levels, enabling coordinated services across multiple family supporting sectors like health and home visiting. As a result, Allegheny County is able to proactively offer support to some of its most vulnerable residents. Allegheny County has created clear, accessible tools the public can use to access its warehouse, including their Analytics tool. While this is largely a health and human services data warehouse, Allegheny County has incorporated some K–12 education data from local school districts, thinking broadly about the types of data that can be connected to best serve their community. These wide data linkages indicate the data collaboration opportunities that could be possible across many sectors (e.g., education, workforce, health), demonstrating how increased data sharing and access can lead to more equitable data usage.
- California's new Cradle-to-Career System, when fully constructed, will link data across multiple agencies and sectors. One exciting component of the new system will be scaling up the California College Guidance Initiative (CCGI), which allows students, parents, and counselors to track alignment between a student's individual high school coursetaking and the admissions requirements for California's public colleges. CCGI incorporates financial aid data from the Free Application for Federal Student Aid (FAFSA), streamlining the application process for state and federal financial aid and promoting more equitable access to higher education.
- Montana is leveraging federal grants to link Tribal Colleges and Universities with the Montana Office of Public Instruction and other four-year universities, giving decisionmakers insight into historic postsecondary and workforce opportunity gaps so they can work to close them.
- The Coleridge Initiative's Multi-State Postsecondary Dashboard will allow states to better comprehend the employment journeys and outcomes of individuals. By utilizing unemployment insurance data and data from the Employment and Training Administration as well as data from the workforce development offices of participating states, each state in the collaborative will be able to better understand the economic outcomes of their residents and college graduates who seek employment in neighboring states. For instance, the multi-state collaborative will allow states to understand the disparate economic impact of the COVID-19 pandemic on different populations within their state.

3. What policies, resources, programs, training, or other tools can facilitate increased data sharing between different levels of government (tribal, territorial, local, state, or federal) around equitable data?

Below are a range of policies, programs, trainings, and other strategies we believe can facilitate increased data sharing across levels of government:

- **Clarification about the use of federal funds** to support infrastructure and capacity (both human and technological) for integrated data systems like an SLDS would help state and local leaders understand how federal funds may be used to support data modernization efforts and the usage of equitable data. Providing clear guidance and technical assistance on how funds may be used, braided, and blended to support SLDS modernization would ease the path of undertaking this modernization.

- **Distribution of federal funds in a non-siloed way** would facilitate increased data sharing, including the sharing of equitable data. Currently, funding comes to states and local governments from specific programs and agencies and is directed to support the data needs related to the work of those programs and agencies. Resources to support state and local data efforts do not anticipate, expect, or encourage integrated data sharing from across agencies and sectors. To create fully functioning SLDS that facilitates secure, usable, and timely data sharing, states need a new federal approach to funding. For example, the current Statewide Longitudinal Data System Grant Program could be expanded to focus on integrating data across education, workforce, and human services agencies, and widen the scope of possible grantees beyond state education agencies to P–20W councils and other statewide data governing bodies. Additionally, a new competitive grant program overseen by a Confidential Information Protection and Statistical Efficiency Act (CIPSEA) agency could be created specifically for the purpose of supporting state efforts to build and modernize their integrated data systems.
- **Expanded privacy technical assistance (TA)** from the federal government could facilitate data sharing between different levels of government, allowing them to utilize shared data to ensure more equitable outcomes for individuals, families, and communities. While the Privacy Technical Assistance Center (PTAC) exists, evolving state and local privacy needs outweigh current capacity. To provide leaders with more direct, real-time technical assistance and guidance, the federal government should make additional investments in PTAC and consider additional federal privacy TA centers.
- Programs and policies designed to **promote human capacity** could increase data sharing. While funding and technical requirements are important to data sharing, investments in human capacity and best practices are equally pertinent. Different levels of government would benefit from designated data teams with experts focused on data collaboration, sharing, and equitable practices.
- **High-quality data governance** is key to establishing a culture of effective and equitable data use between different levels of government. The federal government could promote successful data governance by collecting and sharing best practices by highlighting state laws, regulations, or models that provide strong data governance, among other strategies. For instance, one way to demonstrate effective strategies could be to highlight states like Maryland that have solidified data governance through legislation by establishing in law a requirement for actors to share data with the Maryland Longitudinal Data System Center, and develop and maintain relationships with one another in the process.

6. What policies, resources, programs, training, or tools can make equitable data more accessible and usable for members of the public?

The federal government's decentralized data policies and practices have historically made it difficult for state data users to link and use data collected by individual agencies. However, effective implementation of education and workforce programs relies on states' ability to connect data across agencies to produce reliable, timely, and accurate information for decisionmakers. It is also increasingly clear that giving states access to key federal data would make the information in state systems more robust.

- Congress's recent authorization of the **National Secure Data Service (NSDS**) is an important step in making federal agency data easier to access for state and local policymakers. As the Data Foundation has noted, NSDS offers a way to overcome existing challenges with data sharing and access by providing a central data infrastructure that facilitates coordination between federal, state, and local governments, as well as non-government organizations, to securely link, access, and analyze data for evidence building. Moreover, by connecting the NSDS to the National Center for Science and Engineering Statistics, the data service will fall under CIPSEA, a strong privacy framework used by statistical agencies.

  Through the new NSDS, a vision for effective data use that leads to real, positive impacts for people's education and workforce pathways can become a reality. To be fully successful, however, the federal government should follow these five high-level objectives to address and ultimately leverage state longitudinal data systems (P-20W) to increase educational and workforce equity:
    1. Employ federal incentives and resources to support and encourage data sharing and related systems integration across and within state agencies;
    2. Strengthen longitudinal data systems and related integration efforts for leaders to understand the long-term impacts of education and workforce programs and services receiving public funding;
    3. Improve states' access to standardized federal wage record data that are disaggregated at least by race and include information such as location and hours worked;
    4. Increase states' access to IRS and military enlistment data so they can better provide their residents an equitable understanding of postsecondary outcomes, job and credential quality, and the myriad pathways from K–12 into and through the workforce;
    5. Promote transparent and interoperable data standards wherever possible; and
    6. Disseminate best practices among states, including on issues such as privacy, security, and data governance, to foster peer learning and continual improvement.
- **Open data** and accessible, easy-to-use tools are essential to making data more usable for members of the public. Thus, the federal government should prioritize creating and improving dashboards, portals, and query builders to grant individuals and state and local governments better access to federal data, allowing for more robust data systems and informed decisionmaking.
- Congress should prioritize the passage of the **College Transparency Act (CTA**), now an amendment to the America COMPETES Act, as a way to make postsecondary data more accessible and transparent to students, families, institutions, employers, and policymakers. With CTA, various individuals will have access to data to inform decisions on postsecondary pathways and career journeys.
- The **Education Science Reform Act (ESRA)** has served an important role in rigorous education research and in providing critical investments in state longitudinal data systems. However, the needs of states and other areas of government have evolved; ESRA must be updated to ensure that the time, resources, and human capital involved in producing data and research return value to decisionmakers. Small changes that build on the Strengthening Education through Research Act can enable the Institute for Education Sciences to produce information that meets

the most pressing needs of the moment and improve state capacity to do the same. Additionally, when reauthorized, ESRA must be done so with strategies to improve data access in mind, thinking about how equitable data can be made available to the public.

- To increase data accessibility in the workforce sphere, the federal government should encourage states to **improve the usability of workforce data** by prioritizing new indicators and system improvements that enable action. For example, federal action could encourage participation in cross-state data sharing tools like the State Wage Interchange System (SWIS), even expanding the scope of these efforts by including additional data in SWIS. Further, exploring other programs that provide more federal workforce data back to states to give them access to more robust data on employment outcomes could serve as a way to increase public accessibility.
- From a state perspective, **Georgia has created a virtual "tunnel"** that links data from a single state longitudinal data system directly to district-level student information systems and allows district administrators, principals, teachers, and parents to access state education data through their district's existing program. Local education agency officials can view and compare state and local performance information on specific schools or programs to identify best practices, while teachers and parents have access to detailed longitudinal data to support children in the classroom and at home. With this tunnel, Georgia has combined local data with state-level resources and made it easier to use education data in meaningful ways. In particular, smaller, less resourced school districts can provide teachers and parents a rich amount of data on their children's academic achievement and well-being that they otherwise would not be able to access.

7. In which agencies, programs, regions, or communities are there unmet needs, broken processes, or problems around participation and accountability that could be remedied through stronger collaborations and transparency around equitable data?

There are many unmet data needs, some of which we have described in response to question six. Some of these unmet data needs stem from a lack of trust; even when data is transparent, many communities struggle to trust data because they do not see public officials using it in ways that improve outcomes for people in their communities. The examples below highlight some of these sentiments:

- There is a need to improve institutional, state, and federal data related to Native American communities. The data extracted from Native American communities is often inconsistent, omits important variables, and is produced or used within an environment where the Native communities mistrust the communities collecting the data. New ways of collecting data, like oversampling for Native American communities, using indigenous data collection, and measuring cultural identity rather than just asking whether someone is American Indian or Native American could improve the kind of data collected and thus available for use by Native American communities to better understand the outcomes and pathways of their community members.
- Issues with data collection and transparency raised concerns that the 2020 census was less accurate than previous censuses. Leaders from civil rights groups NALEO and the National Urban

League brought attention to the undercount, noting the negative impacts on communities of color via diminished political representation or distorted funding formulas, among other effects. Stronger data collaboration, collection, and transparency could have created a more accurate count.

- Migrant students and communities suffer from a lack of consistent and reliable data collection. For example, in 2017, Wyoming ended its program for using data to support students in farmworker families. By ending the Migrant Student Information Exchange, experts warn that teachers and administrators are losing data that could minimize the disruption in migrant students' education despite their high mobility rates.
- There have historically been a number of issues and broken processes in the use of discipline data. Biased disciplinary practices and data collection can target specific student groups, including female students of color, disrupting their learning, perpetuating harmful school cultures, and contributing to historic inequities. Additionally, various instances of schools misusing discipline data to target students for monitoring by law enforcement have arisen over the past few years. This practice raises concerns surrounding privacy, transparency, and equity for agencies and communities alike.

To provide value, data systems and collaborations must serve learners and workers, policymakers, and other data consumers working to improve opportunities and outcomes for individuals. There are some bright spots and successful data sharing collaborations across various levels of government; however, more can be done to promote equitable data access, transparency, and usability.

We encourage OSTP to think creatively about the ways the federal government can support data sharing and make data work for all communities, revealing existing social or economic barriers and driving solutions to address them. Our partners, the Data Coalition and Results for America have also offered valuable thoughts and resources on this topic that OSTP should consider. DQC looks forward to working with you to ensure that data policies and practices can equitably achieve federal, state, and local needs.

Please do not hesitate to reach out to me at [redacted] or my team (Jane Clark at [redacted] or Kate Tromble at kat [redacted] ign.org) should you wish to discuss these ideas further.

Sincerely,

[redacted]

Jennifer Bell-Ellwanger
President and CEO

DATA FOUNDATION
data coalition

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October 3, 2022

Office of Science and Technology Policy
Subcommittee on Equitable Data of the National Science and Technology Council

The Data Foundation is a non-profit organization that seeks to improve government and society by using data to inform public policymaking. Our Data Coalition Initiative is America's premier voice on data policy, advocating for responsible policies to make government data high-quality, accessible, and usable.

We support the Office of Science and Technology Policy's commitment to understanding "how federal agencies can better support collaboration with other levels of government, civil society, and the research community around the production and use of equitable data." While our mission is not centered on equity, we recognize the importance of data in measuring and addressing systemic inequities, as well as how improved and more equitable access to data can improve public policymaking. This comment will address questions #3, #4, and #6 by discussing how the National Secure Data Service proposed by the Commission on Evidence-Based Policymaking and authorized in the CHIPS and Science Act can facilitate increased data sharing between different levels of government. It also describes the tools and resources needed to make data more accessible to underserved scholars and research institutions as well as the public.

3. What resources, programs, training, or other tools can facilitate increased data sharing between different levels of government (Tribal, territorial, local, State, or Federal) related to equitable data?

Data linkages are a powerful tool that leverage existing data for evidence building activities that can inform policies that address pressing and long-standing equity concerns. These linkage programs present the potential to create a cross-sector understanding of service use, evaluate policies, and design interventions without creating more burdens on underserved communities to continually provide data to government agencies.

Examples of data linkage pilots can be found in the federal government already. One especially successful program is the data linkage activities at the National Center for Health Statistics (NCHS). NCHS has linked data from their National Health Interview Survey and National Health and Nutrition Examination Survey to administrative data from the Department of Housing and Urban Development, providing an opportunity to examine the relationship between health and housing, as well as to administrative data from the Department of Veterans' Affairs, giving insights into a wide range of the health-related topics for veterans.

These examples demonstrate the value of data linkages, as well as the standardization of data needed to facilitate data sharing between agencies and among jurisdictions that enable such linkage. Bringing together all of these concepts, the recently-authorized National Secure Data Service Act provides an opportunity to increase data sharing and collaboration between governments related to equitable data. **A National Secure Data Service (NSDS) offers a way to overcome existing challenges with data sharing and access by providing a central data infrastructure that facilitates coordination between federal, state, and local governments, as well as non-government organizations, to securely link, access, and analyze data for evidence building**. In August 2022, the CHIPS and Science Act authorized a NSDS demonstration pilot at the National Center for Science and Engineering Statistics (NCSES) at the National Science Foundation. By connecting the NSDS to NCSES, the data service will fall under the Confidential Information Protection and Statistical Efficiency Act (CIPSEA), a strong privacy framework used by statistical agencies that is enforceable by criminal and civil penalties. The NSDS was a central recommendation of the Commission for Evidence-Based Policymaking of 2017 and is a focus of the Federal Advisory Committee for Data for Evidence Building (ACDEB), whose final NSDS implementation report is to be released October 2022.

4. What resources, programs, training, or other tools can expand opportunities for historically underrepresented scholars and research institutions to access and use equitable data across levels of government?

To improve data access for historically underrepresented scholars and institutions, there must be improved data discoverability, formatted in an accessible format, and data must be available under open license. Resources like the NSDS and a Standard Application Process, as mandated by Title III of the Foundations for Evidence-Based Policymaking Act, can help remove some of the traditional barriers to data access such as cost and burden, but challenges will still remain while data sets, particularly those of interest to researchers and scholars investigating social inequality, are unable to find the data needed. Robust metadata standards, which describe access rights, quality, and completeness of demographic data, are needed to aid in discoverability.

Further, data should be available in a format that aids access for researchers. Ensuring the data are made available in a machine-readable format – which is described by OSTP as one "that can be easily processed by a computer without human intervention while ensuring no semantic meaning is lost" – is critical to expanding the use of government data.

Finally, making the data available under an open license so that users have the rights to disseminate and reuse it without financial or legal repercussions removes significant cost barriers for scholars and researchers. The COVID-19 pandemic is one example of how restrictions on the reuse of research data and articles can hamper progress. In March of 2020, OSTP joined other nations in asking scholarly publishers to lift their paywalls on COVID-related research data.

6. What resources, programs, training, or tools can make equitable data more accessible and usable for members of the public?

The Equitable Data Working Group's *Vision for Equitable Data* called for catalyzing existing federal infrastructure to leverage underused data, including expanding protected access. The National Secure Data Service, described above, can achieve this and provide a mechanism for more equitable data access and a foundation for data-driven decision-making across levels of government. By providing a central, CIPSEA-protected data linkage platform, the implementation of a NSDS will enable government and researchers to leverage non-classified data collected by government agencies to better understand implications of policies and programs, and can provide opportunities to identify potential issues with the data related to equity.

Thank you for the opportunity to provide comments on the production and use of equitable data. The Data Coalition is always available to support OSTP's efforts to create a more equitable federal data system. Please contact me at [redacted] if you have any questions or would like to discuss the Data Coalition's interest in this matter further.

Sincerely,

Corinna Turbes
Policy Director
Data Foundation

EDF
ENVIRONMENTAL
DEFENSE FUND™
Finding the ways that work

Environmental Defense Fund

Response to the Request for Information: Equitable Data Engagement and Accountability

Document Citation: 87 FR 54269

Submitted: October 3, 2022

Environmental Defense Fund (EDF) appreciates the opportunity to respond to the Request for Information on how Federal agencies can better support collaboration with other levels of government, civil society, and the research community around the production and use of equitable data.

Environmental justice is critical to successfully enhancing the health and well-being of all Americans. Everyone deserves a safe and clean environment. OSTP can play a key role ensuring data and analysis inspires and enables the work to eliminate disparate environmental health outcomes based on race, ethnicity, and income.

Environmental Defense Fund is a national, non-profit environmental organization dedicated to using science, economics, and law to build a vital Earth – for everyone. EDF's Healthy Communities program strives to make air, water, food, and household products safer through cutting-edge research, wide-ranging partnerships, and a focus on strengthening laws and policies that protect health.

Key Recommendations

In these comments, we provide recommendations based on gaps we have identified in data and analysis production and access. Three key recommendations warrant special attention:

1. OSTP should make access and analysis of fine spatial resolution health data a priority action. As we detail below, fine scale data is needed to fully characterize health inequities.
2. OSTP should coordinate within and across federal agencies to improve access to and analysis of fine resolution air and water data and pollutant source data.
3. OSTP should also coordinate within and across federal agencies to advance cumulative impact assessment of chemical and non-chemical, including climate-related, environmental stressors, to enable targeted services.

We encourage OSTP to consider our recommendations, as well as feedback provided by environmental justice community groups who disproportionately experience the health impacts associated with climate change, air and water pollution chemical exposures, and other environmental and social stressors, in finalizing its approach.

1. Research and Data Collection, Analysis, and Utilization

A. OSTP should enable spatially resolved health data access and integration.

Recommendation: We urge OSTP to address the urgent need to provide access to spatially resolved health data for design, implementation, monitoring and evaluation of policies.

The lack of investment in development and access to high resolution baseline disease rates poses a structural barrier to identification of communities that are hotspots of air pollution health burdens and limits targeted solutions, policies, actions and financing to address these inequities.

We recommend that OSTP convene NIH, HRSA, CMS, and CDC to determine barriers and opportunities for making census tract and finer spatial resolution health data available for environmental and climate justice evaluations.

Comment: Air pollution has a disproportionate burden on communities of color and low wealth. Studies have shown that historically racist policies such as redlining and citing of highways and polluting facilities have resulted in racial/ethnic minority and other disadvantaged populations living in areas with a disproportionately higher number of emitting facilities[1,2] and facing higher exposure burden in comparison with White American populations. In addition, policies and actions to reduce air pollution are generally concentrated in wealthier and less diverse populations, resulting in widening disparities.[3,4] Yet the issues of air pollution–related health impact inequities extend beyond exposure alone. Many of the same racist policies, institutional practices, and poor cultural representations have caused disinvestment in racial/ethnic minority communities, resulting in differential quality and distribution of housing, transportation, economic opportunity, education, food, access to health care, and beyond. All of these inequities manifest in health disparities, higher underlying mortality rates, and greater susceptibility to pollution-caused disease.[5,6]

While there have been steps taken in the right direction, we recommend a _greatly expanded effort to focus on spatially resolved health data required to characterize and monitor changes in inequities that are environmentally mediated_.

To support the variety of census-tract based environmental justice initiatives, OSTP must address the lack of publicly available health data at the census-tract scale and the cost and time involved in accessing restricted datasets. Designing, implementing, and assessing the effectiveness of policies requires monitoring environmentally-related disease rates during and following implementation. Federal and numerous state policies and programs are developing census tract-based tools to define disadvantaged communities for resource allocation (e.g., Justice40, New York CLCPA, Washington, New Jersey, etc.), yet relevant health data at this spatial resolution is rarely available. OSTP can do more to help address health data gaps and access issues due to privacy and identifiability concerns. OSTP can work with HHS and its operating divisions to build upon existing databases (e.g., CDC WONDER and H-CUP) utilizing data analytic methods and statistical models appropriate for small area health analysis.

Health Impact Assessments[7] (HIAs) are increasingly being used to assess current environmental health inequities and estimate benefits of proposed policies at the federal, state and local level. HIAs require baseline health status data (for example: incidence of disease outcomes, rates of hospitalizations or emergency room visits). Oftentimes county-level data is used, despite large magnitudes of health disparities in urban areas and research that has shown aggregation to the county likely underestimates exposure and health inequities.[8,9,10]

Numerous projects EDF scientists have led demonstrate the need for spatially resolved health data. Most HIAs rely on publicly available rates of disease outcomes (mortality rates, emergency room visit rates or hospitalization rates) from H-CUP or CDC WONDER. These are often only available at the county scale. In our study we compared the magnitude, spatial patterns and racial ethnic distribution of estimated air quality impacts when using county scale health data from CDC WONDER and locally developed census block group (CBG) mortality data from the Alameda County Public Health Dept. The analysis found that CBG baseline disease rates yielded 15% and 13% higher spatially aggregated estimates of pollutant-attributable mortality rates compared with the application of county baseline disease rates. Differences were even more evident at the city level. For example, for just Oakland, CBG baseline disease rates yielded 52%, 67%, and 57% higher NO_2, black carbon (BC), and $PM_{2.5}$-attributable mortality rates compared with the application of county baseline disease rates.

Applying CBG baseline disease rates also revealed neighborhoods with high pollutant-attributable mortality rates that were masked when using county-level disease rates. The magnitude of the spatial disparities was also larger when utilizing CBG baseline disease rates: neighborhood–level pollutant-attributable rates varied by factors of 29, 12, and 14 for NO_2, BC, and $PM_{2.5}$ across Alameda County, whereas applying county baseline disease rates yielded lower spatial differences (6, 4, and 3 times, respectively).

Additionally, we found that using CBG instead of county baseline disease rates resulted in a larger percentage of pollutant-attributable cases for CBGs with >50% minority population in Alameda County. Within Oakland, CBGs with the highest percentage of minorities and highest estimated NO_2-attributable mortality rates were in West Oakland near I-880, a high-traffic–volume truck route, and in Chinatown, in the southeastern part of Downtown Oakland. *Overall, inequities in air pollutant attributable health outcomes were underestimated when using the lower spatial resolution health data that is currently publicly available.*

The Bay area study also found that over 5,000 new childhood asthma cases were attributed to traffic related air pollution.[11] This is an average of 1 in 5 cases across the region and up to 1 in 2 cases in some areas. But because there exist no fine scale measures of asthma incidence for children, we were unable to accurately identify air pollution asthma incidence hotspots that take into consideration health disparities. In fact, there is only a single childhood asthma incidence rate available at a state level, which masks the large differences in asthma incidence across communities, neighborhoods, cities and counties across the state.

EDF's recent report on the distribution of $PM_{2.5}$ related health burdens under current and alternative National Ambient Air Quality Standard provides a case study in New Jersey demonstrating the additional value of high-resolution baseline health data in characterizing health burden inequities.[12] The scientists developed and utilized fine scale race and ethnicity stratified rates of pediatric asthma emergency department (ED) visits at the zipcode level. H-CUP normally only has either county level or Zip 3 level data. Comparing the patterns of both baseline disease rates and estimated $PM_{2.5}$-attributable childhood asthma ED visits the report finds:

- Zip 3 level data does not capture the full spatial disparities in childhood asthma ED visits and misses hotspots across the state that are captured by the fine scale zipcode level data.
- This limits the ability to identify the locations of neighborhoods bearing higher burdens of air pollution attributable childhood asthma emergency room visits.
- Coarse scale incidence rates overstate air pollution- asthma ED visits for white populations by 30% and understate incidence for other races by up to 90%.

EXHIBIT 4-2. BASELINE INCIDENCE FOR ASTHMA ED VISITS IN NEW JERSEY AT ZIP CODE AND ZIP3 SCALES

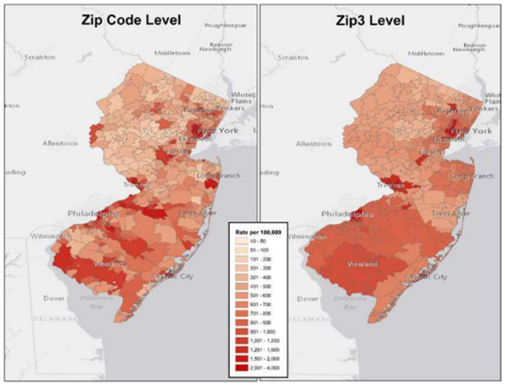
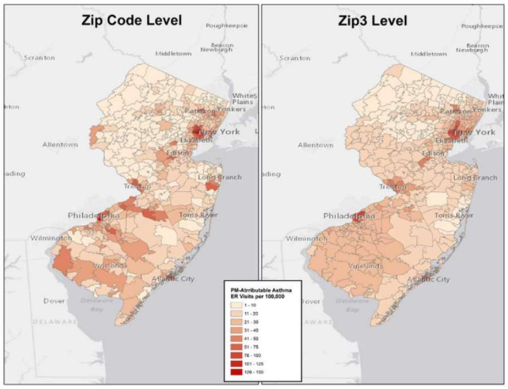


EXHIBIT 4-3. PM-ATTRIBUTABLE ASTHMA ED VISITS IN NEW JERSEY AT ZIP CODE AND ZIP3 SCALES



These studies specifically highlight the need for fine-scale mortality, asthma ED visit, and childhood asthma incidence rate data for air quality health equity analyses and the need for increased investment in race/ethnicity vulnerability assessments across exposure health outcomes.

The National Syndromic Surveillance Program (NSSP) at CDC may serve as a template for addressing identifiability and data analytic challenges. The NSSP has supported development of standardized methods for access, data processing and standardization of healthcare visit data, through support of the Biosense and underlying ESSENCE platforms, and working with state and local health departments to develop best practices in data sharing. The other program we would like to highlight is the HHS emPOWER Program Platform[13] that uses CMS data to identify and protect the health of at-risk Medicare beneficiaries, who rely on electricity-dependent health care services, during climate change related weather emergencies and disasters.

One important limitation of syndromic surveillance is zip code as the smallest spatial unit of analysis. While some states have programs to access processed emergency department visit data at higher spatial resolution outside of their syndromic surveillance programs, the process is not consistent across states, limiting national level analyses. Medicare and Medicaid claims data through CMS is another comprehensive health data source that could be leveraged for development of higher resolution health data for monitoring and evaluating inequities as environmental justice policies are implemented. The cost and time associated with accessing CMS data is prohibitive for many academic researchers and isn't even possible for other organizations without an Institutional Review Board and significant monetary resources. While the National Center for Health Statistics (NCHS) provides access to yearly mortality and birth data, the finest spatial resolution available is at the county level, and race/ethnicity or income subsetting often results in suppression of data for many counties. We were able to work around this to develop higher spatial resolution data by aggregating data over a longer duration of time (e.g., allow census-tract level data when a 5-year period is chosen as the temporal aggregation). But most counties and states do not even have the raw data available at the resolution to enable independent scientists to carry out such analyses.

These barriers to utilizing fine spatial scale health data, particularly those relevant to environmental justice analyses of air pollution and climate policies, must be addressed to more fully characterize and monitor environmentally-mediated inequities in health.

2. Source Data Collection, Analysis, and Utilization

A. OSTP should enable spatially resolved source data access and integration.

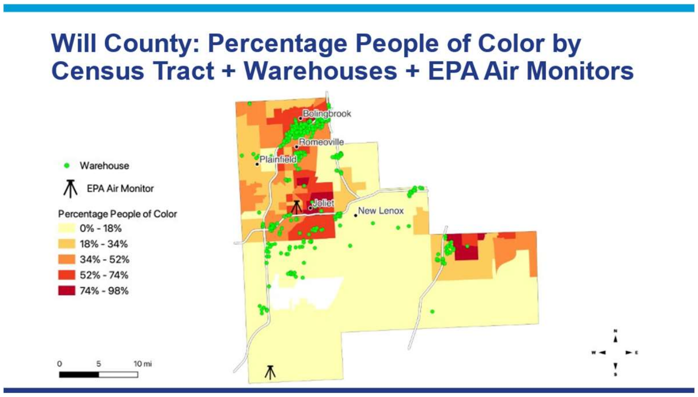
Recommendation: We urge OSTP to dramatically expand access to and analysis of data on sources of environmental exposures. While certain large sources are required to report emissions, other potential sources are not easily understood. In particular, the location and nature of trucks and truck-attracting businesses such as warehouses and waste management facilities are not available at an adequate spatial or temporal resolution to enable accurate attribution of pollution to these sources. The result is difficulty assessing, designing and implementing pollution mitigation policies.

Comment: Transport constitutes a large and growing share of emissions. Lack of data on truck locations and activities impedes accurate assessment of the status quo and accurate comparison of alternatives.

- In Oakland and other cities, EDF and partners analyzed the impact of NO2 on new diagnoses of children's asthma. In the neighborhoods with the most traffic-related pollution, more than 1 in 3 cases of children's asthma are caused by pollution. Even with high resolution data from satellite-informed land use regression models of NO2 these analyses were unable to fully reflect local pollution hotspots due to lack of detailed data on truck activity.
- Scientists at EDF, Harvard Chan School of Public Health and University of North Carolina, using state of the art fine scale air quality modelling and health impact assessment methods, found that electrification of medium- and heavy-duty diesel vehicles will have significant benefits in New York City at a census tract scale.[14] The analysis found that up to 68 percent of childhood asthma ED visits reduced will be accrued in census tracts with >85 percent minority populations if full electrification takes place by 2040. The ability to represent how a policy will reduce health inequities was only possible, in part, because of unique truck traffic data for New York City accessed through

the New York Metropolitan Transportation Council. Even so, this kind of travel demand model does not capture traffic ending or beginning at warehouses or other truck attracting facilities.

- EDF's Proximity Mapping integrates social, demographic and health information for people living within half a mile of a truck-attracting facility such as a warehouse. As a result, the tool can visualize the disproportionate proximity of low-wealth communities and Black, Asian-American, Latino and Indigenous communities to areas where trucks gather. In Illinois, for example, the dataset shows almost 2 million people living within a half mile of an identified warehouse, 138,000 of whom are children under five. Warehouse neighbors are twice as likely to be Hispanic or Latino as the state average. This analysis was only possible due to purchasing a license to a commercial database providing locations of warehouses.



OSTP should work with agencies to produce granular source data and make it accessible, so that understanding where trucks operate does not require teams of scientists and access to unique or private data:

- **DOT:** OSTP should investigate ways to improve access to:
    - Distribution of traffic volume (annual average daily traffic) by vehicle class at resolution finer than county scales (e.g., link level)
    - Location and count of trucks – including local roads, right up to facility gates
    - Age of trucks by location – since age has significant impact on emissions profiles
    - Ownership and secured creditors of trucks – who has an interest in the status quo
    - Location of truck-attracting facilities such as warehouses and waste management facilities, with expected truck counts at facility gates
    - OSTP should facilitate the development of best practices for distributional air pollution health impact assessments as a component of transportation policy analyses

- **EPA**: OSTP should investigate ways to integrate granular truck and truck-attracting facility data into EPA-developed mapping tools such as EJScreen.

- **OSHA:** OSTP should work with OSHA to build occupational health data collection, analysis, and research capabilities regarding worker exposure to truck emissions.

3. Insights on cumulative impacts

A. OSTP should coordinate within and across federal agencies to advance cumulative impact assessment of chemical and non-chemical, including climate-related, environmental stressors.

Recommendation: We urge OSTP to coordinate within and across federal agencies to prioritize assessing the cumulative impact of multiple social determinants of health (also referred to as chemical and non-chemical stressors), with a focus on how non-chemical and climate-related stressors may modify the impact of environmental chemical exposures.

Comment: A cumulative impact assessment explores how social determinants of health, such as from the built, natural, and social environments, interact to cause or exacerbate adverse health outcomes.[15] This type of comprehensive assessment might consider that certain communities lack access to nutritious food and are exposed to higher levels of PM2.5 due to their proximity to major roads. Ultimately, cumulative impact assessments reflect people's real-world experiences, which is a key step in addressing or changing these factors to promote environmental and climate justice.

For example, it is now recognized that obesity is a multi-factorial disease and environmental chemicals such as phthalates or brominated flame retardants, often intentionally added to everyday consumer products, can alter the development and function of adipose tissue and other organs, which ultimately disrupts a body's normal metabolism.[16] Thus, these obesogenic chemicals can determine how much food is needed to maintain homeostasis and thereby increase an individual's susceptibility to obesity. Obesogenic chemicals contribute to increased rates of obesity; therefore, failing to consider them in combination with other factors, such as access to healthful foods, may likely fail to address the high rates of obesity in this country.

Many public health agencies have available data resources and research and regulatory priorities that are relevant to cumulative impact assessments. For example, many agencies have strategic plans to address health disparities and promote environmental justice specifically, such as the National Institute of Environmental Health Sciences (NIEHS).[17] In addition to NIEHS, we recommend that OSTP coordinate with different agencies with have jurisdiction over public health and assess the toxicity or hazards posed by chemicals in the environment and workplace. Examples of these agencies include but are not limited to the National Center of Health Statistics (NCHS), the National Center for Environmental Health (NCEH), the Agency for Toxic Substances and Disease Registry (ATSDR), and the Food and Drug Administration (FDA). There is a unique opportunity for OSTP to play a convening role and ensure that agencies are able to achieve their mandates and make the best use of their own data and analytic capacities, as well as best practices from outside the federal government.

* * *

Environmental Defense Fund appreciates OSTP's consideration of these comments. Please contact Aileen Nowlan, Policy Director, Global Clean Air [redacted] with any questions.

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Submitted via email [redacted]

Dr. Alondra Nelson
Director, Office of Science and Technology Policy
Eisenhower Executive Office Building
[redacted] NW
Washington, DC 20504
Attn: NSTC Subcommittee on Equitable Data

October 3, 2022

Re: Engagement and Accountability RFI

Dr. Nelson,

Elevance Health appreciates this opportunity to comment on the Office of Science and Technology Policy (OSTP) Equitable Data Request for Information (RFI), in support of federal equitable data efforts as described in the Executive Order on Advancing Racial Equity and Support for Underserved Communities Through the Federal Government (E.O. 13985).[1]

Elevance Health is a lifetime, trusted health partner fueled by its purpose to improve the health of humanity. The company supports individuals, families, and communities across the entire care journey – connecting them to the care, support, and resources they need to lead healthier lives. Elevance Health's companies serve more than 118 million people through a diverse portfolio of industry-leading medical, digital, pharmacy, behavioral, clinical, and complex care solutions. In addition, National Government Services (NGS), a wholly-owned subsidiary of Elevance Health, has partnered with federal healthcare agencies for over 50 years to provide technology services, business process services, and clinical solutions.

Elevance Health expands access to care, ensuring coverage is affordable and equitable, so everyone gets the care they need regardless of age, gender, race, ethnicity, language preference, sexual orientation, disability, income, or place of residence—urban, suburban, or rural. We believe addressing Social Drivers of Health (SDOH) is a critical foundation to achieving holistic and integrated care, with the goal of building and maintaining healthy communities. We continually invest in new programs and partnerships to help support not just access to care and supports and services, but also access to the life essentials that form the foundation of healthy living and ease stressors for beneficiaries. We share the agency's perspective that "equitable data can illuminate opportunities for targeted actions that will

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[1] https://www.govinfo.gov/content/pkg/FR-2022-09-02/pdf/2022-19007.pdf

result in demonstrably improved outcomes for underserved communities"[2] With this focus, we offer the following comments and recommendations to question three of the agency's RFI (what resources or other tools can facilitate increased data sharing between different levels of government).

Ensure Alignment of Efforts Across Federal Agencies

We encourage alignment in advancing standards related to equitable data efforts between OSTP and the U.S. Department of Health & Human Services' (HHS) Office of the National Coordinator for Health Information Technology (ONC), given ONC's work in health data interoperability and cross-agency standards alignment role. Specifically, on August 5, ONC released a blog post highlighting Secretary Xavier Becerra's policy directing ONC to engage with and align HHS agencies' health Information Technology (IT)-related activities, offering clear support for ONC's role as set out in the Health Information Technology for Economic and Clinical Health (HITECH) Act.[3] The Secretary confirmed ONC's role in establishing and overseeing a consistent HHS-wide approach for: incorporating standard health IT requirements language in all applicable HHS funding programs, contracts, and policies, and providing direct ONC assistance to HHS agencies to maximize the use of supported standards in their agency programs.

Support Diverse Collaboration and Stakeholder Input

We strongly support diverse collaborations and stakeholder input throughout the federal government's collaborative effort to ensure the use of equitable data (defined as data that allows for rigorous assessment of the extent to which government programs and policies yield consistently fair, just, and impartial treatment of all individuals, including those who have been historically underserved, marginalized, and adversely affected by persistent poverty and inequality) in order to improve outcomes for underserved communities.

Elevance Health supports the inclusion of all healthcare stakeholders, including payers, providers, consumers, and Community-Based Organizations (CBOs), in initiatives and recommends dedicated support and funding to enhance CBOs' participation. We also support the incorporation of the ongoing work of standards development organizations, such

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[2] https://www.govinfo.gov/content/pkg/FR-2022-09-02/pdf/2022-19007.pdf
[3] https://www.healthit.gov/buzz-blog/interoperability/e-pluribus-unum

as Health Level Seven International (HL7), and recommend that system certification for all stakeholders is completed to adhere to implemented data standards.

Adhere to Existing Privacy and Security Standards

Improving health outcomes for historically marginalized communities includes the collection and use of personal and sensitive data. It is important to adhere to existing privacy and security standards, as well as provide user-specific education on the use of this data, to engender trust and continue the use of digitals tools that leverage this information. OSTP, in collaboration with federal partners, stakeholders, and a diverse representation of community leaders, should discuss opportunities to enhance awareness and training specific to personal data collection, including for care providers, tool developers, and intended recipients.

Improve Data Collection in Support of Health Equity

Elevance Health strongly supports the federal government's efforts to advance accurate and reliable demographic data collection that allows individuals to share information on a voluntary basis about their race and ethnicity that aligns with how they identify themselves.

The collection and analysis of this information will aid efforts to identify and address healthcare disparities. Self-reported data is the gold standard, with individuals understanding the purposes of the data collection and the use of the data, and all stakeholders acting collaboratively to mitigate harmful bias and improve care.

We support proposals to collect race and ethnicity data directly from beneficiaries of health programs. This approach promotes the collection and use of accurate and reliable data. We encourage OSTP to work with stakeholders to standardize these types of data collection across programs, using evidence-based and stakeholder-driven demographic data standards for sociodemographic data elements, with the intention of voluntary standardization at a high-level while allowing for local granularization.

***

We welcome the opportunity to discuss our experience and recommendations. Should you have any questions or wish to discuss our comments further, please contact [redacted]

Sincerely,

[redacted]

Elizabeth P. Hall
Vice President

About Elevance Health, Inc.
Elevance Health is a lifetime, trusted health partner fueled by its purpose to improve the health of humanity. The company supports consumers, families, and communities across the entire care journey – connecting them to the care, support, and resources they need to lead healthier lives. Elevance Health's companies serve more than 118 million people through a diverse portfolio of industry-leading medical, digital, pharmacy, behavioral, clinical, and complex care solutions. For more information, please visit **www.elevancehealth.com** or follow us [redacted] on Twitter and Elevance Health on LinkedIn.

ELEVATE
A POLICY LAB TO ELEVATE MENTAL HEALTH AND DISRUPT POVERTY

Yale SCHOOL OF PUBLIC HEALTH
Office of Public Health Practice

Response to the White House Office of Science and Technology Policy (OSTP) RFI
Elevate: A Policy Lab to Elevate Mental Health and Disrupt Poverty
Monday, October 3, 2022

Submitted by:
Barbara Suzi Ruhl, JD, MPH, Policy Director, Elevate Policy Lab
Hilary Hahn, MPH, EdM, Executive Director & Principal Investigator, Elevate Policy Lab
Deborah Sims, Community Champion, East End NRZ Market & Café
Annie Du, Special Assistant, Elevate Policy Lab

The Elevate Policy Lab (Elevate)[1] at the Yale School of Public Health appreciates the opportunity to provide comments on the Office of Science and Technology Policy's (OSTP) Engagement and Accountability Request for Information. We firmly support Federal equitable data efforts, as expressed in President Bidens's Executive Order on Advancing Racial Equity and Support for Underserved Communities Through the Federal Government (E.O. 13985). Further, we commend the White House OSTP for its leadership and commitment to this vital goal.

Overview of Elevate

Elevate is a policy lab at the Yale School of Public Health that works with government partners to elevate mental health and disrupt intergenerational poverty. We aim to advance mental health as a pathway for families to achieve social and economic mobility, thereby seeing families' lives improve as a result. Elevate achieves its mission through several mechanisms. First is the federally recognized **M**ental Health **O**utreach for **M**other**S** (MOMS) Partnership®, an evidence-based program that lowers depressive symptoms and increases family well-being in multiple arenas including economic mobility. Born out of Yale School of Medicine in 2011, MOMS brings quality mental health care within reach of over-burdened, under-resourced mothers.

Elevate also works with government partners in the U.S. to enhance opportunities for growth and success for parents and their children. We infuse government funding streams and policymaking for mental health with capacity. By developing rigorous evidence about what works to reduce maternal depression and improve family social and economic mobility, we can recommend high-return, evidence-based interventions, including the MOMS Partnership®, for public funding. We bring fresh creativity—informed by clinicians, researchers, and the expertise of families themselves—to programming for caregivers in their own communities.

Triple Bottom Line Justice (TBLJ), as a key focus of the Elevate policy agenda, involves simultaneously tackling mental health, economic, and environmental challenges facing under-resourced populations to address the root causes of health inequities and improve outcomes. TBLJ builds on the MOMS Partnership® model to advance behavioral wellness while supporting economic stability and environmental sustainability through an integrated policy and place-based practices methodology. TBLJ is premised on the experience that meaningful engagement of underserved, overburdened, and underrepresented individuals in environmental, economic and health decisions at the local, state, and national government levels improves the health of these individuals and communities and increases the effectiveness of government policies. Elevate is applying the MOMS Partnership® model to increase the capacity of overburdened and under-resourced individuals to meaningfully engage in government decisions that affect their lives.

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[1] https://ysph.yale.edu/elevate/

Elevate Policy Lab Responses to OSTP Questions

Elevate offers the following comments in response to questions posed by the Office of Science and Technology Policy's (OSTP) Request for Information.

Responses to OSTP Questions

1. What are *examples of successful collaborations* involving equitable data between the Federal government and (a) Tribal, territorial, local, and State governments, or (b) local communities?

Elevate Policy Lab is partnering with the East End Neighborhood Market and Café[2] to implement Civic Justice Engagement (CJE) programming in the East End Neighborhood of Bridgeport, CT. Bridgeport's East End bears many burdens that impact ways in which community members live, learn, work, play, develop and worship; these burdens affect a wide range of health, functioning, and quality-of-life risks and outcomes.

Civic Justice Engagement Training (CJET) directly confronts the social determinants of health through community applications of environmental health and economic justice. Our efforts in Bridgeport are having an impact beyond the local community though interest of the federal government that is implementing new authority and appropriations that benefit disadvantaged communities.

CJET has fostered two community collaborations. First, CJET has fostered Breaking Bread for B2H (Brownfields to Healthfields)[3] in Bridgeport and Beyond. "Breaking Bread" is a convening approach to foster shared learning and replication of successful place-based efforts. It brings multiple parties, resources[4], and data together to manage the B2H process. Breaking Bread was recognized by the Federal Interagency Working Group on Environmental Justice in the EPA Annual Environmental Justice Progress Report FY 2019.[5] Collaborators in Bridgeport include community leaders (East End NRZ Market & Café), state government (CT DEEP), and academia (Yale's Elevate Policy Lab).

Second, CJET has engaged the University of Connecticut's Technical Assistance for Brownfields Program. This collaboration produced a Story Map on Mount Trashmore to Mount Growmore that includes CJET. This effort has amplified awareness of CJET to a New England region and national audience through the posting of the Story Map on UCONN's Technical Assistance for Brownfields web page at https://tab.program.uconn.edu/mt-trashmore/.

The success of Elevate's model collaborations integrating family mental health with civic justice engagement is being recognized across the country as Elevate has received inquiries to align CJET with several national initiatives. For example, the US Environmental Protection Agency has reached out to Elevate about exploring alignment with their EJ Academy to incorporate social determinants of health.[6] In addition, CJET was profiled though several venues at the National Brownfields Training Conference 2022. As mentioned before, the Story Map for B2H and Mount Growmore is reaching a national audience of private sector, government, non-profit organizations, academia, and others addressing remediation and redevelopment of contaminated and blighted properties.

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[2] https://eastendnrzmarket.org/

[3] https://custom.cvent.com/F8C578BBFC6D4F8EA289284C163DB9CA/files/3fee58d99a3d4c6c97088c2ff5c0a159.pdf

[4] https://tab.program.uconn.edu/resources/

[5] https://www.epa.gov/sites/default/files/2019-11/documents/11.19.19_ej_report-final-web-v2s.pdf

[6] https://www.epa.gov/oh/ej-academy

2. Among examples of existing Federal collaborations with (a) Tribal, territorial, local, and State governments or (b) local communities involving equitable data, *what lessons or best practices have been learned from such collaborations* ?

Elevate prioritizes contextual and cultural relevance through *both* evidence-based and anecdotal information. Initially, Elevate works with local organizations to conduct a Goals and Needs Assessment (GNA). The GNA is a tool for MOMS Partnership sites to learn more deeply about—and, importantly, directly from—the caregivers in the communities they serve, by asking caregivers to share what they want, what they needs, and what goals they have for themselves and their families. Data generated from the GNA informs program setup and adaptation of the MOMS model to meet the specific needs of the community. Each GNA is co-constructed by Elevate and community partners. Second, Elevate is informed through intensive engagement with community leaders who are women of color. In Bridgeport, Elevate ascertained that place-based stressors impacted well-being.[7] In collaboration with community leaders and state government, Elevate co-created its MOMS Partnership and social determinants of health (SDoH) programming in a manner that concurrently works to directly addresses maternal mental health and overcomes place-based stressors in culturally relevant ways.

CJET programming and equitable data collection is nuanced and complex because it is an "Environmental Justice community centric" approach guided by guiding principles of environmental, health, and economic justice. Grounded in equity, the data collecting process is non-linear, iterative, and adaptive. Accordingly, Elevate has engaged with our community partner in co-creating the adaptation of CJET to address community needs as they evolve, emerge and are increasingly articulated and understood. This approach is fostering relationships and trust by respecting the interests, input, and timeline of the community facing multiple burdens and stressors. Ultimately, Elevate continues to capture the components of this adaptive approach in order to further refine the CJET methodology.

5. What resources, programs, training, or tools *can increase opportunities for community-based organizations to use equitable data to hold government accountable to the American public* ?

Civic engagement is the process of "working to make a difference in the civic life of communities and developing the combination of knowledge, skills, values, and motivation to make that difference."[8] Civic engagement in health, economic, and environmental well-being incorporates approaches developed through environmental justice and civil rights advocacy to address inequities related to SDoH that systemically limit health and well-being for low-wealth and historically marginalized communities. To date, civic engagement activities have been limited in these communities due to reduced general civic awareness, historical marginalization, and lack of social cohesion.[9] Through CJE programming, participants can gain in-depth understanding of administrative authorities and processes, including using equitable data, that regulate government decision-making and relevant impacts associated with SDoH; development of skills to confront inequities stemming from SDoH; and practical application of knowledge and skills in government decision-making proceedings. CJE will help participants align with key stakeholders around related policy efforts.

Many efforts by individuals to become more engaged in their community spring from a concern about equity and justice issues. Coupled with better access to opportunities for social cohesion, community participants can become active and engaged in making change in their lives and communities, which also results in mental health benefits. When people are involved in the planning and decision-making process for actions that affect their health and well-being, populations begin to build social networks, social capital, and trust – all factors that contribute to the health of communities.

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[7] https://issuu.com/elevatepolicylab/docs/gna_findings_from_six_sites

[8] https://www.healthaffairs.org/doi/10.1377/hlthaff.2016.0603

[9] Alexander JA , Comfort ME , Weiner BJ , Bogue R . Leadership in collaborative community health partnerships . *Nonprofit Manag Leadersh* . 2001 ; *12* (2): 159 – 75

Elevate is grateful that the White House OSTP is highlighting the need for better support collaboration with other levels of government, civil society, and the research community around the production and use of equitable data. We look forward to assisting with this process in any way that we can.

Sincerely,

B. Suzi Ruhl, JD, MPH, Director of Policy Hilary Hahn, EdM, MPH, Executive Director Annie Du, Special Assistant	Deborah Sims, Community Champion East End NRZ Market and Café

Elevate Policy Lab, Yale School of Public Health

NSTC Subcommittee on Equitable Data
Office of Science and Technology Policy
Eisenhower Executive Office Building
[redacted] NW
Washington, DC 20504

Dear Subcommittee Members:

Thank you for the opportunity to share with you our input on how the Federal government can encourage equitable data collaboration across different levels of government, grassroots and community organizations, and the broader research community.

The Economic Policy Institute (EPI) is a nonprofit, nonpartisan think tank created in 1986 to include the needs of low- and middle-income workers in economic policy discussions. EPI conducts research and analysis on the economic status of working America, proposes public policies that protect and improve the economic conditions of low- and middle-income workers, and assesses policies with respect to how well they further those goals. In 2008, EPI launched the Program on Race, Ethnicity, and the Economy (PREE) to provide a more focused and integrated approach to exploring and explaining how race, ethnicity, gender, and class intersect to affect economic outcomes in the United States. Over the last 14 years, PREE has become a leader among Washington, DC-based policy and research organizations providing data-driven analysis of large racial economic disparities in the United States that have persisted over generations, and at times have either been improved or exacerbated by public policy decisions.

The following comments are most relevant to the following questions posed by the White House's Office of Science and Technology Policy:

What resources, programs, training, or other tools *can expand opportunities for historically underrepresented scholars and research institutions to access and use equitable data across levels of government* (question #4)?

What resources, programs, training, or tools *can increase opportunities for community-based organizations to use equitable data to hold government accountable to the American public* (question #5)?

What resources, programs, training, or tools *can make equitable data more accessible and useable* for members of the public (question #6)?

In which agencies, programs, regions, or communities *are there unmet needs, broken processes, or problems related to participation and accountability* that could be remedied through stronger collaborations and transparency around equitable data (question #7)?

Like many other research organizations, EPI often leverages federal data to document the economic conditions of workers and their families, assess the impact of economic policies on different demographic groups, and propose policy solutions that effectively support the needs and well-being of all communities across the country. Surveys such as the American

Community Survey, Current Population Survey, and decennial census are critical to obtain an accurate and comprehensive understanding of different communities and their experiences across key areas of life, such as health, housing, employment, economic security, and public benefits use.

These surveys are the foundation of our national data infrastructure, providing critical information about individuals, families and households in the United States while also enabling researchers and policy analysts to evaluate state and federal policy impacts. However, each of these datasets has limitations with respect to coverage, response rates, timely processing, and data availability. In turn, each of those data limitations affects our ability to understand the experiences of communities of color that are underrepresented in national statistics and to develop evidence-based policy solutions to improve outcomes, address disparities and effectively allocate billions of dollars in funding that can measurably improve lives with respect to health care, housing, employment, education, and government services and benefits.

Addressing the limitations of existing data sources requires a significant investment of federal resources to adequately staff the agencies responsible for developing the surveys, collecting the data, and processing the data for use by researchers, community-based organizations, and the public. Through increased investment in our federal statistical infrastructure, we can increase population coverage and survey sample sizes in a way that expands access to more disaggregated data on race, ethnicity, gender identity, geography, and other key demographic variables[1]. This includes the development of new survey instruments and modes of data collection that acknowledge a more inclusive range of lived experiences, the historic systematic exclusion of different communities, and major changes in our society, economy, and demography of the population over time. Investments in federal statistical infrastructure will also allow the federal government to expand its capacity to provide oversight and guidance related to consistent collection and documentation of data across federal, state, and local agencies as the nation works to develop more inclusive systems of classifying the multiple and intersecting layers of identity that contribute to disparate social and economic outcomes. Uniformity in the definitions and concepts used to collect data is paramount to maximizing the efficiency of data collection efforts at all levels of government because it allows more data systems to “talk to each other” in a way that helps us to understand how different demographic groups access and utilize the expansive web of federal, state and local programs.

In addition to building a more robust data collection infrastructure, expanding access to equitable data is critical to equal opportunity within the research community. Allowing a more diverse and representative group of researchers – including racial and ethnic identity, gender identity and research discipline – to have access to more robust data sources also helps to broaden the scope and perspective of research questions being asked to inform policy. Structural barriers faced by people of color and women within academia and other research institutions as well as inequities in institutional resources contribute to unequal access to data.

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[1] https://www.nature.com/articles/s41562-019-0696-1.epdf?author_access_token=E57xxblmWr7_DOVeEeVAadRgN0jAjWel9jnR3ZoTv0PIxsimPnsmvH72Q4G9bC9cqDaMj33xtoaNfyBvqXjkim78b8LFa93XoTK22i78uafSmK2nAOWW7E7m1Y4awiITV4chtVKgn1S5a3Ev5pMrAg%3D%3D

While the practice of restricting access to detailed personal data is important to protecting the integrity of data collection efforts and the privacy of individuals, these practices can also be misused as a way of gatekeeping and restricting access to data in ways that favor better resourced or more well-connected researchers. Careful consideration of practices and process that provide necessary security for survey respondents while expanding access to more robust data sources is essential to overcoming the particularly acute structural barriers faced by historically underrepresented scholars and research institutions, including historically Black Colleges and Universities (HBCUs) and other Minority Serving Institutions (MSIs). Agencies must prioritize engaging these underrepresented groups to facilitate more equal access to data networks, seminars, and tools so they may be better equipped to fully participate in the production of a knowledge base that helps to inform policy. Coupled with efforts to disaggregate data, these groups would have increased research capacity to examine intersections of race, ethnicity, gender, class, and place that affect social and economic outcomes for underrepresented communities.

Finally, access to published research findings based on equitable data should be more readily available to the public. Research and data with important implications for low- to moderate income households and marginalized or disadvantaged communities are often held behind paywalls that limit the access of those who may have an interest or personal stake in the research findings. Academic research journals should provide open access to research that uses government survey data to improve accessibility and general utility. Through significant federal investments in a more robust national statistical data infrastructure and implementation of processes and practices that support expanded equitable data access, the efficacy of national, state, and local data collection efforts can be improved while providing decision-makers with the information needed to develop policies that support more equitable outcomes.

Sincerely,

Adewale Maye
Policy and Research Analyst
Program on Race, Ethnicity, and the Economy
Economic Policy Institute

Valerie Wilson
Director
Program on Race, Ethnicity, and the Economy
Economic Policy Institute

EQUITYMATTERS
PROMOTING EQUITY-IN-ALL POLICY™

October 3, 2022

Equity Matters Response to OSTP Request for Information

Related to EQUITABLE DATA ENGAGEMENT & ACCOUNTABILITY

Contact Person

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1. What are examples of successful collaborations involving equitable data between the Federal government and (a) Tribal, territorial, local, and State governments, or (b) local communities?

There are not many collaborations involving equitable data between the federal government and communities, which is all the more reason why this executive order is so important. At this time in our nation's history, we are faced with a reality where facts are not argued as much as identity and culture. While there is not enough equitable data collaborations, we have seen within our own network that equitable data collaborations are able to incorporate facts, identity, and culture.

Within our network of equity practitioners:

- The Joint Center for Political and Economic Studies and Baltimore Place Matters developed "*Place Matters for Health in Baltimore: Ensuring Opportunities for Good Health for All, A Report on Health Inequities in Baltimore, MD*. The report, supported by a grant from the National Institute on Minority Health and Health Disparities (NIMHD) of the National Institutes of Health, provides a comprehensive analysis of the range of social, economic, and environmental conditions in Bernalillo County and documents their relationship to the health status of the county's residents."

- The National Innovation Services "partnered with the Mayor's Office of Criminal Justice (MOCJ) and the Office of Neighborhood Safety (ONS) to speak directly with the communities most directly affected by violent crime, police violence, and neighborhood disinvestment, learn what communities need to be safe, and build a framework to measure community safety so that the government can better direct their investments to achieve community safety."

- The National Collaborative for Health Equity developed "Community Health Equity Reports (CHER). The reports are supported by a grant from the National Institute on Minority Health and Health Disparities (NIMHD) of the National Institutes of Health. They provide a comprehensive analysis of the range of social, economic, and environmental conditions in different areas around the country and documents their relationship to the health status of that area's residents."

2. Among examples of existing Federal collaborations with (a) Tribal, territorial, local, and State governments or (b) local communities involving equitable data, *what lessons or best practices have been learned from such collaborations* ?

We have learned that there is a distinction to be made between novel practices, emergent practices, good practices, and best practices. Whereas best practices tend to treat the relationship between cause and effect as obvious to all, we have learned and observed that most networks are navigating high degrees of complexity and disorder. As such, we have invested in training our equity practitioners in applied complexity science in order to better understand the continuum of needs and dynamics that influence whether network innovation is effective or not.

3. What resources, programs, training, or other tools *can facilitate increased data sharing between different levels of government (Tribal, territorial, local, State, or Federal) related to equitable data* ?

We utilize sensemaking through applied complexity science, and the Cynefin frameworks specifically. We need significant investment in appropriate AI and opt-in systems that facilitate meaning making and feedback loops between the governing and governed. Such a system would improve network navigation providing a process for collectively responding to chaotic, confused, and complex moments in a way that makes them complicated or clear. In complex, confused and chaotic environments, patterns are revealed in countless meaningful interactions among people and systems. The processing power of our sensemaking software, Spryng.io, makes mass community story collection, analysis, and decision making possible. Gathering many stories is necessary to discern patterns and create a database that allows us to develop actionable insight that support what is working or disrupt what is not. By anchoring the data-ecosystem in a sensemaking process, the generative and decision-making power is shifted to community participants and stories of lived experience become the most valuable form of data and source of discernment.

4. What resources, programs, training, or other tools *can expand opportunities for historically underrepresented scholars and research institutions to access and use equitable data across levels of government* ?

We need real time data that is community generated and controlled. Our systems need differentiated ways to center relevant perspectives, opinions, and data in a way that reflects the clusters of narratives, cultures and identities that make up a network. We believe in deploying story and quantitative approaches simultaneously and in real time using the techniques of applied complexity. In a broad way, our sensemaking practice combines story and meta-data analysis with “adaptive action cycles,” guiding communities to apply the data by asking and answering the questions “What? So what? Now what?” The process is participatory, in that it includes a diverse group of people as designers of the project, and hundreds of people to tell their stories. We return the stories to the community to make sense of how to move forward in complex environments. The process is narrative in that we are gathering stories and allowing story tellers to interpret those stories. And it is inquiry based in that the stories and the patterns that are revealed provide material to stoke the curiosity of people and groups in the system who may wish to learn and shift patterns.

5. What resources, programs, training, or tools *can increase opportunities for community-based organizations to use equitable data to hold government accountable to the American public* ?

Our collaborative can produce regional economic justice/equity reports, which can serve as the catalyst for economic justice through systems change. We can also offer trainings for corporate and government employees, equity practitioners, and community leaders. For example, in partnership with Harvest Moon Consulting, we organized training sessions - called Complexity Inside and Out - to give a good grounding in Applied Complexity Science. We also collaborated with Cognitive Edge to organize training on the Cynefin Framework.

6. What resources, programs, training, or tools can make equitable data more accessible and useable for members of the public?

Significant unmet needs exist in the African American community. African American women have considerable unmet needs as it relates to economic outcomes.Source:Brentin Mock.”The Best and Worst Cities for African American Women” -CityLab January 2020

7. In which agencies, programs, regions, or communities *are there unmet needs, broken processes, or problems related to participation and accountability* that could be remedied through stronger collaborations and transparency around equitable data?

Significant unmet needs exist in the African American community, and African American women, in particular, have considerable unmet needs that extend from a history of economic and health inequities The reality of these long-lived inequities have created conditions of poverty and co-morbidity within the African American community. Our collaborative approach to incorporating community voice and leadership into systems and policy change (e.g. “Do Nothing About Me Without Me”) prioritizes partnering with marginalized communities to identify new data points necessary to advance economic justice and parity. We are able to drive an integrated, high-level research and evaluation agenda that fully incorporates all levels of community and with respect for cultural axiology. Because it is difficult to shift dominant cultural norms that have long excluded and corroded, upstream organizing is necessary for building authentic communities that can manifest and counter harmful practices.

APHSA
American Public Human Services Association

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October 3, 2022

Attn: NSTC Subcommittee on Equitab[redacted]echnology Policy
Eisenhower Executive Office Building
Washington, DC 20504

RE: Engagement and Accountability RFI 87 FR 54269

As the bipartisan, national membership association representing state and local health and human services agencies, the American Public Human Services Association (APHSA) welcomes the opportunity to share insights on how Federal agencies can better support collaboration with other levels of government, civil society, and the research community around the production and use of equitable data. APHSA's members are experts in administering, overseeing, and aligning programs that build resilience and bolster well-being through access to food, health care, housing, employment, child care, community supports, and other key building blocks. Our members are also leading experts in data analysis, health and human services IT systems, workforce development and training, and the legal dimensions of the field.

In our response to the White House Office of Science and Technology Policy (OSTP) Request for Information, APHSA draws on insights from member engagement and APHSA-led initiatives to elevate the priorities of and promising practices discovered through state and local practitioners and policymakers. APHSA's responses to RFI questions most directly draw from the following APHSA initiatives that exhibit successes and lessons learned on fostering equitable data collaborations.

Table 1: APHSA-led Initiatives

Initiative	Description
Coordinating SNAP & Nutrition Supports (CSNS)	Coordinating SNAP and Nutrition Supports (CSNS) is a cohort grant program administered by APHSA and funded by Share Our Strength's No Kid Hungry Campaign. CSNS aims to align the Supplemental Nutrition Assistance Program (SNAP) with other federal, state, and local nutrition supports to combat childhood hunger. Through our CSNS grant program, six funded sites across Hawai'i, Kansas, Mecklenburg, North Carolina, Michigan, New Jersey, and New Mexico are actively working to reduce cross-departmental silos, facilitate partnerships with community organizations, improve the experience of families accessing nutrition supports, and leverage data and technology to address systemic barriers and promote equitable access to nutrition benefits.
SNAP E&T National Partnerships	APHSA, in partnership with the Association of Community College Trustees (ACCT) and the National Community Action Partnership (NCAP), is building a national approach to SNAP E&T by providing technical assistance across two cohorts comprised of community colleges and CAAs to increase understanding, improve coordination with state and local agencies, and scale SNAP E&T partnerships.

	By forming strategic relationships across key national networks, states and local SNAP programs can learn how to best support their community partners and collaborate to develop career pathways leading to quality, sustainable employment for participants of SNAP.
Southeastern Cohort on Young Parents and Families	Third Sector is a national nonprofit that offers technical assistance to government agencies. They convened the Southeastern Cohort on Young Parents and Families which includes Georgia, Kentucky, and South Carolina to identify strategies that increase alignment and coordination between programs and public funding streams and develop new models for collaboration withing and between government agencies, nonprofit partners, and young parent families.[1] APHSA partnered with Third Sector to write a report summarizing key lessons learned from the cohort.

1. What are examples of successful collaborations involving equitable data between the Federal government and (a) tribal, territorial, local, and State governments, or (b) local communities?

The three examples detailed here from the APHSA-led Coordinating SNAP & Nutrition Supports (CSNS) program (described in Table 1) illustrate the potential for equitable data collaborations between State and local governments and local communities to be scaled at the Federal level.

Example 1: Through their CSNS-funded project,[2] the Michigan Department of Health and Human Services (DHHS) established a partnership with the Food Bank Council of Michigan and Poverty Solutions from the University of Michigan to leverage data insights to better understand and reduce food insecurity in the state. The research team at Poverty Solutions combined administrative and publicly available data to develop a public food insecurity map which will be used to establish state priorities for reducing hunger and addressing disparities in food access. The statewide food insecurity map, a major deliverable for the MI CSNS project, draws on data from the Michigan DHHS, Michigan Department of Education, the Food Bank Council of Michigan, the U.S. Census Bureau, and relevant non-governmental surveys and will be publicly available in 2023. This example exemplifies how data from various levels of government and community-based organizations can be used to identify and track progress on key public priorities.

Example 2: The Mecklenburg CSNS Project[3] established a data sharing agreement between their County Department of Social Services (DSS), Economic Services Division (ESD); their Department of Public Health, WIC Office (DPH WIC); and the North Carolina Department of Health & Human Services. This data sharing agreement enables cross-agency access to historic and future SNAP and WIC case data, which is being used to identify gaps in benefit access. This CSNS team further collaborated with a local nonprofit, Loaves and Fishes, to hire a team of Food Security Navigators who have lived expertise with food insecurity to work at the community level to address access gaps born out in data analyses. As of Summer 2022 (the latest project data available), Mecklenburg County observed a 12% increase in SNAP enrollment, and a 13% increase among children. APHSA hopes to leverage the learnings from Mecklenburg CSNS project to scale this model by engaging SNAP administrators nationally.

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[1] *Southeastern Cohort on Young Parents and Families*. Third Sector. https://www.thirdsectorcap.org/southeastern-cohort-young-parents-families/

[2] *CSNS Michigan Spotlight: Data-Driven Strategies to Help End Hunger in Michigan* (Coordinating SNAP & Nutrition Supports Case Studies). APHSA and No Kid Hungry, Share Our Strength. https://files.constantcontact.com/391325ca001/453252e0-9f67-4ca9-8988-ab76d2d243e4.pdf

[3] *CSNS Mecklenburg County Spotlight: Strengthening Community Relationships to End Child Hunger* (Coordinating SNAP & Nutrition Supports Case Studies). APHSA and No Kid Hungry, Share Our Strength. https://files.constantcontact.com/391325ca001/b8fa102d-ea90-4781-bc9a-f16fd405428c.pdf

Example 3: The Kansas CSNS Project[4] created an automated data aggregation and outreach process to increase SNAP and WIC co-enrollment. In collaboration with local nonprofit, Delivering Change, Kansas hired a Family Benefit Navigator who has lived expertise with food insecurity to inform project design and implementation. Kansas executed a data sharing agreement across agencies to exchange SNAP and WIC participant data and develop a dashboard with daily updates available to the Kansas Department for Children and Families and the Kansas Department of Health and Environment. This has allowed their SNAP vendor, Accenture, to begin an integrated outreach campaign to enroll more eligible families.

2. **Among examples of existing Federal collaborations with (a) Tribal, territorial, local, and State governments or (b) local communities involving equitable data, what lessons or best practices have been learned from such collaboration?**

APHSA's administration of the CSNS cohort has surfaced the following lessons surrounding the value of early data sharing agreements, stakeholder involvement, and peer collaboration to executing successful equitable data initiatives.

Lesson 1: Early coordination to establish data sharing/use agreements can enable data exchanges across levels of government and facilitated aligned modernization of service delivery.

A data sharing agreement between relevant programs, agencies, and/or governments should be drafted and executed as early as possible to accelerate implementation of initiatives that improve government service delivery to the public. Data sharing agreements can be leveraged to establish data coordination and analyses processes and create common understanding across agencies, thereby streamlining future data exchanges and reducing administrative burden, for example by minimizing duplicate data collection.

Lesson 2: Early stakeholder involvement and frequent communication is critical for sustaining momentum and overcoming silos.

Target populations should be included in data initiatives from the onset and meaningfully involved throughout analysis to avoid creating differential power dynamics. Partnering with community-based organizations can be an effective way to engage underserved communities and learn how policy impacts the American public. The Mecklenburg CSNS Project referenced above did this by hiring a team of Food Security Navigators in collaboration with a local community-based organization. The Food Security Navigators attended over 250 community events with more than 20,000 attendees to disseminate field surveys assessing residents' knowledge and experience with nutrition assistance programs and barriers to accessing services. As people who have lived expertise with food insecurity, the Food Security Navigators play a critical role in connecting and building trust with the community. Furthermore, Mecklenburg established an executive steering committee comprised of community-based organizations that collaborate to design new strategies to engage with families who are eligible for but not enrolled in nutrition supports.

Additional key stakeholder groups to involve in early discussion include Technology leads and IT departments, Legal teams, and Project Management leads. IT departments can evaluate the feasibility of project proposals, technical implications of data management, and security concerns while legal experts can explore the legal and policy justifications needed to execute data sharing agreements. Project management and sponsorship can heavily influence the success of a data collaboration. Designating a project sponsor to champion the effort helps maintain momentum and remove roadblocks to success.

Lesson 3: Close collaboration among peers and across levels of government, leadership, and relevant stakeholders breaks down silos and promotes project sustainability.

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[4] *CSNS Kansas Spotlight: Forming Connections Between SNAP and WIC to Tackle Food Insecurity* (Coordinating SNAP & Nutrition Supports Case Studies). (n.d.). APHSA and No Kid Hungry, Share Our Strength. Retrieved October 3, 2022, from https://files.constantcontact.com/391325ca001/90c636ac-96e1-4cc5-8e2b-f62af781fdda.pdf

Collaborative efforts across levels of government, leadership, and relevant stakeholders can break down silos and reduce the risk of roadblocks during periods of tense political climate. Peer learning promotes scale of evidence-based solutions and improves efficiency. In the CSNS projects, this was accomplished by implementing a cohort model where States and local governments regularly convened to share updates, anticipate problems, troubleshoot, and co-create innovative practices.

3. What resources, programs, training, or other tools can facilitate increased data sharing between different levels of government (Tribal, territorial, local, State, or Federal) related to equitable data?

Because data is collected and stored differently across systems and levels of government, data collaborations can prove challenging. The tools and resources named below have been leveraged by CSNS project sites to overcome these challenges.

Resource 1: Legal and Policy Data Sharing Guidance

CSNS projects engaged legal experts to identify policy and legal justifications for sharing data. Federal guidance pointing to existing data sharing authorities leveraged across levels of government, precedent and proven practices established by effective state, local, and federal data collaborations, and legal justifications for various uses of shared data could set the foundation for new collaborations and align legal interpretations to promote equitable uptake of modern practices nationwide.

Resource 2: Template Data Sharing/Use Agreements

Template data sharing agreements have proven to be powerful tools for quickly and systematically enabling the use of legal justifications to exchange data across governments and programs. Data sharing templates can reduce administrative burden on government agencies seeking to modernize systems and data processes. Technical assistance to adapt and deploy template agreements for targeted uses can further enable prompt execution of implementation-focused agreements.

Resource 3: Tailored Data Tools

Tools tailored to project needs – such as data dashboards, and other dynamic data visualization and analysis instruments – help agencies effectively organize, share, and understand data. The Kansas CSNS Project created a data lake under a data sharing agreement that houses data from SNAP and WIC programs so that program administrators can view the data collectively, pull reports, and establish and evaluate targeted data-driven program initiatives. In addition, the Michigan CSNS project team built feedback loops within their eligibility system to track referrals, client participation, and utilization of private food banks and SNAP. State and community partners will soon be able to use this data to identify service gaps and opportunities for public and private anti-hunger organizations to streamline access across nutrition supports.

Resource 4: Dedicated Staffing

Several CSNS sites found that project management roles in particular were critical for moving collaborative data projects forward, sustaining momentum, and connecting project activities. Hiring staff specifically dedicated to project management for data collaboration is necessary to build sufficient capacity to carry out these new projects and bring in advanced analytics expertise to draw deeper insights from the data.

Resource 5: Collaboration Frameworks

APHSA, in collaboration with state agencies and third-party providers, created the SNAP E&T Third-Party Partnerships: A Framework to Collaboration and Communication for Improved

Participant Outcomes.[5] Driven by feedback and responses gleaned from state agency staff administering SNAP E&T and third-party direct-service providers, the framework is a reflection of stakeholder voices that examines the mechanics of strong partnerships between agencies and providers, fostered by communication, trust, and collaboration.

4. What resources, programs, training, or tools can increase opportunities for community-based organizations to use equitable data to hold government accountable to the American public?

Throughout the full CSNS cohort initiative, community-based organizations across sites developed and strengthened partnerships with state agencies to use equitable data for increased accountability and transparency to the general public in various ways.

The Michigan and Mecklenburg County CSNS projects in particular have effectively leveraged the tools and resources referenced in our response to question 3. Administering the CSNS cohort has demonstrated the potential for public facing instruments – such as the Mecklenburg survey analyses, and MI Food Security Map mentioned in response 6 below – to convey the impact of community engagement and deepen evaluation practices.

5. What resources, programs, training, or tools can make equitable data more accessible and useable for members of the public?

Public facing maps, dashboards, and narratives are tools governments can use to share data with the public. Outlined below are examples of how CSNS projects employed these tools to make complex data more accessible.

Example 1: The Mecklenburg CSNS Project Food Navigators collaborated with the County Public Information team to craft stories from their outreach work that will be shared on government websites, press releases, and news posts. Public facing narrative work can weave together qualitative and quantitative data in an accessible format that is grounded in context. If these stories are co-created with the communities they highlight, they offer an important opportunity to build trust and resonate with the American public by uplifting and affirming lived expertise.

Example 2: The Michigan CSNS Project created a food insecurity map that will be an essential aid to the Michigan Department of Health and Human Services as they continue to prioritize equity and tailor outreach to historically underserved communities. The public map will help community-based organizations identify the most adversely affected populations for targeted programs and services.

6. In which agencies, programs, regions, or communities are there unmet needs, broken processes, or problems related to participation and accountability that could be remedied through stronger collaborations and transparency around equitable data?

While many programs, agencies, regions, and communities can benefit from stronger collaborations and transparency around equitable data, APHSA highlights in this response the potential in SNAP to close participation gaps and mitigate benefits cliffs.

Priority: Closing benefits participation gaps

Many eligible families are not enrolled in SNAP. Some CSNS projects are addressing this problem by matching SNAP data with data from other programs for low-income families such as WIC to identify enrollment gaps and conduct targeted outreach. This work has reduced administrative burden associated with enrolling clients in separate programs and collecting duplicate data. These collaborations could be further strengthened through partnership with the Federal government by establishing a data sharing

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[5] SNAP E&T Third-Party Partnerships: A Framework to Collaboration and Communication for Improved Participant Outcomes - https://files.constantcontact.com/391325ca001/33e1d0f9-f779-49f9-a813-f96fa0da6642.pdf

agreement where States and local governments can access Federal SNAP data to identify gaps and inequities.

Young families sometimes fall into benefit gaps as they utilize services administered by different offices. The Southeastern Cohort on Young Parents and Families[6] was an effort to provide technical assistance to a cohort of three states to improve services targeted to young parents and families. In Georgia, they found that young parents who were transitioning out of foster care were often unaware they needed to reapply for Medicaid leading to loss of health care coverage. To address this broken process, the Georgia Division of Family and Children Services implemented policies and procedures to increase coordination between Child Welfare and the Office of Family Independence through data sharing agreements and partnership with Medicaid, SNAP, TANF, and other offices that young parents are likely to engage with as they transition out of foster care. The Federal government could use this model and the practices and tools outlined in this letter to help other states implement similar strategies.

Priority: Mitigating benefits cliffs

SNAP E&T provides an opportunity for families with low-income to help stabilize their family, while moving forward on a path to economic mobility. One problem related to SNAP E&T participation is the benefit cliff. There is an opportunity here to address the issue of workers of color being disproportionately concentrated in lower-wage jobs and therefore more likely to rely on benefits. When participants are moved into a job with a slight pay increase, their benefits are often cut or taken away entirely, without regard to family stability. Each incremental pay increase places them in a precarious position where they may lose benefits, but still be unable to able to afford family expenses. This, plus inflation, means that it is nearly impossible for families of color to escape poverty and move up the economic ladder.

Data can be used to fully flesh out the impact of wage increases versus cliff effect. This would empower a participant by providing information that can help them make an informed decision about career pathways. Stronger collaborations and transparency around equitable data also empowers state agencies to develop informed policy solutions.

Conclusion

APHSA appreciates the opportunity to offer insights on how Federal agencies can better support collaboration with other levels of government, civil society, and the research community around the production and use of equitable data. Drawing on successful examples from our member engagement and recent initiatives, we have highlighted a series of best practices, tools, resources, and recommendations that enable effective data collaboration to solve public problems. Data sharing agreements, early stakeholder involvement, and community engagement are key strategies to execute equitable data initiatives. Working across levels, agencies, and organizations breaks down silos and builds a strong foundation for sustained partnership, and APHSA is eager to see greater collaboration in the future.

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[6] *Designing Better Programs for Young Parents & Families*. (2020). Third Sector and APHSA. https://www.thirdsectorcap.org/wp-content/uploads/2020/12/Designing-Better-Programs.pdf

MEMORANDUM

TO: THE WHITE HOUSE OFFICE OF SCIENCE AND TECHNOLOGY POLICY (OSTP)

FROM: THE D'ANIELLO INSTITUTE FOR VETERANS AND MILITARY FAMILIES, SYRACUSE UNIVERSITY

SUBJECT: REQUEST FOR INFORMATION: EQUITABLE DATA ENGAGEMENT AND ACCOUNTABILITY

We wish to identify one example of a successful collaboration involving equitable data between the Dept. of Veterans Affairs and the D'Aniello Institute for Veterans and Military Families at Syracuse University.

Initiative Overview. The D'Aniello Institute for Veterans and Military Families (IVMF) as Syracuse University has been successfully developing regional, multi-sector networks to increase Veteran access to medical and social services through the AmericaServes (AS) program since 2015. Employing human service navigators with lived experience as members of the military community, AS connects Veterans, transitioning service members, and their families to public, private, and nonprofit medical and social service providers that are committed to the shared mission of serving the Veteran and military community. A central component of the AS system includes working with communities to establish an impartial, independent coordinating center that provides centralized support to a network of health and human service providers from multiple sectors. Use of a shared, closed-loop referral platform facilitates efficient realignment of referrals to community-based services, comprehensive follow-up with clients throughout the help-seeking process, and tracking of outcomes. Given the breadth of services and military-centric focus of AS, some Veterans Health Administration (VHA) medical facilities have joined AS networks to increase patients' access to social services and VHA care. As of summer 2022, 18 AS Networks connected over 48,000 unique clients with services in over 20 domains (e.g., housing, health, employment, benefits navigation, etc.).

18+ Communities

110k+ Unique Service Requests

48k+ Unique Clients

1k+ Provider Organizations

Syracuse University D'Aniello Institute for Veterans and Military Families

As of June 30th, 2022

4

VA-IVMF Data Sharing Collaboration. The Veterans Health Administration (VHA) Center for Health Equity Research and Promotion and IVMF recently completed a mixed-methods pilot examining the level of participation of VHA medical facilities in 7 AS networks and found wide variation in whether and how VHA medical facilities participate. By linking AS client data with VHA medical records for the first time, we learned that clients who receive services from both AS and VHA medical facilities are more likely to be racial and ethnic minorities and have greater social risks documented in their health records (e.g., unemployment/poverty, housing instability) than the average VHA patient. We are now in the unique position to examine the impact of AS on racial/ethnic differences in the services and benefits received by Veterans and the potential for AS to dismantle structural inequities that contribute to health and healthcare disparities.

Point of Contact for this Memorandum. Dr. Nick Armstrong, Managing Director, Research and Data, D'Aniello Institute for Veterans and Military Families, Syracuse University [redacted]

THE CENTURY
FOUNDATION

To: The Office of Science and Technology Policy and the the Office of Information and Regulatory Affairs
From: The Century Foundation
Date: October 3, 2022
Re: Request for Information on Advancing Equity with Community Data Partnerships

3. What resources, programs, training, or other tools *can facilitate increased data sharing between different levels of government (Tribal, territorial, local, State, or Federal) related to equitable data* ?

The Century Foundation has been distributing data around access to unemployment benefits during and after the pandemic. This data dashboard tells the story about the long wait for benefits during the onslaught of claims during the pandemic, and the still structural problems facing the system in terms of timeliness and access to benefits. This dashboard was made possible by access to official administrative records from the Department of Labor's Unemployment Insurance Database. This data is made available to researchers on the Department of Labor's website with researchers given the same access to the coding handbooks as the state agencies who must report data. This data transparency has been used by many researchers and is notable for increasing understanding among policymakers at the federal and state level, the media, and advocates for workers.

While there are ways that the DOL could improve access to this data, for example by creating APIs and researcher style code books and data definitions, this is not the main problem. DOL only reports the race, ethnicity, gender and age of eligible clients who receive benefits. This data cannot relate to other data reported on benefit amounts, durations, appeals or eligibility. This greatly hinders the ability of researchers to understand the equity implications of UI benefits policies in and between the states.

DOL should do better. We understand several states have piloted projects by which they are sharing micro data on claimants to DOL for analysis. This type of data sharing should be come increasingly possible as states modernize their computer systems and create relational databases. DOL should move to make such data sharing a regular expectations of states and encourage the sharing of data with researchers by states. Eventually, DOL should create its own ability to share disaggregated and deidentified data with researchers. Developing this capacity is an excellent use of the $2 billion given to US DOL through the American Rescue Plan for UI modernization

This data should be made available to researchers, and there should be tables and cross-tabulations made available to the public. The Department of Labor should report the following data with breakdowns by race, gender, ethnicity, at the national level and by-state.

- Unemployment Insurance recipiency
- Timeliness of claims processing
    - First payment timeliness and nonmonetary determination timeliness
- All appeals data
    - Appeal aging and outcomes
- Denials data
- Fraud prosecution data
- Benefit exhaustion rates
- Any other such data that can be practically disaggregated regarding recipiency, benefit levels, and determination quality

In addition, the Department of Labor should conduct a study on a tri-annual basis analyzing take up and application rates of individuals by major racial and groups, by state. This study would compare administrative data to data from the census bureau to see how many potentially eligible individuals apply for and receive benefits. The USDA puts out a study using micro-data that says how many of the likely eligible individuals for SNAP actually get the benefit. It's published by USDA, and compiled by academics on contract with USDA. This once-every-year study has guided states in their outreach efforts to target groups of eligible Americans for food stamps with low-take up rates, like senior citizens for low-wage workers. Making this data available transparently and at the state level would be transformational for the UI field. https://www.ers.usda.gov/publications/pub-details/?pubid=45414.

4. What resources, programs, training, or other tools *can expand opportunities for historically underrepresented scholars and research institutions to access and use equitable data across levels of government* ?

Data snapshots of workforce participation data disaggregated by race, ethnicity, and gender, and disability status can expand opportunities for accessing data. In 2014, the U.S. Department of Education Office for Civil Rights released a data snapshot, providing salient findings on racially disparate rates of suspensions and expulsions with Black, disabled boys the most likely to be suspended. Implications for the snapshot provided culturally competent and trauma-informed approaches for alternatives to suspensions, including restorative justice circles, or emotional counseling from the school principal. Racism and sexism have combined to leave women underrepresented in industries. Data snapshots on workforce participation, particularly in the construction and manufacturing trades can expound on occupational segregation and in-depth explanations for why women of color are the least represented in certain trades and how workforce providers and federal agencies can cultivate intentional recruitment and belonging for Black and Brown women in industries. This would be particularly helpful with the recent deployment of funding from the The Infrastructure Investment and Jobs Act (IIJA) and The CHIPS and Science Act of 2022. The National Partnership for Women & Families found that Black women will account for fewer than 4 percent of new jobs, Latinas less than 5 percent, Asian American and Pacific Islander women less than 2 percent, multiracial women less than 1 percent and Native women 0.1 percent – just 1,150 jobs out of nearly 800,000 per year, without a focus on reducing occupational segregation. Data snapshots will allow community-based and DEIB organizations to partner with workforce providers and federal agencies on retention practices for women of color in industries and cultivate a racially diverse workforce that reflects the demographics of America.

Urban Indian Health Institute
A Division of the Seattle Indian Health Board

Abigail Echo-Hawk, MA
Director, Urban Indian Health Institute
Executive Vice President, Seattle Indian Health Board

October 3, 2022

The White House Office of Science and Technology Policy
[redacted]
Washington, D.C. 20500

RE: Engagement and Accountability RFI

Dear White House Office of Science and Technology Policy:

Urban Indian Health Institute (UIHI) submits the following comments and recommendations to the White House Office of Science and Technology Policy (OSTP) to inform a whole-of-government response that develops policies and procedures seeking to achieve equitable data partnerships and collaboration between federal agencies and underserved communities, Tribes, and urban Indian organizations (UIO), including Tribal Epidemiology Centers (TEC).

Background on Urban Indian Health Institute

UIHI is the research division of Seattle Indian Health Board,[1] a public health authority, and one of twelve TECs in the country – the only one with a national purview. UIHI conducts research and evaluation, collects and analyzes data, and provides disease surveillance for Tribes and the 62 UIOs nationwide. In 2021, UIHI released *Data Genocide*,[2] a report card grading U.S. States' quality of COVID-19 racial data highlighting the nation's inability to accurately collect, report, and analyze race and ethnicity data which drives health inequity. In response, UIHI has engaged with federal, state, and local public health agencies and policymakers to improve the collection and reporting of COVID-19 surveillance data on American Indian and Alaska Native (AI/AN) populations.

UIHI's expertise in data access and exchange informed the Government Accountability Office (GAO) report titled, *Tribal Epidemiology Centers: HHS Actions Needed to Enhance Data Access*.[3] Through these types of exchanges, UIHI continues to be a leader in the development, implementation, evaluation, dissemination, and translation of Indigenous evaluation and research to reduce diseases, risk factors, and health disparities. I submit the following recommendations to advance the federal government's equitable data partnerships and collaborations with AI/AN communities and community-based researchers.

Strengthening Tribal and Community Engagement, Participation, and Expertise for Shaping Public Health Systems

Advancing equity-centered data systems requires federal agencies to increase engagement and participation with underserved populations to appropriately address structural racism in public health designs and operations. By incorporating community engagement and participation, public health systems can leverage appropriate expertise for program implementation and design to respond to emerging and ongoing health disparities. Through Tribal and community engagement, health equity and well-being can advance for underserved populations.

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[1] SIHB is one of 41 Indian Health Service-designated Urban Indian Organizations in the Urban Indian Health Program, as defined by Section 4 of the Indian Health Care Improvement Act, and a Health Resources Service Administration 330 Federally Qualified Health Center.

[2] Urban Indian Health Institute. (2021). Data Genocide of American Indian and Alaska Natives in COVID-19 Data. Retrieved from: https://www.uihi.org/projects/data-genocide-of-[redacted]erican-indians-and-alaska-natives-in-covid-19-data/

tes Government Accountability Office. (March 2022). Tribal Epidemiology Centers: HHS Actions Needed to Enhance Data Access. Retrieved m: https://www.gao.gov/assets/gao-22-104698.pdf

- **Uphold Indigenous Data Sovereignty.** Indigenous data sovereignty is the right for Tribes to govern the collection, ownership, and application of its own data, including data collected on its Tribal citizens. Indigenous data sovereignty can inform data sharing guidance between Tribal, federal, state, and local government agencies. When designing data systems, federal agencies must consider the effects and data storage on AI/AN populations.
- **Engage Native stakeholders by upholding Tribal Consultations and implementing Urban Confer Policies.** To support the growing AI/AN population, each federal agency must uphold the rights of Tribal Consultation policies[4] and implement an Urban Confer policy, similar to the Indian Health Services policy. Once established, this process should be used to conduct a Tribal Consultation and Urban Confer to determine whether Tribal affiliation and/or AI/AN population data should be collected and reported. An urban confer does not impede on the rights of Tribes but rather supports the trust and treaty obligations to AI/AN populations residing in urban areas.
- **Establish community engagement to support public health data system design.**[5] During the early stages of planning efforts to address COVID-19, I was the only Native American on the National Academies of Science, Engineering, and Medicine: Framework for Equitable Allocation of COVID-19 Vaccine. Representation from underserved communities must increase within advisory groups, councils, committees, workgroups, and interagency public health design for informing federal decision-making.
    - ***Supplement the EO workgroup with an interagency data council responsible for equity, racial justice, and social and public health data*.**[6] The interagency council would prioritize systemic drivers of health inequities, establish a process for using public health data, and create a longitudinal and sustainable program.

Evaluate and Assess the Federal Government's Data Systems for Equity

Federal government agencies must consider existing gaps in data collection systems, methods, practices, and policies to improve equitable data. Structural racism has perpetuated health disparities within AI/AN populations resulting in AI/AN life expectancy dropping from 71.8 years to 62.5 years, the same U.S. population life expectancy in 1944.[7] Concurrently, the CDC is not publicly reporting state-level data on racial/ethnic composition of people vaccinated or receiving boosters. In 2021, I co-authored a Morbidity and Mortality Weekly Report, which found that AI/AN people experience disproportionate morbidity and mortality due to COVID-19.[8,9] However, due to gaps in state reporting on race and ethnicity, only 23 states were included in the analysis as they were the only states that had collected 70% or more of racial and ethnic data – resulting in an undercount of AI/AN morbidity and mortality. Federal agencies can advance data equity through systemic changes to better inform programmatic and policy efforts for reducing health disparities.

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[4] Presidential Memorandum on Tribal Consultation. (2009). Retrieved from: https://obamawhitehouse.archives.gov/the-press-office/memorandum-tribal-consultation-signed-president

[5] National Commission to Transform Public Health Data Systems. (2021). Charting a Course for an Equity-Centered Data System: Recommendations from the National Commission to Transform Public Health Data Systems. Retrieved from: https://www.rwjf.org/en/library/research/2021/10/charting-a-course-for-an-equity-centered-data-system.html

[6] Robert Wood Johnson Foundation. (2021). Charting a Course for an Equity-Centered data System: Recommendations. Retrieved from: https://www.rwjf.org/en/library/research/2021/10/charting-a-course-for-an-equity-centered-data-system.html.

[7] National Center for Health Statistics. (2022). Provisional Life Expectancy Estimates for 2021. https://www.cdc.gov/nchs/data/vsrr/vsrr023.pdf.

[8] Centers for Disease Control and Prevention: Morbidity and Mortality Weekly Report. (2020). COVID-19 Among American Indian and Alaska Native Persons – 23 States, January 31 – July 3, 2020. Retrieved from: https://www.cdc.gov/mmwr/volumes/69/wr/pdfs/mm6934e1-H.pdf.

[9] Centers for Disease Control and Prevention. (2020). COVID-19 Mortality Among American Indian and Alaska Native Persons – 14 States, January – June 2020. Retrieved from: https://www.cdc.gov/mmwr/volumes/69/wr/mm6949a3.htm.

- **Implement recommendations from *A Vision for Equitable Data.*** [10] Pursuant to *Executive Order (EO) 13985: Advancing Racial Equity and Support for Underserved Communities Through the Federal Government,* the Equitable Data Working Group suggests several efforts to improve data availability, transparency, and quality, including:
    - **Conduct robust equity assessments of federal programs.** For the federal government to achieve equitable data practices, a whole-of-government approach must consider existing gaps in data practices and methods for reporting on underserved groups, identifying gaps in evidence-based assessments, and identifying and rectifying inequality in federal data.
    - **Leverage underused data by establishing data sharing agreements (DSA) through Tribal Consultation and Urban Confer.** DSAs increase collaboration across agencies and communities to allow for comprehensive large-scale data sharing that can be monitored and managed under the agreements. Tribal Consultations and Urban Confers must be conducted before DSAs can be finalized in order to uphold federal trust and treaty obligations to AI/AN people.
- **Adopt recommendations of the OPEN Government Data Act.**[11] The Open, Public, Electronic, and Necessary (OPEN) Government Data Act increases the public's access to federal agency data to strengthen public health data systems. The Act would require federal agencies to:
    - ***Publish machine-readable data.*** To support accessibility and usability of data by the public, selected government data must be available in a structured format that can be automatically processed.
    - ***Develop a single point of entry for the public to access agency data.*** To achieve data equity, there must be a single point of entry to optimize accessibility for public users while eliminating administrative burdens for government agencies responding to multiple requests on highly frequented data sets.
    - ***Designate a point of contact to assist the public.*** For optimal usage of federal data sets, each agency must have a point of contact to support data usage, accessibility, and concerns of the public.
- **Invest in non-governmental data system interoperability for improved data collection and long-term system development.**[12] Increased investments are needed to improve the dissemination of high-quality and real-time information between public health systems.[8] For example, the CDC received $550 million[13] for improving interoperability, which resulted in: an increase from 187 to 10,200 healthcare facilities sending information from their electronic health records to state and local health departments, and; a 37% increase in the number of data sets accessible on the CDC website, with 1,444 new data sets created. This type of investment can support migrating legacy data systems and sustaining new data systems.
- **Increase public data training.** Tribes and community-based organizations are best suited to evaluate and analyze data on our community. Without collaboration with communities on federal datasets, AI/AN data is at risk of being misinterpreted, underutilized, and

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[10] A Vision for Equitable Data: Recommendations from the Equitable Data Working Group. (2022). Issued to the President in April 2022. Pursuant to Executive Order 13985 (January 20, 2021) on "Advancing Racial Equity and Support for Underserved Communities Through the Federal Government". Retrieved from: https://www.whitehouse.gov/wp-content/uploads/2022/04/eo13985-vision-for-equitable-data.pdf

[11] H.R. 1770: OPEN Government Data Act. 115th Congress (2017-2018).

[12] National Commission to Transform Public Health Data Systems. (2021). Charting a Course for an Equity-Centered Data System: Recommendations from the National Commission to Transform Public Health Data Systems. Retrieved from: https://www.rwjf.org/en/library/research/2021/10/charting-a-course-for-an-equity-centered-data-system.html

[13] Centers for Disease Control and Prevention. (2021). DMI Basics: The Why, What, and How of Data Modernization. https://www.cdc.gov/surveillance/pdfs/dmi_basics_external_audiences-march_2021.pdf.

misunderstood. Federal agencies must improve the sharing, training, and accessibility of federal datasets.

  - **Develop a framework to increase data literacy**. Federal agencies can support the expansion of analytic competencies through trainings, narratives, and courses to support the public health data workforce.
  - **Provide data user training and communities of practice workgroups.** Due to the extensive codes of federal datasets, federal agencies can provide user training and code books to support community-based researchers.

Develop Minimum Standards for Integrating Best Practices Developed by Community-Based Researchers

Ensuring accurate data on AI/AN populations is reported is critical for better understanding where continued investments and culturally responsive systematic changes are needed to reduce health disparities within AI/AN populations. To address issues with data collection, use, and dissemination, I request the federal government implement the following best practices when collecting, working with, and reporting AI/AN data. These data practices are detailed in UIHI's *Best Practices for American Indian and Alaska Native Data Collection,*[14]*Charting a Course for an Equity-Centered Data System,*[15] and *A Vision for Equitable Data*:[16]

- **Invest in community-relevant and nationally significant metrics on structural factors that influence health outcomes**. Data collection on upstream causes of inequity will improve measurements on how systems segregate, discriminate, and exclude.
- **Develop methods for interpreting public health data that include community input, paying attention to messaging, communication, and narrative.** Advance data interpretation training for the workforce, the public, and communities.
- **Generate disaggregated statistical estimates to characterize experiences of historically underserved groups using survey data.** The EO supports advancing racial equity by disaggregating data. Federal datasets often misreport on underserved communities due to incompetent data practices in evaluation and assessment.
- **Increase non-federal research and community access to disaggregated data for evidence-building.** This can result in improved data management and analysis to more accurately identify and report on meaningful trends across populations. For example, UIHI provides community health profiles[17] and a COVID-19 dashboard[18] to support decision-making of Tribes, government entities, elected officials, and key stakeholders to inform policy and program implementation.
- **Aggregate data across time and/or geography.** Analyze data across three-to-five years to build larger samples. Another consideration for aggregating data is to combine several adjacent counties into one group, or present data at the state level to reflect demographics and outcomes of AI/AN people.
- **Use weighted sampling for AI/AN populations.** Weighted sampling is the statistical practice that allows for the population being analyzed to accurately reflect how its proportion in the total population is being represented from which it is being abstracted.

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[14] Urban Indian Health Institute. (2020) Best Practices for American Indian and Alaska Native Data Collection. Retrieved from: https://www.uihi.org/resources/best-practices-for-american-indian-and-alaska-native-data-collection/

[15] Ibid.

[16] Ibid.

[17] Urban Indian Health Institute. (2022). Community Health Profiles. Retrieved from: https://www.uihi.org/urban-indian-health/data-dashboard/

[18] Urban Indian Health Institute. (2022). Retrieved from: https://www.uihi.org/covid-19-data-dashboard/

- **Oversample the AI/AN population.** Oversampling is an intentional sampling process designed to incorporate typically low prevalence members of a certain community. Oversampling helps adjust population distribution of the dataset.
- **Collect accurate and meaningful community-level data that support small-area estimates**. Community- level data will enable local and Tribal health departments to better prioritize and address community health challenges and measure improvements.
- **Conduct mixed-methods research (quantitative and qualitative).** Mixed-methods research gives voice to participants and can include storytelling, focus groups, and key informant interviews. Often, epidemiologists produce quantitative research findings that are not statistically significant when working with small populations, but that does not mean the data is not important or indicative of change or disparity.
- **Mandate a standard definition of AI/AN across databases that is developed through Tribal Consultation and Urban Confer.** Federal data systems must ensure a standard definition of AI/AN which encompasses all AI/AN, including those who identify with multiple races and/or Hispanic ethnicity. This is critical to allow greater comparability of racial information across areas and ensures racial categories align with self-identification of race.
- **Mandate the collection and reporting of race and ethnicity data**. A federal mandate on the collection and reporting of race and ethnicity will improve the surveillance and monitoring of AI/AN data and improve the utility of data for Tribal public health authority partners.
- **Demand accountability**. Enforce the collection and reporting of race/ethnicity by county, state, and federal agencies by providing resources, incentives, and penalties**.** Federal agencies must not only mandate the complete collection and reporting of race/ethnicity but must also hold jurisdictions accountable with enforcement mechanisms.
- **Ensure the collection and analysis of multiple race and ethnicity categories**. From 2010 to 2020, the AI/AN population grew by 86.5% (4.5 million people), including a 160% increase in people who identified as AI/AN alone or in combination with one or more races. Federal datasets must disaggregate or remove ‘Multi-Race’ or ‘Two or More Races’ categories and allow race ‘Alone’ and ‘In Combination’ with other races and ethnicities. AI/AN should be reported as “AI/AN alone”, and this definition should include those who are AI/AN in combination with another race.
- **Collect tribal affiliation, when appropriate**. This allows for the collection of which Tribe, or Tribes, an individual identifies with. UIHI recommends using “tribal affiliation” in contrast to “tribal citizenship,” as only Tribes determine and define Tribal citizenship. If using electronic data collections tools, include an inclusive list of all federal- and state-recognized Tribes with a write-in option for First Nations or other Indigenous identifiers not listed.
- **Report limitations of data collection and analysis.** When releasing a report, it is important to list, explain, and discuss study limitations so they are accounted for when evaluating the results and outcomes, and to allow future studies to improve upon limitations.

Adopt the U.S. Government Accountability Office (GAO) Recommendations
The GAO’s public health data recommendations for collaborating with Tribes and urban Indian communities can benefit all federal agencies to develop a well-informed whole-of-government response. Federal agencies, such as the Department of Health and Human Services (HHS), CDC, Indian Health Service (IHS), Department of Justice (DOJ), and Department of Interior (DOI), have an administrative obligation to uphold recommendations made to AI/AN populations in two recent GAO reports. The *Tribal Epidemiology Centers: HHS Actions Needed to Enhance Data Access*[19] report highlights necessary actions to be taken by HHS to improve TEC’s access

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[19] Ibid.

to federal public health data, and [20] makes recommendations for the DOJ and DOI to uphold for the Not Invisible Act and Savanna's Act to improve data systems and response on the Missing and Murdered Indigenous Women and People (MMIWP) Crisis. The OSTP should incorporate these recommendations to ensure these obligations are upheld to AI/AN populations to advance data equity.

- **Develop a policy clarifying the federal data that are to be made available to TECs as required by federal law.** This includes clarifying the monitoring systems, delivery systems, and other protected health information that TECs can access.
- **Encourage Federal Department Directors to develop written guidance for TECs on how to request data.** This will provide transparency on the process of data requests and expected timelines for receiving data that will support building trust and partnership with Tribal public health authorities.
- **Require federal agencies to develop a plan for accomplishing ongoing analyses of AI/AN data in existing federal databases.** This includes identifying relevant data trends and areas of concern within AI/AN populations.
- **Require federal agencies to develop a strategy to educate the public on entering data into government databases like NamUs.** This includes identifying opportunities to meet with AI/AN populations who are affected by varying social determinants of health to conduct local levels of response.
- **Require federal agencies to develop a plan to conduct specific outreach to Tribes, Tribal organizations, and UIOs regarding the ability to publicly enter information into federal data systems like NamUs.** This also includes other non-law enforcement sensitive portals.

Respectfully,

[redacted]

Abigail Echo-Hawk (Pawnee), MA
Director, Urban Indian Health Institute
Executive Vice President, Seattle Indian Health Board
[redacted]

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[20] The Government Accountability Office. (October 28, 2021). Missing or Murdered Indigenous Women: New Efforts Are Underway but Opportunities Exist to Improve the Federal Response. Retrieved from: https://www.gao.gov/products/gao-22-104045

Ohio Response RFI

This following is in response to the White House Office of Science and Technology Policy Request for Information on how Federal agencies can better support collaboration with other levels of government, civil society, and the research community around the production and use of equitable data as prepared by the Ohio Department of Health's Data Equity Team led by Chief Health Opportunity Advisor, Jamie Carmichael.

1. What are *examples of successful collaborations* involving equitable data between the Federal government and (a) Tribal, territorial, local, and State governments, or (b) local communities?
   - The Community Wellbeing: Social Determinants of Health Dashboard uses all federal publicly available data from the Census Bureau, CDC and American Community Survey at the census tract level which helps to understand which programing most benefit specific communities by providing insight into the conditions that impact Ohioans' ability to live out a healthy lifestyle.

     Community Wellbeing: Social Determinants of Health | DataOhio

   - The Ohio Health Improvement Zones (OHIZ) Dashboard uses publicly available data from the Census Bureau, American Community Survey and the Social Vulnerability Index (SVI) developed by the CDC to help understand the themes and indicators of socioeconomic status and demographics that affect the resilience of individuals and communities to understand what factors contribute to their levels of risk and aid in all phases of improving health in communities.

     Health Improvement Zones | Ohio Department of Health

   - The Operation Warp Speed (OWS) Tiberius Platform uses publicly available data from the Department of Health and Human Services and integrates federal, state, local, private and open data provider data for distribution, planning, tracking, modeling and analysis ecosystem to support as it relates to COVID-19

     Login | Palantir (hhs.gov)

   - General Federal vaccine administrative data provided to tribal, territorial, local and state governments and local communities during COVID response.

2. Among examples of existing Federal collaborations with (a) Tribal, territorial, local, and State governments or (b) local communities involving equitable data, *what lessons or best practices have been learned from such collaborations*?
   - Establish a protocol to Open access to the data make decisions and add context ,
   - Simplify methods of automating and extracting federal data

3. What resources, programs, training, or other tools *can facilitate increased data sharing between different levels of government (Tribal, territorial, local, State, or Federal) related to equitable data*?
   - Equitable Data Guidance and Standards be provided to states to include the following:
     - Methods for analyzing data beyond disaggregation
     - Standards for collecting, storing, comparing and sharing data
   - Funding for Data Capacity Building
     - Data literacy training
     - Data specific and small area estimate trainings

4. What resources, programs, training, or other tools *can expand opportunities for historically underrepresented scholars and research institutions to access and use equitable data across levels of government*?
   - Standards
     - Collecting granular race data to better understand where people are, their culture, lived experience in conjunction with geospatial and other data

     - Data sharing and including people in discussions about their own data

   - Training
     - Community informed and led while still protecting privacies

5. What resources, programs, training, or tools *can increase opportunities for community-based organizations to use equitable data to hold government accountable to the American public*?
   - Tailored programs fully dedicated to transforming the capacity of those who work with data regularly
     - Data academies

       City of Chicago | Data Portal | City of Chicago | Data Portal

   - Collaborations with Community Based Organizations
     - Needs assessment surveys and asset mapping to collect meaningful data
     - Community engagement to ensure data is community informed and led

6. What resources, programs, training, or tools *can make equitable data more accessible and useable* for members of the public?
   - Data Accessibility
     - Make data portals more centralized ensuring that its catalogued data sets are properly identified.

    - Training on data visualization and reporting so that it can be easily understood
    - Provide culturally and linguistically adapted materials

7. In which agencies, programs, regions, or communities *are there unmet needs, broken processes, or problems related to participation and accountability* that could be remedied through stronger collaborations and transparency around equitable data?

- Oversampling for Race and Ethnicity
    - National Survey for Children’s Health Ohio has provided oversamples for more precise information analyses for race and ethnicity data
    - BRFSS oversampling
    - Ohio Pregnancy Assessment Survey
- Funding for oversampling

Nilesh Kavthekar
[redacted]
Brooklyn, NY 11237

To: NSTC Subcommittee on Equitable Data
Re: Engagement and Accountability RFI

To whom it may regard:

I am an independent journalist writing on economic inequality, issues in the labor market, and concentration of corporate power. I previously worked in the technology sector, specifically at Uber, where I became very acquainted with the asymmetric data advantage that large corporations have over the public. I have used a variety of government data sources in my analyses so far (e.g. wage growth data from FRED, National Labor Relations Board union election data, and other data from state governments).

I'm highly interested in seeing new types of data to help answer questions about the current state and historical trends for economic mobility, inequality, and differences in various economic and political outcomes across various income levels.

In response to question 5 of the RFI ("What resources, programs, training, or tools can increase opportunities for community-based organizations to use equitable data to hold government accountable to the American public?"), I can provide my experience here.

Need for more transparency into business activity by income level: one of the key determinants of a person's wage growth in time is their access to new entrepreneurial opportunities. However, one of the with current data on business formation provided by the US Census Bureau, it is impossible to see look at cuts of business formation by different groups such as:

- Income level (or parents' income levels)
- Race
- Gender

Being able to access more data about business formation along these dimensions will help journalists, academics, and other citizens better understand how economic mobility is being shared (or not) across all underrepresented groups.

Need for more transparency into self-employed people: currently, in the Current Employment Statistics Survey ("Establishment Survey"), there is no indication in the regular jobs updates how many people are currently self-employed. That is because whereas payrolls for employees are regularly reported, and there is a precedent of tracking employees specifically, there has not been as much infrastructure set up around knowing how many people are doing self-employed work at a given time. This could be potentially causing a very large discrepancy in data reported by different US jobs surveys, as discussed in this article by Joseph Politano: https://www.apricitas.io/p/we-have-a-chance-to-end-americas.

Given that this population will increase significantly in the coming years, it is essential to have more statistics around this population. Having companies regularly report how many self-employed people received contractual payments in a given month, and being able to understand different cuts of this data (e.g. estimated income level, race, gender) will be essential to understand the composition of the self employed workforce.

For example, a large increase in the self-employed workforce may not necessarily be a good economic indication if those individuals have just left stable, higher paying jobs where they are an employee (for example, to become an Uber driver) Conversely, an increase in high-income self employed workers may also be seen as a good thing.

Need for more transparency into equality statistics of businesses: there is a large category of metrics that would be extremely insightful to understand the behavior of businesses. For example, being able to see aggregate statistics of businesses in the US will be extremely helpful in these dimensions:

- Revenue levels
- Profit levels
- Profit margin levels
- Number of employees
- What percentage of their employee base is low, medium, and high income people
- Breakdown of company employment by race and gender
- How large the contract revenue is with 1099 workers (independent contractors), and demographic information of these workers

These statistics can help the public understand trends in terms of the concentration of corporate power, how large companies are shifting which populations they employ/contract with, and which populations benefit from corporate growth.

Need for more transparency into transport network operator data in cities: cities such as New York, Chicago, and others have mandated that large transport network companies like Uber, Lime, and Doordash give more data to help inform public transit decisions. This data has not been mandated by the Department of Transportation but it is highly important. Given that these companies have expanded to be such a large presence on the roads, and because of the implications for so many other public organizations, it is only fair that this data is made public.

Understanding trip length, locations, and other information can empower transit operators to make more empowered decisions about new public transit lines, roads to be serviced, etc. In addition, this data can be shared with the Department of Labor as it aims to understand the aggregate effects of these transport network companies on wages, employment, and impact on taxi drivers and other industries.

Thank you so much for reading my RFI. I am happy to make myself available to answer any further questions.

Best,
Nilesh Kavthekar

October 3, 2022

Denice Ross
U.S. Chief Data Scientist

Dear Ms. Ross:

Thank you for this opportunity for state leaders to respond to the request for information (87 FR 54269) on equitable data engagement and accountability from the White House Office of Science and Technology Policy (OSTP) and the Subcommittee on Equitable Data of the National Science and Technology Council. We are excited to share the following information on the vision, value, projects, and products of an emerging network of multistate data collaboratives.

3. What resources, programs, training, or other tools can facilitate increased data sharing between different levels of government (Tribal, territorial, local, State, or Federal) related to equitable data?

Background

Multi-state data collaboratives are developing as professional affinity networks above and beyond the basic technology and tools necessary for state agencies to share relevant data within and across state boundaries. With support from foundations and other funding, an administrative entity (the National Association of State Workforce Agencies) and a platform and training organization (the Coleridge Initiative), the collaboratives are empowering member state agencies to:

- Identify shared research questions that are critical to a thriving society;
- Build cross-sector (e.g., workforce, education, human services, corrections) innovation sandboxes to explore how research might address those questions; and
- Accelerate development and scaling of local and timely insights and data products that, if they choose:
    - Rely on both in-state and out-of-state administrative data sources; and
    - Can be shared and scaled.

Multi-state data collaboratives provide state agencies:

- Access to ideas, practices, and relationships with more states, through a structured network;

- Streamlined data access through common agreements to enable both regional and national project partnerships;
- Access to project revenue streams;
- Better, more effective engagement with federal agencies and policymakers; and
- Most importantly, more frequent and rapid data product development leading to better policymaking and practice.

Multi-State Data Collaboratives	
Vision	**Value**
State-led, useful, and innovative projects	Timely, valuable, & actionable information and products developed by and for states
Common priorities	Collective priority and goal setting
Streamlined data agreements	Streamlined mechanisms for joint work within and across collaboratives
Shared training	Information and resource sharing
Capacity building and community of practice development	Unified voice in national discussions
Shared governance framework	Shared administrative and technical support
Exploration of data products in new domains	Possibilities for revenue to support joint projects

As the administrative organization supporting the network of multistate data collaboratives, the National Association of State Workforce Agencies (NASWA) works (currently under a foundation grant) as an honest broker across sectors (e.g., workforce, higher education, human services, corrections) to support:

- Collaborative governance, including facilitating the development and implementation of a final governance model, convening the regular meetings of the governing bodies, and identifying and convening advisory experts;
- Development of final bylaws and execution of an agreement (MOU) among states and the administrative organization (NASWA) that sets out the conditions for common data projects;
- Outreach to and engagement of additional states;
- Enhanced visibility to external research institutions and policymakers;
- Critical partnerships with higher education, human services, and other state associations to support state agency engagement; and
- Implementation of grant-funded opportunities for collaborative training and product development.

NASWA also provides expert support to the Coleridge Initiative, the entity providing the data platform and supporting advanced data analytics training. The Coleridge Initiative, which is also a non-profit entity, provides a secure remote access environment, the Administrative Data Research Facility (ADRF), which has been authorized to host both state and federal workforce and education data. The ADRF's security protocols (user identity, password complexity and expiration, etc.) follow strict FedRAMP guidelines and the 'five-safes' best practice. All user access activity is logged and monitored. The ADRF has provided secure access to over 300 confidential government datasets from 50 different agencies at all levels of government.

The Coleridge Initiative also built a complementary Applied Data Analytics (ADA) program to train government employees to perform applied data analysis with confidential individual-level data generated through administrative processes and extensive project-focused work. The aim of the ADA program is to help agencies tackle important policy problems by using modern computational and data analysis methods and tools. It has demonstrated the potential value of working with individual-level data across agency and jurisdictional lines for hundreds of government agency staff from federal, state and local agencies.

Since 2017, the Coleridge Initiative has partnered with over a dozen top universities and organizations to provide this professional development training to participants across more than 100 government agencies and 40 states, facilitating cross-agency and cross-state collaboration to address shared policy challenges. The guiding research questions that have framed the training and class projects have focused, and will continue to focus, on issues of equity. Courses have concentrated on exploring employment outcomes for Temporary Assistance for Needy Families (TANF) recipients, examining the unemployment to reemployment trajectories of Unemployment Insurance (UI) claimants, and investigating employment outcomes of foster care youth. Projects completed within those courses have investigated the interaction of race, ethnicity, and gender with program outcomes such as and employment stability and earnings.

Research Questions

Through the emerging multi-state data collaboratives, state agencies are working together to identify shared agency priority questions focused on specific populations, such as historically underserved, marginalized, and adversely affected by persistent poverty and inequality. An example of work that is already underway is the following:

- How can the UI program improve service delivery for underserved and marginalized populations (e.g., race and ethnicity, age, gender, ability, geography) based on the following measures?
    - Recipiency rate;
    - Percent of applicants who receive first UI payments;
    - Certification time lapse;
    - Percent of filers in low-filing industries;
    - Claimants who exhaust UI benefits.

  Data from these measures will create more robust profiles of various claimants and challenges they may have within the UI program. One process outcome from the likelihood to file (i.e., recipiency rate) will be knowing more about claimants who do not make it to or through the front door. The profile of those claimants and their challenges may pinpoint certain processes within service delivery system that could be changed to make the filing experience easier and less complicated. Knowing the profiles of claimants who fail outside of the normal range for timely payments will also point to user or system challenges that could be changed or improved. Having robust profiles of claimants who exhaust or nearly exhaust UI benefits before reemployment also will yield valuable information about interventions for specific populations earlier in their UI journey/experience and if the profiles of claimants who have challenges are similar to claimants who exhaust benefits, it become predictive information that can be used for early Service Delivery interventions to improve user experience. It will also be highly instructive to know the sectors and occupations that have low-filing profiles. This data might point to interventions in specific industries. For instance, national research has shown that unionized workers have higher likelihoods to file for UI than non-unionized workers. We also know that workers in home healthcare, childcare, and retail and hospitality are lower wage workers who have higher financial distress profiles and could benefit tremendously if eligible and are not currently filing for UI.

Further examples of questions that the collaboratives have expressed a strong interest in exploring, or where they have already completed substantial work, include the following:

- How can we use data to support and improve connections and access to post-secondary education and training for UI claimants, and what are the associated employment and earnings outcomes, particularly for underserved and marginalized populations (e.g., race and ethnicity, age, gender, ability, geography)?
- What are the employment and earnings outcomes for post-secondary completers, by institution and major, focused on underserved and marginalized populations (e.g., race and ethnicity, age, gender, ability, geography)?
- What are the employment and earnings outcomes for public school students who enroll in alternative post-secondary programs?
- What is the value of post-secondary credential attainment for specific credentials aligned with occupations or industry sectors, and how does that look for underserved and marginalized populations (e.g., race and ethnicity, age, gender, ability, geography)?
- Who are post-secondary non-completers and what are the completion, employment, and earnings outcomes associated with alternative strategies to engage and support them in post-secondary programs, particularly for underserved and marginalized populations (e.g., race and ethnicity, age, gender, ability, geography)?
- What are the employment and earnings outcomes of registered apprenticeship and work-based learning strategies, particularly for underserved and marginalized populations (e.g., race and ethnicity, age, gender, ability, geography)?
- What are the nature and dynamics of the essential workforce (e.g., childcare workers, teachers) at the regional labor market level, including employment trajectories, and how do labor market, public policy and economic factors influence the workforce?
- What new measures of leaver wage progression for TANF recipients would be more effective for policy and practice decisions?
- How can the collaborative data-sharing ecosystem leverage cross-program and interstate social determinants of health (SDOH) data to support better service and outcomes for Medicaid customers?

4. What resources, programs, training, or other tools can expand opportunities for historically underrepresented scholars and research institutions to access and use equitable data across levels of government?

To broaden the reach of analytical capacity and data product relevance, the multi-state data collaboratives will be issuing Requests for Information (RFIs) to solicit interest from external researchers in developing data tools and products using state administrative records housed in the ADRF. This will create more streamlined and cost-effective opportunities for research institutions working with a sponsor state or states, including historically underrepresented scholars and research institutions, to access de-identified state administrative data and collaborate on data tools and products that address equity through workforce development, education and training, and other aspects of civil society. Especially for research institutions that have smaller capacity and budgets, this could be a game changer and create new and accessible entry points to participate in evidence-based policymaking activities.

As MDRC, a nonprofit, nonpartisan education and social policy research organization, has aptly described, information regarding individual workers' earnings—a critical outcome measure—is maintained in state labor or employment security agencies for the UI program. "Currently, an evaluator must obtain this data from each state agency where it is housed. Because evaluations of governmental programs take place in multiple jurisdictions, the evaluator must spend considerable resources to ascertain each state's requirements for data acquisition and then apply for the data. State statutes and administrative procedures govern access, and these procedures differ among the states. The significant costs of these data acquisition efforts are passed on to the federal agency and ultimately to taxpayers. And not all evaluators can successfully overcome the hurdles imposed by state agencies for access to the data—thereby limiting what policymakers know about program performance. The costs for the states to make the data available are also significant. While states typically charge for transmitting the data to the evaluation firm, costs associated with the negotiation for the data in the first place are likely not covered and thus are also passed on to state taxpayers."[1]

The Coleridge Institute's ADA training courses detailed in the response above can build equity among scholars, analysts, and researchers by specifically recruiting participants who identify with under-represented demographic populations. An example of this approach was the Coleridge Initiative's ADA course conducted in partnership with the United Negro College Fund and Excelencia, "Leveraging Big Data to Achieve Equity." This 2021 workshop was an effort to increase data-based research capacity among institutions of higher education that serve a large share of Black and Latinx students.

6. What resources, programs, training, or tools can make equitable data more accessible and useable for members of the public?

Working through the emerging multi-state data collaborative structure, states have developed exploratory projects into collaborative data products that are informing practice among state, local, and regional leaders. Two core collaborative data products are the Unemployment to Reemployment Portal and the Multi-State Postsecondary Report, which have been replicated and expanded upon through collaborative efforts.

Unemployment to Reemployment Portal

Created by the State of Illinois, this interactive tool draws in weekly de-identified UI claims data, processed through the Coleridge Initiative's secure ADRF environment, and allowed participating states to identify which local labor markets and equity groups were hit the hardest by COVID-19 induced

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[1] "Improving Access to Federal Data for More Efficient Evaluations," Testimony of Gordon L. Berlin, President, MDRC, Before the Human Resources Subcommittee of the House Ways and Means Committee, March 20, 2012 (https://www.mdrc.org/publication/improving-access-federal-data-more-efficient-evaluations).

layoffs, analyze the overall economic impact on those local economies, and document the recovery paths for these markets and groups.

The Unemployment to Reemployment Portal has been replicated by the states of Indiana and Tennessee. The states of Texas and Ohio created UI data tools inspired by the Illinois tool. Planned expansions include the states of Wisconsin and Arkansas. Illinois is currently enhancing the portal to generate timely measures of reemployment activity.

Multi-State Postsecondary Report

Developed by the Kentucky Center for Statistics, the Multi-state Postsecondary Report is dynamic tool that connects postsecondary graduates with in-state and out-of-state employment outcomes. Users can explore the connection between employment outcomes associated with credential level, major earned, and state origin. The Multi-state Postsecondary Report empowers states to better understand the employment outcomes of individuals who participated in their state's education programs. Currently, the states of Kentucky and Ohio contribute data to the Multi-state Postsecondary Report.

Plans are underway to add data from Indiana and Tennessee. The states of New Jersey, Rhode Island, and Virginia recently received a Democratizing our Data Challenge grant through the Coleridge Initiative to bring the Multi-state Postsecondary Report to the Eastern States Longitudinal Data Collaborative. The state of Ohio also received a Democratizing our Data Challenge grant to incorporate workforce credentials and data on postsecondary "non-completers" into the dashboard.

On the Horizon – New and Emerging Projects, Products and Priorities

- Illinois and Missouri – Study of turnover in the early childcare and education workforce
- New Jersey – Developing a K-12 data model for the ADRF
- Indiana – "Return on Credential Investment" app
- Southern Regional Data Collaborative – Recently established four working groups to focus their efforts in developing collaborative projects and products. The four priority topics, which they are viewing through an equity lens enhanced by equity data, are:
    - What is the value of post-secondary credential attainment for specific credentials aligned with occupations or industry sectors?
    - Who are post-secondary non-completers and what are the completion, employment, and earnings outcomes associated with alternative strategies to engage and support them in post-secondary programs?
    - How can we use data to support and improve connections and access to post-secondary education and training for UI claimants and what are the associated employment and earnings outcomes?
    - How can we refine the Unemployment to Reemployment Portal to create additional timely measures of UI program participation and claimant and employer labor market activity?

Sincerely,

Midwest Data Collaborative (MWC):

[redacted]

George Putnam, Chair, MWC Interim Executive Committee, and

LMI Director, Illinois Department of Employment Security

[redacted]

Anna Hui, Member, Interim Executive Committee, MWC, and

Director of the Missouri Department of Labor and Industrial Relations

____

Coretta Pettway, Interim Executive Committee, MWC, and

Assistant Deputy Director, Ohio Department of Job and Family Services

Southern Region Data Collaborative (SRDC):

[redacted] tee, and

Executive Director, Kentucky Center for Statistics (KYSTATS)

Eastern States Longitudinal Data Collaborative (ESLDC):

[redacted]

Dana Brandt, Chair, ESLDC Interim Executive Committee, and

Director, DataSpark, University of Rhode Island

WELCOMING AMERICA

NSTC Subcommittee on Equitable Data
Office of Science and Technology Policy
Eisenhower Executive Office Building
[redacted] Washington, DC 20504

Re: Comment in Response to the RFI from The White House Office of Science and Technology Policy (OSTP), on behalf of the Subcommittee on Equitable Data of the National Science and Technology Council.

To whom it may concern:

Welcoming America issues the Comment in Response to the request for information issued by The White House Office of Science and Technology Policy (OSTP), on behalf of the Subcommittee on Equitable Data of the National Science and Technology Council on how Federal agencies can better support collaboration with other levels of government, civil society, and the research community around the production and use of equitable data.

Welcoming America is a nonprofit that supports communities in building a welcoming society where every person, including immigrants, can fully contribute to and shape our shared prosperity. Our network encompasses more than 300 local government and nonprofit members in 47 states, working through public-private partnerships to advance inclusion and equity for people with migrant backgrounds. We commend the agency for seeking stakeholder input and seeking to build longer-term partnerships with states and localities and know that our membership of government Offices of Racial Equity and New Americans, and community-based coalitions, welcome the opportunity to engage over the long term, as we have with numerous federal agencies on issues of access, opportunity and equity among underserved communities.

The Equitable Data Working Group emphasized the need for the Federal government to use equitable data to (1) encourage diverse collaborations across levels of government, civil society, and the research community and (2) be accountable to the American public and Welcoming America strongly agrees with these assertions. Our members and local city and county jurisdictions often need data that supports commitment to policies and programs of inclusion and would be better able to trust federal data if they knew more equitable practices were in place. They would also be able to better advocate for specific groups of underserved and under-represented populations if data could be and was on a regular basis aggregated in ways that supported targeted programs.

Welcoming America is not a think tank but works directly with communities, therefore we would like to address the following questions referenced in the RFI.

What resources, programs, training, or other tools *can facilitate increased data sharing between different levels of government (Tribal, territorial, local, State, or Federal) related to equitable data*?

We strongly believe that activating the Task Force on New Americans which was laid out via the Executive Order on Legal Immigration to help "ensure that our laws and policies encourage full participation by immigrants, including refugees" is one way to facilitate data sharing. Critical data on the needs and assets of our immigrant communities is siloed in specific agencies and that failure to share that data stifles creative and innovative approaches to programming, as well as access to critical services like language and workforce development. We also believe an active and robust Task Force on New Americans is an essential component of the administration's broader goals of advancing racial equity and reducing undue burdens for Americans to access critical government services.

Within the jurisdiction of the agency, we urge a specific focus on underserved populations reflected among immigrant communities where data may be difficult to identify because of fears related to status or the challenges of disaggregating data to discern between native-born and immigrant Black populations, for example.

Trusted intermediaries like Welcoming America can serve as a resource to the agency in identifying such opportunities and gaps.

What resources, programs, training, or tools *can increase opportunities for community-based organizations to use equitable data to hold the government accountable to the American public*?

Welcoming America serves as a link to numerous community-based organizations and would welcome the opportunity to support capacity building and linkages. Many community-based organizations are unaware of existing resources or the appropriate channels to utilize data for accountability, and this is particularly the case among organizations representing and serving immigrant populations.

Communities that support immigrant civic leadership through programs like "natural helpers" are perfectly poised to act as the link between governmental agencies and community partners. These programs are also very well positioned to be engaged stakeholders and support the kinds of accountability that will make data more useful and accessible to communities.

Thank you for your consideration,

Welcoming America

To: Denice Ross, U.S. Chief Data Scientist
White House Office of Science and Technology Policy (OSTP)

From: Jennifer Erickson, Senior Fellow
Federation of American Scientists (FAS)

Date: October 3rd, 2022

I am writing as a Senior Fellow at the Federation of American Scientists about the urgent need to save more lives and address equity through the opening of data related to organ donation, procurement, and transplant.

Thirty-three Americans - disproportionately people of color - die each day for lack of an available organ transplant. People of color are more likely to need organ transplants, and less likely to receive them. COVID damages organs, both exacerbating the need for transplants, and existing inequities - leading three Congressional Committees to call reform of federal organ donation contractors an "urgent health equity issue." This puts organ donation reform squarely within the Biden-Harris administrations key priorities, related to both Executive Orders for Equity and Equitable COVID response.

Organ donation is managed by 58 federal monopoly contractors - both the national contractor overseeing the system as the organ procurement transplantation network (OPTN, current contractor the United Network for Organ Sharing, UNOS) and 57 organ procurement organizations (OPOs).

These 58 monopolies have never once faced competition for their contracts, and the results have been deadly. According to an August 2022 bipartisan report from the Senate Finance Committee "[f]rom the top down, the U.S. transplant network is not working, putting Americans' lives at risk."

UNOS's failures have been documented by the Senate Finance Committee and investigative reporting, including two front page stories in the Washington Post in August 2022 - one related to antiquated technology and another to deadly patient safety issues being ignored. And OPO failures are no longer a matter of debate: the Centers for Medicare and Medicaid Services (CMS) has classified the majority of OPOs as failing to meet tier one performance standards, leading to thousands of unnecessary deaths each year.

The result of these contractor failures lead to as few as one in five organ donors being recovered. And of kidneys recovered from generous American organ donors, one in four are thrown in the trash, often due to basic UNOS and OPO errors.

Put simply, if we had a fully efficient system, there would be no waiting list in America for heart, lungs, or livers, and the kidney waiting list would be dramatically reduced.

A key driver for why UNOS and too many OPOs have been able to fail for so long is opacity of data. Opening OPTN and OPO data immediately so that the government - and the public - can see evidence of effective and equitable performance is critical. Opening such data would put the United States in line with international standards, and would fuel the necessary oversight and accountability that will save lives and address equity. Consider research showing that OPOs are only 50% as likely to turn up for a case involving a Black donor versus a white donor.

Disparities of treatment (e.g., by race/ethnicity and by urban/rural status) must be public, and must be urgently addressed - including through replacing failing contractors with competent ones who will serve their entire constituencies.

Answers to specific RFI questions follow. I am happy to answer any questions, and firmly believe that organ donation disparities are as outrageous as they are fixable: the federal government simply has to open and follow the data to save more lives.

Jennifer Erickson
Senior Fellow, FAS

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4. What resources, programs, training, or other tools can expand opportunities for historically underrepresented scholars and research institutions to access and use equitable data across levels of government ?

Currently, some of the most valuable research is simply not possible due to data opacity from UNOS and OPOs. For UNOS, too often data that should be available are not and where data are available, they are made available only to favored researchers. (Forbes in 1999 referred to UNOS as a "cartel" - and the situation has only devolved since.)

Additionally, OPOs are required by CMS to collect process data (e.g., information about referrals received, approaches to next of kin made, etc - see CFR § 486.328), however - bizarrely - are not required to share such data with CMS or the public.

Simply put: CMS must require OPO process data to be shared with CMS and made publicly available for evidence of effective and equitable performance.

This is unquestionably possible. In fact, FAS is engaged with a collaboration with the Massachusetts Institute of Technology (MIT) and pro-reform, pro-transparency OPOs committed to accountability and equity. OPOs have transferred their data to MIT, which is de-identifying the data and will make these data available via a public dataset this year - proving this is possible for all OPOs. The critical point is this should not be optional - rather, required of all OPOs, as federal contractors engaged in a life-and-death public service funded by taxpayers.

Supporters of organ donation open data include leaders of the Senate Finance Committee, the House Oversight Committee, the ACLU, public health physicians, leading data scientists, alumni of the previous four administrations (Clinton, Bush, Obama, and Trump), all five past Chief Technology Officers of the Department of Health and Human Services (HHS), the National Kidney Foundation, the American Society of Nephrology, Organize, and the Global Liver Institute.

5. What resources, programs, training, or tools can increase opportunities for community-based organizations to use equitable data to hold government accountable to the American public ?

6. What resources, programs, training, or tools can make equitable data more accessible and useable for members of the public?

Answer to questions 5 & 6

Once critical OPTN and OPO data are open, the government (including HRSA and CMS, ideally aided by USDS and OSTP) should take care to make sure these data are useable by all stakeholders.

For example, to see OPO performance, a member of the public would now have to go the Quality, Certification, Oversights, and Report page of CMS, click on the OPO Public Performance Report on the left, and then access a locked excel spreadsheet - navigating acronyms across and multiple tabs to see the simple information about whether an OPO was passing or failing.

What's more, no data are made available by CMS to show equitable performance - for example, procurement rates by OPO by race/ethnicity. External researchers did that analysis, and published it in Axios, with shocking results.

There is massive unexplained variability in organ recovery across the country. While overall organ recovery varies by 4-fold (which is already alarming), when looking at variability of recovery of donors by race the results are an 8-fold variability of recovery of Asian donors, a 10-fold variability of OPO recovery of Black organ donors, and a 13-fold variability of Hispanic donors across the country. Because same ethnicity matches are more likely in transplant, these disparities absolutely harm patients of color on the organ waiting list (as well as showing a callous disregard for donor families).

FAS and Organize engaged alumni of USDS at BloomWorks to visualize these results - see here for overall OPO performance, here for disparities in recovery of Black donors, and here for an example of state OPO data visualization (California) and here for an example of a single OPO data visualization (OneLegacy, the Los Angeles-based OPO).

7. In which agencies, programs, regions, or communities are there unmet needs, broken processes, or problems related to participation and accountability that could be remedied through stronger collaborations and transparency around equitable data?

HRSA oversees the OPTN contract/contractor. CMS is responsible for OPOs. Two ongoing Congressional investigations (Senate Finance and House Oversight) have laid bare the dire consequences of opacity and lack of accountability at both UNOS (the OPTN contractor) and OPOs (the majority of which are failing CMS tier 1 performance standards).

Therefore it is critical for HRSA and CMS to open OPTN and OPO data along the lines mentioned above in an accessible way to show evidence of equitable and effective performance from the nation's own federal organ contractors.

Epidemiology and Infection

cambridge.org/hyg

Original Paper

Cite this article: Rivera R, Rosenbaum JE, Quispe W (2020). Excess mortality in the United States during the first three months of the COVID-19 pandemic. *Epidemiology and Infection* **148**, e264, 1–9. https://doi.org/10.1017/S0950268820002617

Received: 19 June 2020
Revised: 21 October 2020
Accepted: 27 October 2020

Key words:
COVID-19; epidemiology; excess deaths; infectious disease; natural disasters

CI: confidence intervals; COVID-19: Coronavirus Disease 2019; ED: emergency department; ILI: Influenza-like Illness; MSS: Mortality Surveillance System; NCHS: National Center for Health Statistics; NSSP: National Syndromic Surveillance Program; NYC: New York City; PCR: Polymerase chain reaction; SARS-CoV-2: Severe Acute Respiratory Syndrome Coronavirus 2; US: United States

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Excess mortality in the United States during the first three months of the COVID-19 pandemic

R. Rivera[1], J. E. Rosenbaum[2] and W. Quispe[1]

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Abstract

Deaths are frequently under-estimated during emergencies, times when accurate mortality estimates are crucial for emergency response. This study estimates excess all-cause, pneumonia and influenza mortality during the coronavirus disease 2019 (COVID-19) pandemic using the 11 September 2020 release of weekly mortality data from the United States (U.S.) Mortality Surveillance System (MSS) from 27 September 2015 to 9 May 2020, using semiparametric and conventional time-series models in 13 states with high reported COVID-19 deaths and apparently complete mortality data: California, Colorado, Connecticut, Florida, Illinois, Indiana, Louisiana, Massachusetts, Michigan, New Jersey, New York, Pennsylvania and Washington. We estimated greater excess mortality than official COVID-19 mortality in the U.S. (excess mortality 95% confidence interval (CI) 100 013–127 501 *vs.* 78 834 COVID-19 deaths) and 9 states: California (excess mortality 95% CI 3338–6344) *vs.* 2849 COVID-19 deaths); Connecticut (excess mortality 95% CI 3095–3952) *vs.* 2932 COVID-19 deaths); Illinois (95% CI 4646–6111) *vs.* 3525 COVID-19 deaths); Louisiana (excess mortality 95% CI 2341–3183 *vs.* 2267 COVID-19 deaths); Massachusetts (95% CI 5562–7201 *vs.* 5050 COVID-19 deaths); New Jersey (95% CI 13 170–16 058 *vs.* 10 465 COVID-19 deaths); New York (95% CI 32 538–39 960 *vs.* 26 584 COVID-19 deaths); and Pennsylvania (95% CI 5125–6560 *vs.* 3793 COVID-19 deaths). Conventional model results were consistent with semiparametric results but less precise. Significant excess pneumonia deaths were also found for all locations and we estimated hundreds of excess influenza deaths in New York. We find that official COVID-19 mortality substantially understates actual mortality, excess deaths cannot be explained entirely by official COVID-19 death counts. Mortality reporting lags appeared to worsen during the pandemic, when timeliness in surveillance systems was most crucial for improving pandemic response.

Introduction

The number of Coronavirus Disease 2019 (COVID-19) deaths may be under-reported, and COVID-19 may be indirectly responsible for additional deaths. The Centers for Disease Control and Prevention issues guidelines to determine cause of deaths, but underestimating the death toll of natural disasters, heatwaves, influenza and other emergencies is common. In some cases, the underestimates can be extreme: chikungunya was officially associated with only 31 deaths during a 2014–2015 epidemic in Puerto Rico, but time-series analysis estimated excess mortality of 1310 deaths [1]. Hurricane Maria's mortality was officially only 64 deaths, but a 95% confidence interval for estimated excess mortality was between 1069 and 1568[2]. Deaths directly due to the COVID-19 pandemic may be underestimated due to under-diagnosis [3], insufficient postmortem severe acute respiratory syndrome coronavirus 2 (SARS-CoV-2) tests, not seeking healthcare [4] and ascertainment bias. Deaths indirectly due to an emergency are also common, due to an overloaded health system [5] or lack of healthcare access for routine care: during the 2014 West Africa Ebola epidemic, lack of routine care for malaria, HIV/AIDS and tuberculosis led to an estimated 10 600 additional deaths in the area [6]. Health emergencies may also lead to indirect deaths from economic, social and emotional stress [7] and crowded emergency departments [8].

In this study, we estimate excess all-cause, pneumonia and influenza mortality during the COVID-19 pandemic, which includes deaths both directly and indirectly related to COVID-19. Directly related COVID-19 deaths include deaths in patients who have undetected SARS-CoV-2 due to false-negative tests [9] not seeking healthcare [4], or being turned away from the emergency department due to emergency department crowding [8]. Testing and forensic staff shortfalls lead to lack of postmortem testing. Indirect deaths are deaths not due to COVID-19 and may include deaths among patients due to emergency department crowding [8]; avoidance of hospitals due to fear of the virus; or avoidance of healthcare due to the accompanying economic recession, such as loss of employment or income, or loss of health insurance coverage [10].

Methods

Data and measures

Weekly all-cause, pneumonia and influenza mortality for each state from 27 September 2015 (week 40) to 9 May 2020 (week 19) were obtained from the National Center for Health Statistics (NCHS) Mortality Surveillance System (MSS) data release on 11 September 2020. The MSS presents weekly death certificate counts, without regard to whether deaths were classified as related to COVID-19. Based on ICD-10 multiple cause of death codes, pneumonia and influenza deaths were also made available. The timeliness in death certificate reporting varies by region, state and cause of death [11]. We use pneumonia and influenza mortalities because COVID-19 deaths could be misclassified as pneumonia or influenza. The NCHS divides New York State into two jurisdictions: New York City (NYC) and non-NYC New York State, and we leave them separate for plots and combine them for statistical models.

We identified 13 jurisdictions within this data that had high numbers of reported COVID-19 deaths through 9 May 2020. The states were: California, Colorado, Connecticut, Florida, Illinois, Indiana, Louisiana, Massachusetts, Michigan, New Jersey, New York, Pennsylvania and Washington.

Population estimates were from Vintage 2019 Census yearly estimates for 1 July of each year 2010–2019, which were used to obtain weekly population estimates [12].

We obtained COVID-19 mortality counts through 9 May 2020 from the COVID-19 Tracking Project, the New York Times and the Centers for Disease Control Provisional Deaths. Usually, CDC provisional counts were the highest estimate [13–15]. These three mortality counts differ, so we used the higher number in all cases to be conservative with respect to the null hypothesis that excess mortality can be explained entirely by official COVID-19 death counts: that is, the lower bound of excess mortality is below official COVID-19 deaths. To assess whether the COVID-19 pandemic was associated with reduced emergency department (ED) utilisation not for COVID-19, we identified 3 of the United States top 5 causes of death that present with acute symptoms that require immediate treatment, for which the choice not to seek healthcare may result in death: heart disease, chronic lower respiratory diseases and cerebrovascular disease. Among the 59 National Syndromic Surveillance Program (NSSP) jurisdictions, we were only able to obtain daily ED visits in New York City for asthma symptoms. We obtained daily counts of asthma ED visits, age group (5–17, 18–64, 65+), borough and date from the New York City Department of Health and Mental Hygiene's EpiQuery website from 1 January 2016 to 9 May 2020. This study is an analysis of publicly available data in broad categories such that individuals cannot be identified, so it is not human subjects research and is exempt from requiring human subjects board review.

Statistical analysis

We construct two models to capture the temporal behaviour of death certificate data to estimate excess mortality during the COVID-19 pandemic: a semiparametric model and a conventional model estimating the difference in current death totals starting from the beginning of the pandemic and the projected deaths under normal conditions [16]. In what follows, we briefly describe each excess deaths model. See Appendix for further details.

Semiparametric model

We use a semiparametric model to capture the temporal behaviour of mortality while measuring how the pandemic alters the 'normal' mortality pattern. This model was successfully deployed to estimate excess deaths due to Hurricane Maria in Puerto Rico [2].

Specifically, we define a general additive model with the following covariates: the natural logarithm of population as an offset, a smooth function of week of the year, year category and a binary variable coded as 1 for dates on or after the start of the pandemic and 0 prior to the starting point; its coefficient presents the possibility that the mean death rate has changed after the start of the pandemic at some location. The week of the year is modelled non-parametrically with a penalised cyclic cubic regression spline function to capture seasonal mortality variations [15]. Preliminary analysis indicated overdispersion, so we used a quasi-Poisson model to estimate the dispersion parameter [17]. We estimated coefficients by a penalised likelihood maximisation approach, where the smoothing penalty parameters are determined by restricted maximum likelihood. The residuals of the fitted model did not present remaining temporal dependence.

To estimate cumulative excess deaths, we sum the coefficients of the indicator for the start of the pandemic. Approximate simulations from the Bayesian posterior density are performed to obtain 95% credibility intervals, which we refer to as confidence intervals throughout.

For each state, we determine excess deaths due to the COVID-19 pandemic from a starting point through 9 May, the date of the most recent complete mortality data at the time of our analysis. The starting point was the date after the most recent inflection point in all-cause mortality, suggesting the onset of the COVID-19 pandemic, chosen to balance concerns of deaths prior to the official first cases and the sensitivity of the model to detect small excess mortality in the limited available data, exacerbated by the provisional counts being lower than actual deaths: 29 February for Washington state, 28 March for Florida, Indiana and Massachusetts and 21 March for the remaining 9 states and for the United States as a whole. This semiparametric model can incorporate population displacement [2], but we are not aware of significant displacement during the pandemic. Specifically, New York City was uniquely affected during this first wave of infections, with a public perception of widespread community infections acquired in a crowded metropolitan area that relies on public transportation. Analysis of data from smart phones finds that about 400 000 New York City residents, 5% of the population of New York City, left the city between 1 March and 1 May 2020, and departures were characterised by substantial wealth and race disparities [18]. NYC residents dispersed to locations around the country, with most locations receiving less than 4000 people from this total, a negligible addition (<1%) to the state populations; locations receiving more than 4000 people included non-NYC New York State, Pennsylvania, New Jersey, Connecticut and Florida [18].

A conventional excess deaths analysis

We also estimate excess mortality using a conventional excess mortality method: we fit a quasi-Poisson semiparametric model as above until 1 February 2020. The deaths from 8 February 2020 forward should follow a Poisson distribution with some expected rate; the maximum-likelihood estimator of such rate is the mean weekly deaths during this period. Weekly deaths are

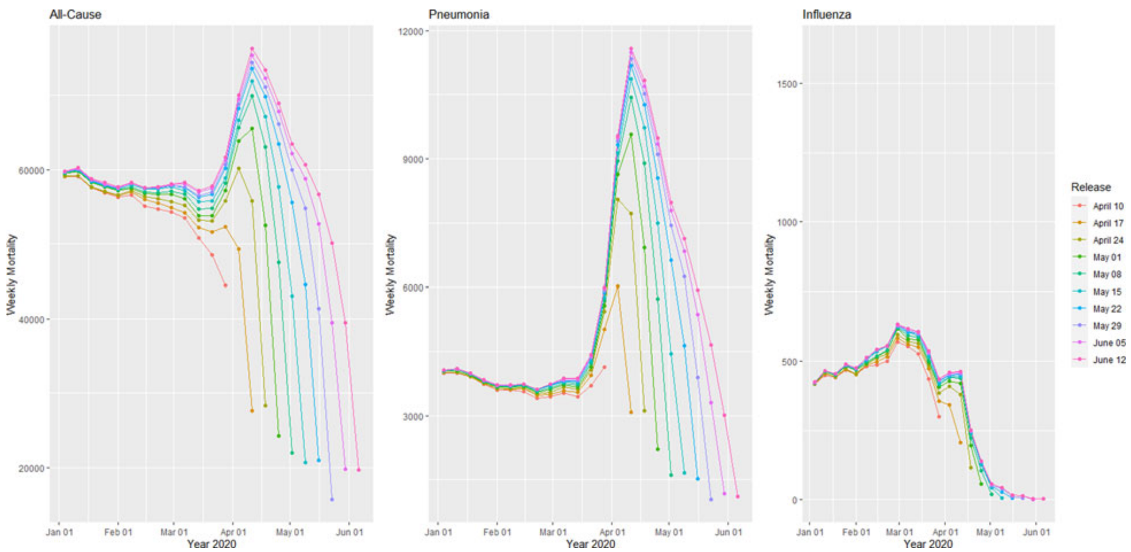

Fig. 1. Provisional weekly all-cause, pneumonia and influenza mortality counts for the United States from weekly data releases 10 April–12 June 2020.

approximately normally distributed with a variance that accounts for overdispersion according to the scale parameter in the fitted model. From this distribution, we simulate 10 000 weekly deaths and subtract the results from the posterior distributions of the fitted results. The 95% confidence interval is the range between the 2.5% and 97.5% percentiles of all excess deaths.

The models were fit using version 1.8-28 of the *mgcv* package in R 4.0.2 [19, 20]. All code and data have been made publicly available (https://github.com/bakuninpr/COVID-Excess-Deaths-US). The statistical analyses were conducted between April and September 2020.

Assessing reduction in emergency department utilisation

To evaluate whether there was a reduction in emergency department visits during the period from 21 March to 9 May, we fit a quasi-Poisson regression model for daily number of asthma-related emergency department visits in New York City syndromic surveillance data, controlling for borough, age group and date, with a binary variable for date after 21 March 2020; this model estimated a dispersion parameter of 1.95.

Results

Provisional death counts increase with each data release, especially for recent weeks. The variation on reporting timeliness by state hinders excess death assessment for the United States. Figure 1 shows all-cause mortality counts for successive data releases. Successive releases of weekly mortality counts 'blanket' each previous release, with gaps between the lines representing differences in each data release. During the pandemic, large gaps between successive data releases during periods of higher deaths suggests that mortality reporting lags are larger during periods of elevated deaths: the discrepancy between the number of all-cause deaths for the last week of the 1 April data release and the corresponding entry of the 12 June release is 18%. In contrast, the discrepancy between the number of all-cause deaths for the last week of the 29 May data release and the corresponding entry of the 12 June release is 75%. The effects on mortality of the COVID-19 pandemic is clearly seen in Figure 2, although the effect has substantial local variation. All states have excess pneumonia mortality (Fig. 3), and New York City shows hundreds of excess influenza deaths over several weeks (Fig. 4).

In the United States, we observe greater all-cause and pneumonia deaths (Fig. 5). Using the semiparametric model, between 21 March 2020 and 9 May 2020 we are 95% confident that all-cause excess deaths in the United States were between 100 013 and 127 501, compared with 78 834 reported COVID-19 deaths, which is at least 21 179 more deaths than official COVID-19 deaths for the same time period. Pneumonia excess deaths were between 40 066 and 47 391. Using the conventional method, we found a 95% confidence interval of 106 940 and 143 478 for all-cause excess deaths in the United States, and 41 613 and 47 841 for pneumonia deaths.

For each state Table 1 presents 95% confidence intervals for all-cause, pneumonia and influenza excess deaths. We estimated greater excess mortality than COVID-19 deaths in 10 of 13 states: Florida, Indiana and Washington present significant all-cause excess mortality but there was no evidence of them exceeding official COVID-19 death counts. However, relative to expected numbers of pneumonia and influenza deaths, we observe excess pneumonia deaths in all states studied, and excess influenza deaths in New York while excess influenza deaths in New Jersey are less clear (Table 1). We evaluated influenza mortality in the District of Columbia, the other urban-only area, but influenza deaths were not higher than usual (not shown), in contrast to New York City.

With the conventional model, we estimate more excess all-cause deaths than reported COVID-19 cases except in Colorado, Florida, Indiana and Washington (Table 1); and once more excess pneumonia deaths are observed for all states. These results are also consistent with the excess mortality results for the earlier data release covering through 9 May 2020 (not shown).

The results of the semiparametric and conventional models are generally compatible. But since our conventional model also reflects random fluctuations in mortality, prediction intervals

Fig. 2. Weekly all-cause mortality grouped by year and state starting on week 40 of 2015 until 9 May 2020.

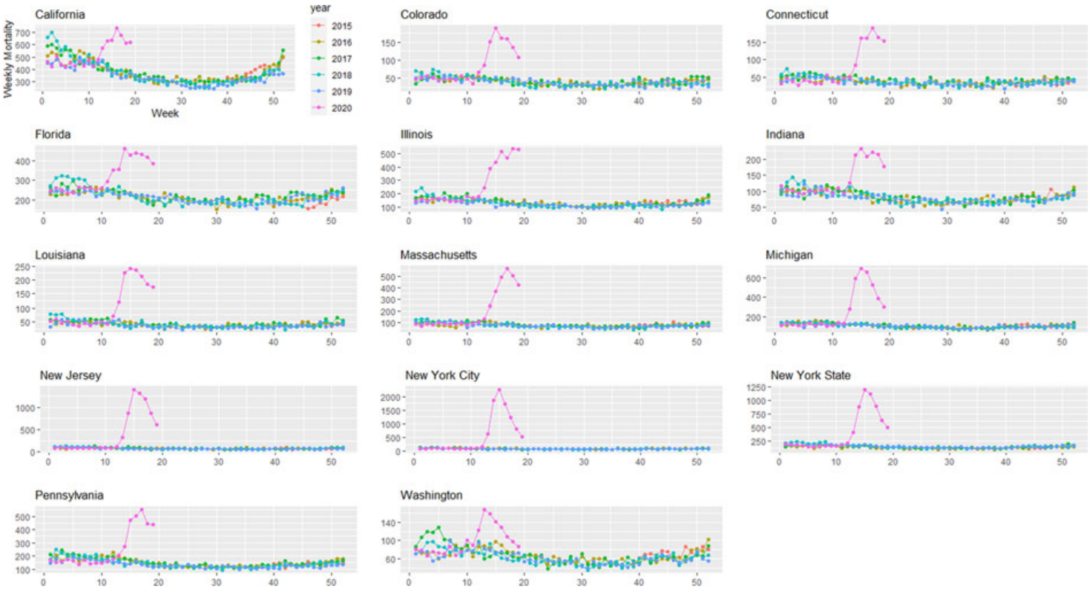

Fig. 3. Weekly pneumonia mortality grouped by year and state starting on week 40 of 2015 until 9 May 2020.

are obtained, which naturally present larger variation than confidence intervals. Treating the deaths as fixed [16] would lead to intervals that are misleadingly short on width. The larger uncertainty in the conventional model makes it harder to interpret excess deaths.

Using the quasi-Poisson model with the outcome daily emergency department visits for asthma syndrome in NYC, we found that during this period, asthma visits were 64% lower than expected, a substantial drop (IRR = 0.36, 95% CI 0.34–0.37).

Discussion

We find substantial excess all-cause mortality that exceeds the number of documented COVID-19 deaths in most of the 13 states evaluated: California, Colorado, Connecticut, Illinois, Louisiana, Massachusetts, Michigan, New Jersey, New York and Pennsylvania. Up until 9 May, we estimate over 100 000 excess deaths in the U.S. due to the COVID-19 pandemic. Mortality underestimation may reduce the public's willingness to adhere to costly and stressful non-pharmaceutical interventions, such as governors' orders to stay at home, wear masks and engage in social distancing.

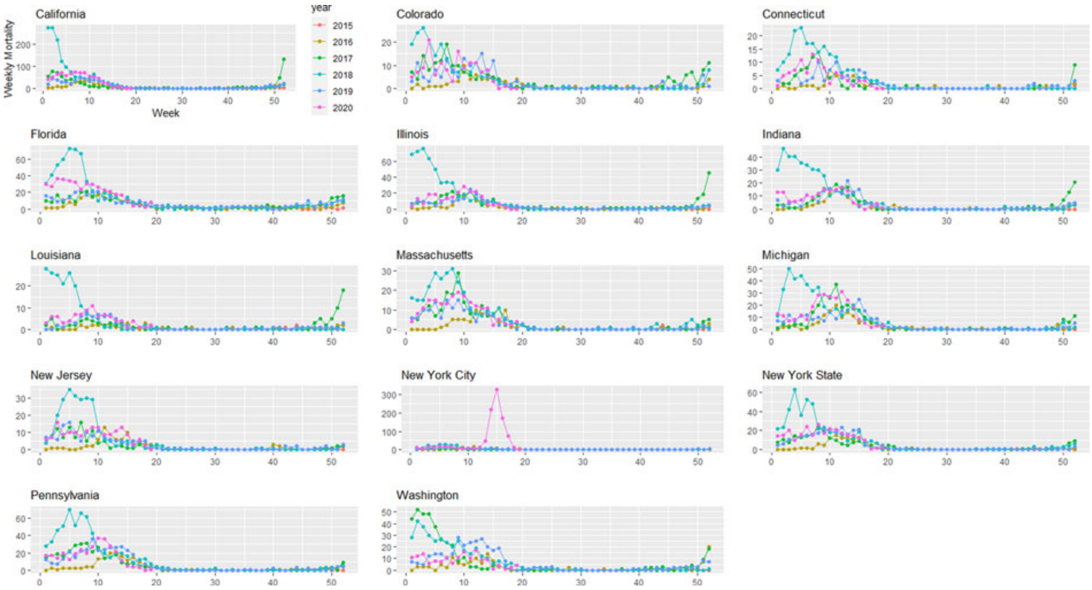

Fig. 4. Weekly influenza mortality grouped by year and state starting on week 40 of 2015 until 9 May 2020.

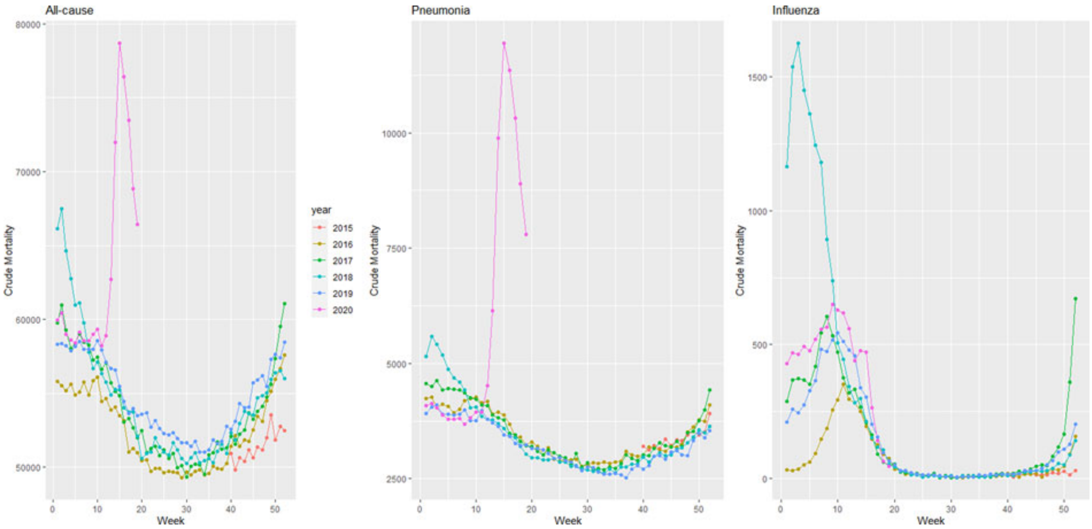

Fig. 5. Weekly mortality in the United States by year starting on week 40 of 2015 until 9 May 2020.

Mechanisms for excess mortality

The CDC has established guidelines for certifying COVID-19 deaths [21] and whether to collect postmortem specimens for SARS-CoV-2 testing [22]. We propose the following potential mechanisms for underestimation of pandemic death toll: underdiagnosis of COVID-19 due to low availability of SARS-CoV-2 tests; indirect deaths from not seeking care for emergent non-COVID-19 conditions; not seeking care for what appeared to be non-severe COVID-19 and then experiencing sudden declines characteristic of COVID-19; or needing treatment for COVID-19 or other ailments and being turned away from emergency departments due to crowding, and subjective interpretations of guidelines. COVID-19 test access has been quantified as the percent of SARS-CoV-2 polymerase chain reaction (PCR) tests that are positive; the percent of PCR tests that are positive decreased during this period, suggesting increased test access [23]. However, substantial heterogeneity in test availability across states [13] means that excess mortality may not decrease substantially unless test availability increases in high-prevalence states.

Some excess mortality may include indirect deaths from emergent non-COVID-19 conditions due to delaying healthcare, due to fear of becoming infected with SARS-CoV-2 during the

Table 1. Excess all-cause, pneumonia and influenza mortality 95% confidence intervals from 2 models, from states with the largest reported COVID-19 mortality data as of 9 May 2020, and with official COVID-19 toll

		COVID-19	All-cause excess deaths		Pneumonia excess deaths		Influenza excess deaths	
Jurisdiction	Start date	Deaths	Semiparametric	Conventional	Semiparametric	Conventional	Semiparametric	Conventional
California	21 March 2020	2849	(3338, 6344)	(3638, 9058)	(1729, 2370)	(1969, 2900)	(−75, 52)	(120, 359)
Colorado	21 March 2020	1130	(1175, 1730)	(960, 1882)	(620, 803)	(557, 807)	(−26, 15)	(−61, 36)
Connecticut	21 March 2020	2932	(3095, 3952)	(3092, 4008)	(651, 844)	(638, 864)	(−20, 5)	(−63, 18)
Florida	28 March 2020	1840	(1271, 2856)	(392, 3934)	(1100, 1439)	(1373, 1966)	(−39, 21)	(−200, 7)
Illinois	21 March 2020	3525	(4646, 6111)	(5111, 7357)	(1974, 2422)	(2088, 2566)	(−20, 44)	(8, 129)
Indiana	28 March 2020	1490	(1400, 2078)	(1198, 2613)	(679, 882)	(588, 941)	(−28, 14)	(−60, 66)
Louisiana	21 March 2020	2267	(2341, 3183)	(2522, 3834)	(1042, 1263)	(970, 1288)	(−3, 27)	(14, 68)
Massachusetts	28 March 2020	5050	(5562, 7201)	(5516, 7152)	(2044, 2456)	(2012, 2439)	(−100, 39)	(−111, 34)
Michigan	21 March 2020	5036	(5581, 7171)	(5514, 7474)	(2386, 2926)	(2458, 2910)	(−52, 28)	(−36, 138)
New Jersey	21 March 2020	10465	(13 170, 16 058)	(13 834, 15 567)	(5550, 6539)	(5879, 6375)	(2, 46)	(−46, 61)
New York	21 March 2020	26584	(32 538, 39 960)	(35 632, 38 802)	(12 016, 14 310)	(12 860, 13 623)	(694, 911)	(640, 930)
Pennsylvania	21 March 2020	3793	(5125, 6560)	(4653, 6809)	(1757, 2135)	(1686, 2135)	(−65, −8)	(−96, 90)
Washington	29 February 2020	925	(559, 1633)	(421, 1796)	(358, 623)	(359, 674)	(−3,72)	(−20, 78)
United States	21 March 2020	73834	(100 013, 127 501)	(106 940, 143 478)	(40 066, 47 391)	(41 613, 47 841)	(15, 1385)	(−33, 2896)

All data used included mortality until 9 May 2020 included in the 4 September 2020 data release.
The semiparametric method uses a starting date, but the conventional method does not.
The table presents prediction intervals using the conventional method, although we refer to confidence intervals throughout for consistency.

COVID-19 pandemic. Other research suggests that patients with heart attacks and stroke delayed seeking care due to the COVID-19 pandemic [24]. Our research suggests some deaths could include deaths from chronic lower respiratory diseases, such as deaths due to not seeking care for asthma syndrome. In this research study, we were not able to access emergency department visit data for acute coronary syndromes, only asthma syndrome ED visits in NYC. When the complete 2020 mortality data are released, we would expect more deaths at home coded as chronic lower respiratory diseases, cardiovascular disease and cerebrovascular diseases than usual; normally, these are three of the top five causes of death in the US, so reduced care-seeking could contribute substantially to excess mortality [25].

Patients who suspect COVID-19 may not seek healthcare or may be turned away from emergency departments: these patients would not have SARS CoV-2 test results, so they would not be coded as COVID-19 deaths. Many patients with influenza-like illness (ILI) never seek healthcare, including patients likely to have severe effects: about 45% of patients with heart disease and 52% with COPD delay at least 3 days [26], and during a flu pandemic care-seeking increases by only about 10 percentage points [4]. Dyspnoea/breathlessness predicts healthcare seeking for ILIs [27]. However, most severe or fatal COVID-19 cases do not present with dyspnoea [28], and lung damage can be substantial even without dyspnoea [29]. Sudden health declines have been observed in COVID-19 inpatient populations: patients decline in minutes from ambulatory/conversant to unresponsive and requiring resuscitation [30], and such sudden health declines could also occur in outpatient populations.

Some but not all of the excess COVID-19 mortality is captured by pneumonia excess mortality, but some sudden deaths seem to occur among patients without apparent pneumonia [31]. These deaths may be due to cardiac injury [32], kidney or liver injury [33], or hypercoagulability [34]. Further, our results suggest that excess deaths for cardiovascular, cerebrovascular, kidney or liver failure without coding for COVID-19 may be apparent when these data become available.

Advantages of the semiparametric model

The CDC estimates and publishes excess mortality counts during the COVID-19 pandemic, but without quantifying uncertainty like our methods do. It can be shown that under a mixed model representation, the semiparametric model estimates are the best linear unbiased predictors [35]. Moreover, the intervals from our two methods always overlap. Yet the semiparametric method yields more precise confidence intervals than a conventional approach, which must estimate prediction intervals. Prediction intervals are wider than confidence intervals because they account for uncertainty in post-pandemic deaths. That is, for week 19 of 2020, the conventional model estimates excess deaths as the difference between the observed deaths, and what pre-pandemic projected forward model expects the number of deaths to be. Those observed deaths in week 19 are subject to random variation in mortality which the interval must account for. In contrast, the semiparametric model estimates excess deaths as the difference of two expected values: expected mortality with a pandemic period indicator and expected mortality without a pandemic period indicator. Intervals of parameters are always narrower than for random variables. Wider intervals hinder interpretation of excess deaths, so we focus on the results from the semiparametric model. The semiparametric model is also less affected by under-reporting during the pre-pandemic period than the conventional approach.

Misclassification of excess deaths

We quantify higher pneumonia mortality than expected in all 13 states and higher influenza deaths primarily in New York. For New Jersey, even when adjusting for COVID-19 official deaths, pneumonia and influenza mortality, excess deaths are still significant, which raises two potential explanations: COVID-19 deaths may have been misclassified or New Jersey may have had more indirect deaths than other states. With only limited cause of death data, our analysis is unable to distinguish between misclassified COVID-19 deaths and indirect deaths.

Many excess influenza deaths in New York City appear to be misclassified COVID-19 deaths. If NYC's COVID-19 emergency declaration led people with seasonal influenza not to seek care, we would expect to see a sharp reduction in the number of positive influenza cases around the date of the emergency declaration. However, the number of positive influenza tests in New York City decreased steadily throughout March 2020 with no steep drop around the date of the COVID-19 emergency declaration [36]. Because seasonal influenza seemed to taper off during March 2020, while influenza deaths in NYC increased until April 11th. This suggests that many excess influenza deaths were misclassified COVID-19 deaths, rather than a resurgence of undiagnosed influenza. The apparent misclassification of COVID-19 deaths as influenza in New York City does not appear attributable to urbanicity because we observed no excess influenza mortality in the District of Columbia, the other urban-only area. The likely misclassification of COVID-19 deaths as influenza may be due to heterogeneity in cause of death determination and/or COVID-19 presentations between New York City and the states examined. Alternatively, the misclassification may occur in many jurisdictions, but it is more detectable in NYC due to the large number of deaths.

Mortality displacement hypothesis

Excess mortality during heatwaves and influenza pandemics often shows mortality displacement (or harvesting effect), where subsequent mortality declines [37]. Longer observation periods could detect mortality displacement, but inconsistent non-pharmaceutical intervention policies across the United States may cause elevated mortality due to COVID-19 to persist over longer durations than during typical influenza pandemics.

Strengths and limitations

Our hypothesised mechanisms for excess mortality are based on existing research, but the available mortality data are insufficient to test these hypotheses. For example, deaths at home are not published weekly or systematically. The available U.S. data include data aggregated over all states stratified by age (0–17, 18–64, 65 +) and region; however, these data do not allow identification of all-cause mortality trends by region or age because some states' data are incomplete, even by the available completeness measure, which understates completeness during periods of elevated mortality.

Our analysis examines excess deaths associated with the COVID-19 pandemic. It is likely that the longer the period since the beginning of the pandemic, the more indirect causes of death are included in our excess deaths estimate. The vast majority of excess mortality is not attributable to social distancing or the pandemic-induced recession because recessions are generally associated with lower mortality [38]. Furthermore, the statistical methods used can estimate excess mortality in regions with considerable increases in fatalities. In regions with very small number of increased deaths, our methods may not be able to detect the effects of the pandemic because the confidence intervals would be too wide.

We can evaluate whether emergency department visits for asthma in New York City decreased during the COVID-19 pandemic but not whether the decrease in asthma ED visits increased mortality because chronic lower respiratory mortality data from this period are not currently available. We were unable to obtain data from the other 58 NSSP jurisdictions, or for acute coronary syndromes that could suggest stroke or heart attack.

Implications for policy and practice

Research can identify populations at risk for mortality that may not be included in the official COVID-19 counts, and the overlap with groups affected by other health disparities, so resources can be allocated to the most affected communities. Excess mortality may be reduced by prioritising research, including random sample testing of people without symptoms and postmortem tests [39]. To avoid ascertainment bias, random sample postmortem testing can identify atypical disease presentations that may be under-recognised in clinical settings. In the face of testing limitations, postmortem tests may be viewed as expendable, but postmortem testing can improve patient care by identifying gaps in diagnosis and treatment.

To identify under-use of healthcare for cardiovascular and cerebrovascular conditions, National Surveillance System Program data should include these indications and current data should be available for all NSSP locations. New York City's system suggests that this change to make data more quickly available is feasible. NSSP jurisdictions are given substantial discretion over which syndromes are included and may consider centralised standards impractical, but such standards would make data useful nationwide, in addition to locally.

Future federal pandemic planning should include upgrades to state vital statistics infrastructure, so that all states can report deaths in a timely fashion. As suggested after earlier pandemics [40], pandemic planning should identify how to release more detailed data so that research can discriminate between mechanisms of excess mortality, especially for high-vulnerability jurisdictions. Research using detailed data will find some spurious findings, including cases who died with the virus but not of the virus, but more detailed data will save lives by identifying vulnerable communities to allocate resources to, as well as atypical symptoms of the disease.

Conclusions

Excess all-cause mortality exceeding the number of reported COVID-19 deaths is evident in the United States and in many states during the first three months of the pandemic. Greater test availability, including postmortem tests, can yield more accurate mortality counts and case-fatality ratios and increase the public's willingness to adhere to non-pharmaceutical interventions to reduce transmission.

Acknowledgements. We thank Farida Ahmen, Michael Augenbraun, Stephan Kohlhoff, Josh Marshall and Tracey Wilson for helpful conversations, and our spouses/partners for childcare. We also thank the reviewers and editor for their feedback. This research study was partially supported by NSF Grant OAC-1940179.

Conflict of interest. Authors have no conflict of interest to report.

Data availability statement. Data are publicly available but updated weekly. A copy of the data release is shared through GitHub.

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Appendix

Detailed methods

Semiparametric excess mortality model

Covariates include week of the year, year, an indicator function that presents the possibility that the mean death rate has increased after the start of the emergency in a location, and the natural logarithm of population as an offset. Week of the year is modelled non-parametrically to capture seasonal mortality variations. Let D_t = number of certified deaths at time index t, N_t = population size. We use p_t as an indicator of time period t falls in. The indicator variable permits us to estimate excess deaths. Specifically, $p_t = 0$ represents the pre-emergency period; $p_t = 1$, the period after the emergency. Moreover, let $week_t$ = week of year, and $year_t$ = a categorical year effect.

Assuming D_t follows a Poisson distribution, we fit a semiparametric model;

$$\log(\mu_t) = \log(N_t) + \beta_o + \beta_1 p_t + f(week_t) + year_t \tag{A1}$$

where $\mu_t = E(D_t|t,p_t,N_t,week_t,year_t)$. The natural logarithm of N_t is an offset variable; while f is a smooth function of *week*, which accounts for within year variation. f is fit using a penalised cyclic cubic regression spline [19].

Preliminary analysis indicates overdispersion, so we used a quasi-Poisson model to estimate the dispersion parameter [17]. We estimated coefficients by a penalised likelihood maximisation approach, where the smoothing penalty parameters are determined by restricted maximum likelihood. The residuals of the fitted model (1) did not present remaining temporal dependence.

The fit of model (A1) can be used to estimate excess deaths through the difference between the estimated model with $p_t = 1$, *vs.* the estimated model with $p_t = 0$. Let $\widehat{\mu_t} = E(D_t|t,p_t = 1,N_t,week_t,year_t)$, $\widehat{\psi_t} = E(D_t|t,p_t = 0,N_t,week_t,year_t)$, and $\widehat{b_o}, \widehat{b_1}$ estimate β_o,β_1 respectively. Then [2],

$$\hat{\mu} - \hat{\psi}_t = e^{\hat{b}_o + \hat{f}(week_t) + year_t}(e^{\log(N_t)\hat{b}_1} - 1) \tag{A2}$$

When $p_t = 0$, then $\widehat{\mu_t} - \widehat{\psi_t} = 0$. Equation (A2) is the maximum likelihood estimator for expected excess deaths at t.

To estimate cumulative excess deaths we use (A2)

$$\sum_{t=q}^{r} (\widehat{\mu_t} - \widehat{\psi_t}) \tag{A3}$$

for any time period starting at index q and ending at r. Approximate simulations from the Bayesian posterior density are performed to obtain 95% credibility intervals, which we refer to as confidence intervals throughout.

Conventional mortality method

Conventional excess mortality methods build a temporal mortality model until time $m < T$, then use this model to predict deaths from time $m + 1$ to time T, and excess deaths are the difference between the deaths between times $m + 1$ and T and the predicted deaths from the model. Uncertainty is usually quantified through the uncertainty of the parameters on the regression model [16], which ignores natural random fluctuations in mortality from time $m + 1$ to time T. We tackle this problem combining the Bayesian posterior density described in the semiparametric model section with uncertainty on weekly mortality.

First, we fit a quasi-Poisson semiparametric model similar to the one presented in the previous section, but here we only use data until 1 February 2020. The deaths from 8 February 2020 forward should follow a Poisson distribution with some expected rate; the maximum likelihood estimator of such rate is the mean weekly deaths during this period. The weekly deaths are approximately normal with a variance that accounts for overdispersion according to the scale parameter in the fitted model. From this distribution, we simulate 10 000 weekly deaths and subtract the results from the posterior distributions of the fitted results. The 95% confidence interval is the range between the 2.5% and 97.5% percentiles of all excess deaths.

ASIAN AMERICANS
ADVANCING
JUSTICE
AAJC

VIA EMAIL

October 3, 2022

NSTC Subcommittee on Equitable Data
Office of Science and Technology Policy
Eisenhower Executive Office Building
[redacted]
Washington, DC 20504
Email: [redacted]

Re: Request for Information; Equitable Data Engagement and Accountability
(Document Citation 87 FR 54269)

Asian Americans Advancing Justice – AAJC submits this comment in response to the White House Office of Science and Technology Policy (OSTP) federal register notice regarding the Request for Information; Equitable Data Engagement and Accountability, 87 FR 54269 (September 2, 2022). Asian Americans and Native Hawaiian and Pacific Islanders (NHPIs) comprise vastly diverse racial groups. Without accurate disaggregated data, some of the most disadvantaged in our communities are rendered invisible, leaving their needs unmet. Detailed data are also critical to our ability to break down the stereotype of the "model minority," which has been used to erase the history of exclusion and discrimination against Asian Americans and NHPIs. We write to provide comments to help foster collaboration between all levels of the Federal government, promote engagement of communities that access or participate in Federal programs in data collection and research, and create opportunities for the broader community to publicly access equitable data, including disaggregated and granular data.

Organizational Information

Advancing Justice | AAJC, a nonprofit, nonpartisan 501(c)(3) organization, was incorporated in 1991 and opened its Washington, DC office in 1993. For over thirty years, we have served as the leading Asian American voice on civil rights issues in our nation's capital. Our mission is to advance civil and human rights for Asian Americans and to build and promote a fair and equitable society for all. Our expertise on issues of importance to the Asian American community is widely acknowledged in the media, by the public, and by policymakers at the federal, state, and local levels.

Advancing Justice | AAJC considers data collection and reporting to be the backbone of its mission. We have been working to eliminate the barriers that have historically resulted in the undercounting and underreporting of Asian Americans and NHPIs in federal data collection and analysis efforts, particularly in the decennial census count. Our permanent census program monitors census policy and educates policy makers—including through testifying at Congressional hearings—and conducts community outreach and education on the surveys conducted by the Census Bureau.

GUIDING PRINCIPLES FOR APPROACHING DATA EQUITY

Prioritizing Data Disaggregation

The collection of detailed data are particularly critical for Asian Americans, who are among our nation's fastest growing and most diverse racial groups.[1] Often viewed as homogenous, these communities include more than 30 detailed subgroups that can differ dramatically across key social and economic indicators.[2] While Indian Americans have an average poverty rate of 6%, Mongolian Americans and Burmese Americans have a poverty rate of 25%.[3] Roughly 75% of Taiwanese Americans hold a bachelor's degree, yet only 14% of Laotian Americans do.[4] Another example can be found in health disparities. A study showed that "19.4% of Asian adults compared to 12.9% of whites report[ed] being without a usual source of health care, with Cambodian and Vietnamese [Americans] … three times more likely to skip doctor visits due to cost compared to all Asian [Americans] or U.S. residents."[5] The study further found that U.S.-born Vietnamese American women represent one of the highest risk groups for breast cancer at a rate of being four times more likely to die of breast cancer than any other Asian American groups and that Korean American children are four times more likely to have no health insurance as compared to others. Finally, disaggregating data on the prevalence of smoking in New York City showed that while the prevalence in smoking was lower overall in Asian Americans compared to whites (14.1% vs. 18.6%), that was not the case for some Asian American subgroups, where the actual prevalence of smoking was much higher, such as 35.5% in Korean Americans.[6] And while Japanese Americans, Filipino Americans, and Indian Americans all have English language proficiency at or above 80%, only 36% of Bhutanese Americans speak English proficiently.[7]

We strongly believe in the collection of detailed race and ethnicity data by Federal agencies. Without this requirement, Federal agencies are unlikely to adopt collection of detailed race and ethnicity data. They have long had the option to, but we have not seen significant movement toward detailed reporting when it is not mandatory. Thus, we believe that the requirement should be made of all Federal agencies for data disaggregation, with a process OMB could administer that would allow agencies to apply for an exemption where such collection and reporting of detailed data would create undue hardship or privacy concerns, in which case they must collect and report data based on the minimum categories.

Moreover, we believe Federal agencies should be required to collect detailed race and ethnicity data even when such data could not be responsibly reported due to statistical reliability and confidentiality concerns. This will provide us the option to aggregate the data across time for the same group, (i.e., pool the responses across a period of time), which could address statistical reliability and confidentiality concerns.

Prioritizing Granular Data

In addition to disaggregating data by racial and ethnic group, the federal government must ensure the data it produces illuminate geographical differences by providing Asian American and NHPI data at different geographic levels: local, state, and federal. The more granular the data—for example, drilling down to the county or city level—the more likely it is that problems can be identified in specific localities. While

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[1] https://www.pewresearch.org/fact-tank/2021/04/29/key-facts-about-asian-origin-groups-in-the-u-s/.

[2] https://www1.nyc.gov/assets/immigrants/downloads/pdf/Fact-Sheet-NYCs-API-Immigrant-Population.pdf.

[3] Id.

[4] https://theconversation.com/asians-could-opt-out-of-naming-a-country-of-origin-on-the-2020-census-a-policymakers-nightmare-92714.

[5] https://www.pfizer.com/news/articles/health_disparities_among_asian_americans_and_pacific_islanders#:~:text=In%20fact%2C%2019.4%25%20of%20Asian,all%20Asians%20or%20U.S.%20residents.

[6] Id.

[7] https://www.pewresearch.org/fact-tank/2021/04/29/key-facts-about-asian-origin-groups-in-the-u-s/.

collecting geographic data should be a priority, granular data on socio-economic status and language ability also provide targeted information that can help address some of the most pressing issues in the Asian American and NHPI community and improve civil rights outcomes. Overlaying geographic data with disaggregated data by Asian American and NHPI subgroups is a first step. The collection of intersectional data can provide evidence of continued discrimination and address problems in order to begin driving solutions.

Not Collapsing Asian Americans or NHPIs into an "Other" Category

We believe it is a necessary step for the federal government, academic institutions, and other organizations that collect data to end the use of an "All Other Races" category. While the practice may have made the presentation of data easier for agencies and others, whereby they could present data on a few racial and ethnic groups, such as white, Black, and Latino, and then presented the rest as "All Other Races" data, the practice does not serve the public at large, particularly those that comprised "All Other Races."

For example, combined, Asian Americans and NHPIs are the "majority" populations in the state of Hawaii.[8] Communities of color are the majority populations in the state of California.[9] Demographics have significantly changed over the last several decades. Asian Americans remain among the fastest growing groups in the United States, with 38.6% growth between the 2010 and 2020 Censuses.[10] The NHPI population also grew rapidly between 2010 and 2020, at 29.5%.[11] These communities are often lumped into "All Other Races," making these fast-growing communities invisible. The practice moving forward should be to have agencies report on the data for, at a minimum, all racial and ethnic categories, with the addition of data on detailed groups as available. We hope that sets a precedent in academia and other industries. Regardless of the reasons why the "All Other Races" category was initially constructed, is no longer acceptable because the diversity within the "All Other Races" category renders this information essentially useless. If "All Other Races" is being used because the study does not have enough data to disaggregate by race, this should be addressed in the methodology. Similarly, if the researcher(s) is/are not motivated to collect disaggregated data at the onset, the results cannot be relied upon. Ultimately, there is no acceptable reason for the use of "All Other Races" in today's changing world.

Creating Accessible Data for the Public

To promote equity and democratic participation and engagement, the federal government should release the maximum amount of data to the public without compromising individual privacy. For individuals who do not have expertise in data manipulation, providing publicly accessible dashboards allows them to see trends easily. Offering trainings about how to best access data could further help educate communities and increase the impact of equitable data collection. And while it is important that data be easily understood by individuals lacking statistical expertise, the data must also be accessible at different levels of statistical competency. Thus, in addition to producing easy-to-understand data products, agencies should provide the underlying data, with proper technical documentation, so that experts can assist communities and advance solutions requiring more complicated statistical analysis. An example of an agency providing both easy-to-understand products and the underlying data can be found with the U.S. Census Bureau's release of its determinations made under Section 203 of the Voting Rights Act. Not only does the Bureau provide the determinations and support materials (such as comparison tables), it also provides a public use dataset that

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[8] http://aapidata.com/wp-content/uploads/2018/05/HI-2018.pdf.

[9] https://www.ppic.org/publication/californias-population/.

[10] https://www.census.gov/library/visualizations/interactive/race-and-ethnicity-in-the-united-state-2010-and-2020-census.html.

[11] Id.

allows organizations, such as ours, to further analyze the data to determine, for example, jurisdictions that just missed coverage.[12]

How We Collect Data Equitably

While the content of the data that are collected matters tremendously, the methods used to collect data should also reflect our commitment to equity and civil rights. For example, surveys should be available in-language. Before these are widely distributed, they should be reviewed by community members to ensure translations are accurate and understandable. And we must guarantee they are distributed widely, including to households lacking internet access and other hard-to-reach individuals.

SPECIFIC USE CASES FOR ASIAN AMERICAN AND NHPI COMMUNITIES

As an organization committed to advancing the civil and human rights of Asian Americans, we offer use cases on how these guiding principles play out in our own work on immigration, education, telecommunications, technology, and media, and anti-Asian hate.

Immigration

Some overarching principles undergird the equitable collection of immigration data. It is important to ensure immigration data are accessible to the community and can be used by community members and experts. More dashboards like those available from Customs and Border Patrol (CBP) would increase opportunities for community-based organizations (CBO) to use equitable data to hold government accountable to the American public. Regular updates of the data are far more useful than end of year reports. Quarterly reports allow researchers to review the rate at which family-based immigration visas are being processed.

There are specific actions federal agencies can take to improve data equity in the immigration space. Immigration and Customs Enforcement (ICE) presents the most problems in terms of access to equitable data. ICE's data are often late, incomplete, and not publicly available except through outside organizations like Transactional Records Access Clearinghouse (TRAC), which analyzes ICE data obtained through Freedom of Information Act (FOIA) requests. This makes it difficult to get a sense of whether deportations of Southeast Asian Americans have decreased. It also poses challenges in studying how ICE implements its enforcement priorities.

While the yearly annual report for ERO (Enforcement and Removal Operations) usually includes data on removals by country of citizenship, two issues exist.[13] First, the data are often late. The Fiscal Year 2021 report has yet to be released. The long delay between the end of the fiscal year and the release of the ICE ERO data make it hard to identify any issues with ICE operations in a relevant time frame. Second, the data are presented in pdf format, and are not cross tabulated. This poses challenges to analyzing trends in terms of enforcement across different categories (like how many individuals from a particular country of citizenship have criminal convictions when apprehended by ICE).

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[12] https://www.census.gov/programs-surveys/decennial-census/about/voting-rights/voting-rights-determination-file.html. For an example of how our organization used that dataset to produce additional analysis, see https://www.advancingjustice-aajc.org/publication/jurisdictions-and-languages-just-missed-coverage-2021-section-203-determinations.

[13] https://www.ice.gov/doclib/news/library/reports/annual-report/eroReportFY2020.pdf.

CBP is better than ICE because it provides publicly available dashboards[14] that allow for deeper analysis, including a dashboard[15] that includes some enforcement statistics for the current fiscal year to date. CBP also has datasets in CSV format available for download that allow for some independent analysis/manipulation. For example, CBP offers a data tool to explore data around southwest land border encounters.[16] The data can be filtered by fiscal year, CBP component, certain characteristics related to family, country of citizenship, and legal authority. It is useful for CBP to have all its datasets available on one website, with CSV files for download and data dictionaries available. Nevertheless, the datasets are not as useful as they could be, especially because they lose crucial information about country of citizenship. The datasets vary in terms of how many countries are included in the "other" category. For southwest border encounters, for example, the citizenship variable only includes El Salvador, Guatemala, Honduras, Mexico, and Other, despite Other accounting for almost half of all encounters.

United States Citizenship and Immigration Services (USCIS) has some data available, but mostly in pdf format.[17] Expanding the types of files available for download will improve data accessibility and impact. Department of Homeland Security (DHS) publishes data about legal immigration and migration flows online. These data are also better than ICE. It includes perhaps the most comprehensive breakdown of legal immigration and adjustment of status information.[18] Immigration statistics are centralized on one page.[19] However, there are still some issues. First, the cross tabulations are limited. For example, there is no raw dataset with information about the age of different refugees by country of origin. Second, unlike CBP, there is a dearth of dashboards that allow for easy manipulation of the data. Third, in the case of family-immigration statistics, reports are often delayed – for example, it is unclear how close USCIS and the State Department are to reaching the cap on family-based immigrant visas for this fiscal year, because data are only available for the first two quarters of this fiscal year.

Thus, many organizations rely on TRAC immigration data to have access to some of those tools.[20] But those data are based on federal data recovered through FOIA requests – it would be more efficient if ICE presented the same kind of data without TRAC having to issue FOIA requests to ICE and others.

Telecommunications, Technology, and Media

For Asian Americans and NHPIs, one of the first and primary challenges to broadband access is accurate data. Few studies on broadband access specifically focus on Asian Americans, fewer still disaggregate their data, and even fewer data exist for Pacific Islanders.[21] Below, we outline some specific areas where additional data and disaggregation would benefit the Asian American and NHPI community, while also detailing opportunities for additional interagency collaboration.

The Universal Administration Co. (USAC) website states that they publish total households enrolled and state enrollment data weekly, zip code data monthly, and county data quarterly.[22] However, the data do not appear to be published on a regular or timely schedule. Having access to real-time enrollment information would be helpful to know how effective outreach efforts are in targeting unserved and underserved

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[14] https://www.cbp.gov/newsroom/stats/cbp-public-data-portal.

[15] https://www.cbp.gov/newsroom/stats/cbp-enforcement-statistics.

[16] https://www.cbp.gov/newsroom/stats/southwest-land-border-encounters.

[17] https://www.uscis.gov/tools/reports-and-studies.

[18] https://www.dhs.gov/immigration-statistics/special-reports/legal-immigration.

[19] https://www.dhs.gov/immigration-statistics.

[20] https://trac.syr.edu/immigration/.

[21] https://www.advancingjustice-aajc.org/sites/default/files/2021-05/2021.05.06%20E%26C%20Broadband%20Disparities%20Testimony.pdf.

[22] https://www.usac.org/about/affordable-connectivity-program/acp-enrollment-and-claims-tracker/.

communities. Moreover, having broadband mapping data that overlay census data would illustrate what communities are unserved or underserved, and would increase efforts to promote broadband equity. The Federal Communications Commission (FCC) is currently going through a process to update the agency's broadband data and mapping tools. We encourage the FCC to engage in this as a regular process as the current maps are inadequate. Finally, we have concerns over how the government is collecting and using biometrics data. While Government Accountability Office reports offer some information, there are still too many unknowns. Information about the data agencies have access to, what biometrics information they collect, and what they use it for are essential. For example, we know that DHS has access to multiple databases – including state driver's license data – and that they use biometrics, but it is unclear how they are using these data, if they are purchasing data from other databases, who has access to these data, and whether they share data with other government agencies.

Education

Disaggregating data, providing more granular data, eliminating the "Other" category, and collecting data equitably are especially important when it comes to improving educational outcomes for Asian Americans and NHPIs. Ideally, data should be disaggregated by Chinese, Asian Indian, Filipino, Japanese, Korean, Vietnamese, Pakistani, Cambodian, Hmong, Laotian, Thai, Taiwanese, Burmese, Bangladeshi, and Nepalese sub-populations, "Other Asian" sub-populations (to capture less-populated communities), and Native Hawaiian, Samoan, Chamorro, Tongan, iTaukei, Marshallese, and "Other Pacific Islander" sub-populations. If possible, subgroups such as the lu Mien and Montagnards under Asian American should also be disaggregated. This is not only true for students; these data must also be collected about staff and teachers. When available, disaggregated data provides insight into educational disparities within the Asian American and NHPI community.

More granular data will provide further insight into educational disparities as they apply to Asian Americans and NHPIs. Specifically, data on English learner status, sex, disability, college and career readiness, staffing and finance (e.g., teacher experience and per-pupil expenditures), household income, and parental education should be collected. More data on curriculum, specifically the number of Asian American Studies classes and data on how many credit hours are spent teaching different subjects, would help address curricular inequalities. Data should also be collected on anti-Asian hate incidents in schools. Moreover, data on the English language ability/language preference of parents should be tracked.

We strongly support the collection of school climate and safety data as these are especially important for our communities. At a national level, a 2016 study showed U.S.-born Laotian and Cambodian men, ages 18-39 years, were reported to have the highest incarceration levels of all Asian Americans and NHPIs at 7.26% of their total population, and many Southeast Asian American males report being stereotyped by their teachers as troublemakers, gang members, delinquents, and failures.[23] Students with disabilities are disproportionately disciplined, further highlighting the importance of this particular data collection.[24] We are hopeful that such data will continue to be gathered and recommend that further analyses be conducted to investigate disproportionate discipline of other disadvantaged groups, specifically English learners and recent arrivals to the United States.

Finally, it is essential that these data are made available to the public, as parents and students can use this information to make informed decisions about their educations. Recently, the availability of user-friendly data has allowed students, parents, and advocates to access data regarding their own schools as well as

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[23] http://store.samhsa.gov/product/A-Snapshot-of-Behavioral-Health-Issues-for-Asian-American-Native-Hawaiian-Pacific-Islander-Boys-and-Men-Jumpstarting-an-Overdue-Conversation/SMA16-4959.

[24] https://www2.ed.gov/programs/osepidea/618-data/LEA-racial-ethnic-disparities-tables/disproportionality-analysis-by-state-analysis-category.pdf.

schools attended by others, which has helped shape advocacy and build greater understanding of unequal educational opportunity. All data should be publicly reported for transparency, civil rights enforcement, monitoring, and research purposes.[25] These data are especially important in the wake of the pandemic, when access to educational opportunity was not equitably available. Data can help make those inequalities transparent and provide the impetus for remedies.

Anti-Asian Hate

The flaws with hate crimes data are systemic – largely arising out of the fact that reporting by law enforcement agencies is not mandatory but voluntary. The anti-Asian hate crimes and hate incidents that make the news—as well as those reported to Advancing Justice's Stand Against Hatred site, Stop AAPI Hate, and other community groups—are deeply troubling. And yet we know that they very likely are only a fraction of what our communities are facing since hate crimes are chronically un- and under-reported.[26] As detailed in a recently-released report from the Movement Advancement Project, only an estimated 3.6% of hate crimes are reported to the FBI each year.[27] There is a significant gap between the FBI's Uniform Crime Reporting Program's database of reported hate crimes and overall hate crime experiences of people living in the United States, as collected by the Department of Justice's National Crime Victimization Survey.[28]

Even with concerns about under-reporting, we saw a significant increase in hate crimes against Asian Americans in 2020. The FBI's 2020 Hate Crimes Report documents a significant increase in criminal incidents over 2019, including a 76% increase in hate crime incidents motivated by anti-Asian bias: 279 hate crime incidents against individuals of Asian descent were reported in 2020, compared to 158 incidents reported in 2019.[29] Passage of the COVID-19 Hate Crimes Act, which incorporates the Jabara-Heyer NO HATE Act, was an important step forward to promote better hates crimes reporting and data collection.[30] But it is not enough. To combat racism effectively, we must have data to make informed decisions about prevention. In addition to following the guiding principles provided here (e.g., not collapsing Asian American data into an "other" category, disaggregated by subgroups, etc.), we urge the Department of Justice and other agencies involved in collecting hate crime data to address the systemic issues that prohibit accurate data reporting on anti-Asian hate.

Conclusion

We appreciate the opportunity to provide comments on Equitable Data Engagement and Accountability. We look forward to working with the Administration on its ambitious equitable data efforts described in the Executive Order on Advancing Racial Equity and Support for Underserved Communities Through the Federal Government (E.O. 13985), including the *Vision for Equitable Data* issued to the President in April 2022. Please contact Terry Ao Minnis, Senior Director of Census and Voting Programs, at [redacted] if you have any further questions.

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[25] http://www.seattleschools.org/modules/groups/homepagefiles/cms/1583136/File/Departmental%20Content/siso/disprof/2011/disprof_2011.

[26] https://www.npr.org/2021/03/11/975592502/asian-americans-experience-far-more-hate-incidents-than-numbers-indicate.

[27] https://www.lgbtmap.org/file/2021-report-hate-crime-laws.pdf.

[28] Id.

[29] https://abcnews.go.com/US/hate-crimes-asians-rose-76-2020-amid-pandemic/story?id=80746198, *see also,* https://crime-data-explorer.fr.cloud.gov/pages/explorer/crime/hate-crime.

[30] Public Law No: 117-13.

CMS Alliance to Modernize Healthcare (Health FFRDC)

Strategic Recommendations for CDC Supporting Community-Based Organizations' Data Needs on Homelessness

Task Order No. 75D30119F05691

Version 6.0

August 19, 2022

Prepared for:
Centers for Disease Control and Prevention (CDC)

CMS Alliance to Modernize Healthcare Federally Funded Research and Development Center

Sponsor: Center for Surveillance, Epidemiology, and Laboratory Services Public Health Informatics Office

Record of Changes

Version	Date	Author / Owner	Description of Change
0.50	July 12, 2022	MITRE	Initial Annotated Outline
1.00	Jul 22, 2022	MITRE	Initial Draft
2.00	Jul 25, 2022	MITRE	Second Draft – Expanded Recommendation Options
3.00	Jul 27, 2022	MITRE	Third Draft – Prepared for collaborative walkthrough of with CDC
4.00	Jul 29, 2022	MITRE	Fourth Draft – Addressed first round of CDC comments
5.00	Aug 12, 2022	MITRE	Fifth Draft – Addressed second round of CDC comments
6.00	Aug 19, 2022	MITRE	Sixth Draft – Addressed final round of CDC comments

Executive Summary

The Centers for Disease Control and Prevention (CDC) is committed to improving the health of people experiencing homelessness through improvements in scientific research, enhancement of health systems, and techniques to increase the utility of public health information.

Through this report, the MITRE team provides a synthesis of field observations concerning the capacity of community-based organizations to serve individuals experiencing homelessness across the nation. MITRE's observations are derived from multiple sources. These included semi-structured interviews with organizational leaders and data systems administrators in select urban and rural counties, an electronic survey administered to Housing and Urban Development (HUD) grantees across a broader geographic distribution, and a technical panel of subject-matter-experts invited from across levels of government and national coalitions. **Section 2. Methodology** denotes the specific steps and sub-activities involved, and **Section 3. Findings** presents all the resulting observations and outputs; **Table 2. Proposed Solutions** presents a list of all proposed solutions to current gaps and challenges in the field**.**

The MITRE team has also developed a strategic recommendation with six proposed options for CDC action. This can be found in **Section 4. Strategic Recommendation**. The Strategic Recommendation, aligning Objectives, and options for CDC action are provided in-brief below:

Strategic Recommendation: Establish a joint working group between CDC and HUD to establish a hub for resources and technical assistance for community based organizations (CBOs) and to support coordinated data modernization efforts across CBOs and key federal agencies.

- **Strategic Objective 1**: Support CBO data collection by providing technical assistance and resources.
    - **Option 1A:** Support jurisdictions to develop data warehouses that integrate data infrastructure for homeless and health implemented by studying the cost-effectiveness of "innovator" and "early adopter" jurisdictions.
    - **Option 1B:** Increase CBOs' ability to access available and appropriate regional- and national-level support by disseminating a directory of technical and skill-building resources.

- **Strategic Objective 2**: Enhance housing and health interoperability by strengthening interagency partnerships and collaboration.
    - **Option 2A**: Support state, tribal, local, and territorial bodies to receive impactful, aggregated housing and health data by providing resources across jurisdictional lines with federal grantors.
    - **Option 2B**: Break down data siloes by strengthening federal partnerships with the HUD, SAMHSA, ED, DOJ, and DOL.
    - **Option 2C**: Aid existing and new Continuum of Care (CoC)-level learning collaboratives to improve operations in focused topic areas (e.g., outreach and enrollment data standardization) by studying learning collaboratives' educational approaches, leadership structure, costs, and tools.
    - **Option 2D**: Improve data quality on homelessness, including the interoperability of systems between CBOs, healthcare, and public health, by assembling a committee of stakeholders across federal organization including HUD and HHS.

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Introduction

Homelessness is an important factor that impacts an individual's health and well-being.[1] People experiencing unstable housing or homelessness are at increased risk of exposure to infectious diseases and violence and may experience higher rates of uncontrolled chronic conditions. The National Alliance to End Homelessness reports that there are over a half a million people experiencing homelessness in the U.S.;[2] on a given day, 17 per 10,000 Americans experience homelessness, with a shortened average life expectancy of 50 years.[3] Community based organizations (CBOs), defined as public or private not-for-profit resource hubs that provide specific services to communities and targeted populations, play a vital role supporting people experiencing homelessness.[4] Many CBOs connect people experiencing homelessness to temporary shelter and affordable housing, as well as provide case management and access to other essential health and social services. CBOs are well positioned to collect data on the utilization of services offered to the populations they support.[5]

This document refers to "homelessness" broadly, often expanding beyond the criteria put forth by the U.S. Department of Housing and Urban Development (HUD): "individuals who lack resources and support networks to obtain permanent housing, [including persons who] are trading sex for housing; are staying with friends, but cannot stay there longer for 14 days; are being trafficked; [and,] left home because of physical, emotional, or financial abuse or threats of abuse and have no safe, alternative housing." HUD's four categories under which individuals and families may qualify as homeless include: 1) literally homeless; 2) imminent risk of homelessness; 3) homeless under other Federal statuses; and 4) fleeing/attempting to flee domestic violence. Specific criteria vary by state and locality, and all are valid and included for the purposes of this research.

For many diseases, the Centers for Disease Control (CDC) does not have access to timely or complete data about the health and needs of people experiencing homelessness. This impacts CDC's ability to ensure that timely, correct, and contextual information is available to make critical decisions and to facilitate delivery of necessary resources.

To address this challenge, MITRE has worked in collaboration with CDC to assess the ecosystem of CBO data collection and sharing; with additional collaboration with a panel of experts, MITRE identifies actionable opportunities for CDC to impact CBO processes and outcomes.

Purpose

The purpose of this document is to provide CDC with actional recommendations to improve the CBO data collection and sharing ecosystem. The MITRE team leveraged multiple data sources to develop recommendations, including:

- Primary data from key informant interviews and an electronic survey
- Secondary data from federal and state data integration reports
- Primary data from multiple convenings of a Technical Expert Panel (TEP)

Additional information is available in the complementary document "CBO Environmental Scan," developed by the MITRE team as part of the same effort.

Scope

Our team developed proposed solutions presented in this document using the data collected as described in the Methodology section. We do not intend for this document to serve as a formal implementation plan or a definitive list of solutions to resolve the domain researched. Instead, we envision this document to represent an initial set of proposed solutions filtered down to the highest priority based on TEP members' time and contributions. A formal implementation plan would be necessary to consider factors related to cost, feasibility, and timeline.

Federal and Regional Landscape

The MITRE team identified a number of government agencies, networks of local organizations, and essential technologies that make up the current governance structure of the ecosystem of data collection and sharing. These include government agencies, local networks of organizations, and essential technologies.

Federal Scope

HUD plays a major role in federal support for people experiencing homelessness. HUD administers programs that provide housing and community development assistance and is responsible for national policy and programs that address America's housing needs to improve and develop the Nation's communities and enforce fair housing laws. HUD administers a series of programs that address homelessness. HUD's Continuum of Care (CoC) program provides grants to states, local governments and CBOs to help them meet community needs; HUD's CoC grants provide funding support to 6,597 local programs implemented by CBOs. Additionally, HUD's Special Needs Assistance Program (SNAPS) Strategy sets overarching goals around data quality in CoC systems.

The Department of Health and Human Services (HHS) is another highly impactful organization supporting people experiencing homelessness. HHS was created to protect the health of all Americans and provide essential human services. Recently, HHS partnered with HUD to establish programs to improve access to affordable, accessible housing, and the critical services that improve community health. Additionally, they launched a national Housing and Services Resource Center as a hub for this coordinated effort. Like HUD, HHS funds grant programs and research that are impactful to homelessness, as well as several information resource centers and sponsor activities that provide critical information to a variety of audiences who support people experiencing homelessness.

Regional Scope

A CoC is a regional or local planning body that coordinates housing and services funding for people experiencing homelessness. The CoC program is designed to promote a community-wide commitment to ending homelessness; it supports the partnership between CBOs and the effective usage of grant funding and services. Lead CoC organizations govern and direct the remaining entities that are members of their local CoC. Additionally, the CoC helps direct the implementation of the Homeless Management Information System (HMIS), the foundational system for collecting and sharing data pertaining to people experiencing homelessness in the geographic area served by the CoC.

A HMIS is a class of database applications used to collect client-level data and information on the use of housing and other services to people experiencing homelessness. Each CoC lead organization is responsible for selecting and implementing an HMIS solution that complies with HUD standards. This system is critical for generating reports and sharing data with other state and federal systems that facilitate program funds. CoC lead organizations also coordinate data audits and quality checks.

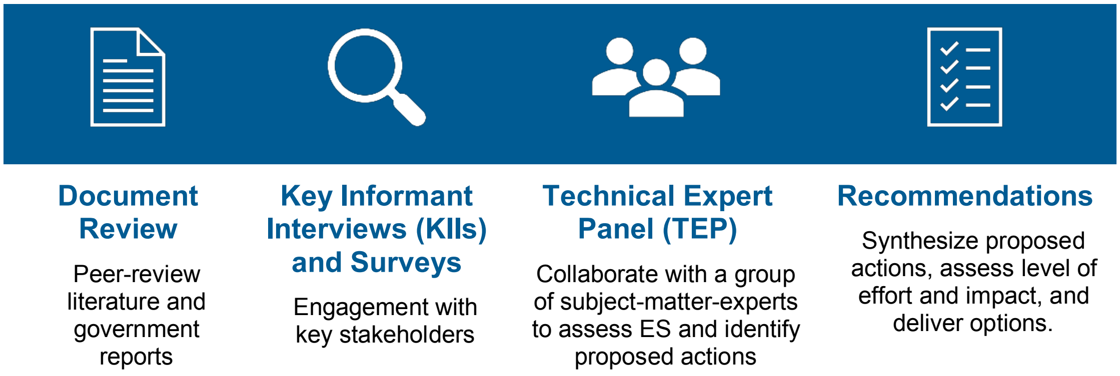
Methodology

The MITRE team conducted four main activities (**Figure 1. Project Activities**).

- First, the team conducted an Environmental Scan (ES) that involved a document review of published and gray literature which helped to identify key players in the domain ecosystem, and key informant interviews (KII) and surveys of representatives from community-based-organizations and state, territorial, local and tribal grantee organizations.
- Following the ES, the MITRE team worked collaboratively with CDC to convene a Technical Expert Panel (TEP) to validate and augment the ES findings, as well as contribute proposed actions.
- Finally, MITRE synthesized results from the TEP to develop a strategic recommendation for CDC and associated objectives and options for action.

Figure 1 illustrates and describes the workflow of the project, starting from Document Review, Key Informant Interviews (KIIs) and Surveys, Technical Expert Panel (TEP), and Recommendations.

Figure 1. Project Activities



Document Review

Peer-review literature and government reports

Key Informant Interviews (KIIs) and Surveys

Engagement with key stakeholders

Technical Expert Panel (TEP)

Collaborate with a group of subject-matter-experts to assess ES and identify proposed actions

Recommendations

Synthesize proposed actions, assess level of effort and impact, and deliver options.

Environmental Scan

MITRE's ES is a document delivered prior to this current report that synthesizes CBOs' current capacities and processes for collecting and sharing data pertaining to people experiencing homelessness. For this project, the MITRE team defined CBO as a non-profit, non-governmental or charitable organization that represents community-based needs associated with the segment of the community experiencing homelessness. The MITRE team focused the ES to discern the current state of data management within CBOs, and data-sharing activities between CBOs and governmental public health agencies. The ES was delivered prior to this report.

Key Informant Interviews

The MTIRE team used key informant interviews (KIIs) as the first and primary method to qualitatively assess CBOs' barriers and facilitators in the collection and sharing of homelessness data. The team used the following steps during this stage of the project:

1. CBO Selection: Selected based on demographic and geographic diversity factors of the recipients of HUD grants.
2. Interview Guide Development: Developed a semi-structured interview guide that facilitated a core set of discussion topics while allowing participants to elaborate on unique and impactful topics.
3. Outreach and Recruitment: Communicated with selected CBOs through direct email tailored to each potential candidate and phone calls. Once interest was established, a video-conferencing meeting invite was sent to the participant.
4. Interviews: Conducted each KII with a primary participant, one or more additional representatives from the CBO invited by the primary participant, and a MITRE interviewer and notetaker.
5. Qualitative Data Analysis: Coded interview to identify statements that were categorized based on 6 objectives set for the ES; coding was facilitated using the qualitative data management software NVivo.

Electronic Survey

The team developed a complimentary survey to collect additional information from organizational leaders that represented CoCs. The team completed the following steps during this stage of the project:

1. Survey Development: Drafted and finalized an electronic questionnaire to capture additional information on the data collection and sharing practices of CoC participants. The survey was hosted through SurveyMonkey.
2. Identify Target Audience: A listing of all HUD grantee CoCs' contacts associated with grants was used to identify survey participants. The list of grantees was sent an email invitation to participate in the survey along with a link to the platform.
3. Analysis: Surveys were completed by the participants anonymously. The team exported the data and leveraged Microsoft Excel primarily to view and analyze the data as well as to generate visualizations of responses.

Continuum of Care and Homeless Management Information System Supporting Documentation

To assess consistency in HUD communication across geographic regions and CoCs, the MITRE team analyzed a variety of documents including policies, HMIS training and implementation manuals, and training guides. The majority of the "Policies and Procedures Manuals" contained three main sections that were impactful to project objectives: a Data Quality Plan, a Security Plan, and a Privacy Plan. All manuals were managed using NVivo software to identify common and unique text to support an exploratory analysis.

State Data Warehouse Landscape

To further understand the operation of centralized data systems managed by states, MITRE performed a rapid assessment of state-based data warehouses that were mentioned or elaborated on in KIIs and survey results.

Technical Expert Panel

For this project, the MITRE team defined a TEP as a group of individuals in relevant fields for the project, including federal and state agencies, interagency councils, national and local non-governmental organizations, healthcare providers, and community programs. The MITRE team convened the TEP to support the development of strategic recommendations. The purpose for engaging the TEP was to gather expert opinion, additional artifacts, and proposed solutions to the data-related obstacles and challenges first identified in the ES. The MITRE team provided the TEP the opportunity to challenge, validate, or augment the initial ES findings through targeted discussions.

Panel Selection

MITRE identified potential TEP members and member organizations through stakeholder engagement before and during key informant interviews, as well as interaction with CDC and MITRE subject matter experts. MITRE also identified points of contact for potential member organizations whose appropriate representatives had not been identified. Potential members were then filtered to give the TEP a balanced member list between federal government agencies, national CBO member organizations, and local CBOs in high population areas. The project team selected two co-chairs from national CBOs who had professional experience both leading collaborative initiatives across diverse agencies, and specifically connecting health data to homelessness data. The complete list of members and organizations can be found in Appendix B.

Session Activities

MITRE conducted three sessions with the TEP, described in **Table 1. TEP Meeting Schedule**.

Table 1. TEP Meeting Schedule

Session	Date	Description
0	NA	Prior to Session 1, MITRE developed a TEP Charter to communicate project objectives, define TEP objectives and provide detailed descriptions of member roles, operations, and outputs. Additionally, two chairpersons were selected to help lead the TEP. The ES document was also disseminated to all TEP members upon confirming their commitment.
1	April 27, 2022	MITRE introduced the project background and objectives, MITRE’s roles, and scope of the TEP’s responsibilities. The first half of the session was dedicated to introducing TEP members to each other. The second half was dedicated to presenting the project’s initial findings.

2	June 9, 2022	MITRE provided a recap of ES findings and led an interactive activity to prioritize the thematic findings most resonant to members. During the activity, MITRE facilitators used probing questions and other techniques to explore pain points and solutions with TEP members.
3	June 28, 2022	MITRE synthesized results from Session 1 and 2 into a list of proposed solutions. MITRE facilitators then led two interactive activities to validate, prioritize, and collect evidence for identified solution areas. This session included an exercise to rank the level of effort and impact each proposed solution may require or affect.

Each session used various tools to maximize collaboration between the TEP members and the outputs of each of these sessions can be found both in Section 3.2 Technical Expert Panel Feedback of this report, or in formal meeting minutes delivered to CDC and TEP members previously.

Findings

The following sections describe MITRE's findings from the ES and feedback from the TEP.

Environmental Scan Findings

Through the ES, our team arrived the following themes and findings based on information received directly from CBOs through interviews and the survey:

- **Data Collection**
  - CBOs use multiple methods to collect data (e.g., electronic forms, paper forms, intake interviews, etc.) which forces many CBOs to do manual data entry.
  - Manual data entry into program-level databases and delays between collection and entry lowers overall data quality and requires training of outreach staff collecting data (examples included manual export/import, pen and paper, or direct entry [immediately vs delayed]).
  - CBOs align their data and quality controls around funding sources reporting requirements.
  - HUD requirements and HUD's universal data elements are the primary focus in HMIS data capture and sharing while niche or specialized elements become isolated in custom systems managed by each CoC.
  - Lack of designated funding for data management, staffing, and technology makes data quality monitoring and improvement difficult.
  - Limitations include consent and privacy policies and a lack of system integration.
  - An interoperable, centralized system would incentivize partnerships and data sharing.

- **Infrastructure**
  - HUD changes reporting requirements annually, which requires system and process changes that cause delays.
  - Significant effort is spent on developing training for data collection staff that is not standardized across software or CoCs.
  - Data gaps are created, and data quality is negatively impacted by outdated and costly technology, non-technical administrators, insufficient and rapid turnover of staff, and fragmented data systems.
  - Ability to customize system features facilitates data collection, analysis, and sharing.
  - Many funding sources require very specific data elements that are not standardized or reusable by other system or programs.
  - Shared use of the same IT system or tool or funding source facilitate more sharing.
- **Data Sharing & Partnerships**
  - Data sharing is particularly desirable regarding substance use, behavioral health, domestic violence, and youth status.
  - Increased quantity and quality of data sharing between CBOs serving the same client pool would decrease the use redundant resources as well as increase quality of care and services to individual clients.
  - Sharing to public health agencies and other government agencies was easier than those agencies sharing back to CBO. There is an opportunity for improved data sharing and quality when the data are available to be shared between CBOs and not just aggregated upward to government databases.
  - There is minimal data sharing from public health agencies to CBOs.
  - Data is siloed by category (school, justice, physical health, mental health, homelessness, etc.) and organizations are all collecting the same data about the same people versus sharing data with each other.
  - Aggregated data are easier to share than person- or line-level data.
  - External partnerships could include granting limited HMIS access to other CBOs or Public Health Agencies in addition to sharing data outwards.
  - Sharing agreements (MOUs) between organizations facilitated data sharing

An additional product of the ES was the identification of key stakeholders in the ecosystem of support for people experiencing homelessness. A full listing of stakeholders can be found in Appendix C. Appendix **C. Stakeholders**.

Technical Expert Panel Feedback

The TEP consisted of 20 members representing 16 organizations; a full list of TEP members can be found in Appendix B. Using findings identified in the ES, the MITRE team tasked the TEP with prioritizing findings within each theme by indicating each finding as high priority or low priority. From that exercise, MITRE identified the following top priority findings within each theme:

Data Collection

1. Lack of designated funding for data management, staffing, and technology makes data quality monitoring and improvement difficult.
2. CBOs align their data and quality controls around funding sources reporting requirements
3. HUD requirements and HUD's universal data elements are the primary focus in HMIS data capture and sharing while niche or specialized elements become isolated in custom systems managed by each CoC.

Infrastructure

1. Data gaps are created, and data quality is negatively impacted by outdated and costly technology, non-technical administrators, insufficient and rapid turnover of staff, and fragmented data systems.
2. Many funding sources require very specific data elements that are not standardized or reusable by other system/programs
3. Shared use of the same IT system or tool or funding source facilitate more sharing.

Data Sharing and Partnerships

1. Data is siloed by category (school, justice, physical health, mental health, homelessness, etc.); organizations are all collecting the same data about the same people versus sharing data with each other.
2. There is minimal data sharing from public health agencies to CBOs.

Additionally, some findings were marked as lower priority. Those findings are:

Data Collection

- Manual data entry into program-level databases and delays between collection and entry lowers overall data quality and requires training of outreach staff collecting data (examples included manual export/import, pen and paper, or direct entry [immediately vs delayed]).
- CBOs use multiple methods to collect data, which forces a lot of manual data entry.

Infrastructure

- Significant effort is spent of developing training for data collection staff that is not standardized across software or CoCs.

Data Sharing and Partnerships

- Perceived value to data sharing including potential cost sharing in non-duplication of efforts and direct impact to organization mission and the individual.
- Data sharing is particularly desirable regarding substance use, behavioral health, domestic violence, and youth status.

- External partnerships could include granting limited HMIS access to other CBOs or public health agencies in addition to sharing data outwards.

The TEP discussed a set of potential solutions to address the highest priority findings (See **Table 2. Proposed Solutions**). The quantity of "high priority" and "low priority" tallies indicated during TEP Session 3 determined the TEP's level of interest in each solution. "NA" indicates that the solution had no responses from the activity; however, this does not indicate lack of interest from a qualitative discussion perspective. Solutions have been aligned to MITRE's final strategic recommendation in the form of Options for CDC action (See **Section 4. Strategic Recommendation**); proposed solutions representing valid approaches to existing issues that fall outside of CDC's scope for direct action are marked with an **asterisk (*)**. They have been included to prompt deliberation and consideration as CDC shares these findings with stakeholders whose scope may differ in breadth.

Table 2. Proposed Solutions

Proposed Solution	TEP Interest	Included in Option
Regular data feedback from public agencies to community-based organizations.	High	2A
Convene a learning collaborative to establish data-sharing best practices (e.g., data use agreements).	High	2C
A common data dictionary (standardized definitions across state, federal, and local agencies) and common data model, defined as a uniform set of metadata and standardized data schemes.	High	1C
Services to assist CBOs with data sharing (e.g., legal guidance).	High	2B
Provision of funds to support non-HUD funded CBOs.	High	*
Standard, technical guidance and assistance for CBOs to collect accurate data.	High	1B
Investment in interoperable systems (e.g., HMIS, electronic health record, housing database) with rigorous privacy considerations.	High	*
Turn-key templates, tools, and guidelines outlining data sharing agreements and processes for bi-directional sharing.	High	1B
Validated and standardized instrument to capture housing and homelessness status.	High	2B
Increase information technology-focused grant funding for data modernization.	High	*

Proposed Solution	TEP Interest	Included in Option
Improvement in the collection of behavioral and mental health related data.	High	1B
A unified system provider reduces friction in training and operation.	Medium	*
Mapping of information type from CBOs to appropriate data receivers (e.g., grantors).	Medium	2A
A threshold level of compatibility or interoperability between mandated reporting systems and CBO's existing infrastructure.	Medium	*
Provision and/or facilitation of quality hardware and software to grantees.	Medium	*
A nationally available training library providing resources for HMIS and data quality improvement	Medium	1B
Concerted interagency effort between CDC and HUD to support technology and training	Medium	2B
Establish a clear set of data elements desired by CBOs that are missing from current reporting requirements.	NA	2C
Provision of additional funds to CBOs equal to administrative costs for data collection, or study cost-effectiveness of utilizing such funds.	NA	*
Study of utility and cost-effectiveness of state data warehouses to improve data and evidence-based interventions.	NA	1A

Asterisk (*): Proposed solutions representing valid approaches to existing issues that fall outside of CDC's scope for direct action. These have been included to prompt deliberation and consideration as CDC shares these findings with stakeholders whose scope may differ in breadth.

Strategic Recommendation

To support CDC's interest in improving the experience and quality of data collected and shared by CBOs serving people experiencing homelessness, MITRE presents one, overarching strategic recommendation, two strategic objectives, and six options (1A-2D) as sub-tasks to advance the overall strategy.

The strategic recommendation describes a forward-leaning approach to maximize CDC's strategic partnerships to convene key players in the domain space. Following that, two strategic objectives address key impact areas identified through the ES and TEP. Contained in each objective are sub-task options scoped as individual approaches to achieve the strategy.

STRATEGIC RECOMMENDATION:

Establish a joint working group between CDC and HUD to establish a hub for resources and technical assistance for community based organizations (CBOs) and to support coordinated data modernization efforts across CBOs and key federal agencies

MITRE recommends establishing this joint effort given the predominance of project findings revealing the need for specific collaborative actions between CDC and HUD. Working in collaboration with other leaders in this space, particularly grantors, will ensure accessible resources for CBOs.

This collaboration could support four categories of resources and efforts to support CBOs as follows:

1. Learning and training collaboration around data collection, reporting, monitoring and evaluation, and quality improvement
2. Technical support with HMIS and other technical resources
3. Communication and connection with multi sector partners
4. Establishment of a collaborative longitudinal interagency team to support data coordination efforts and conduct integrated analyses

The ES and TEP findings revealed the need for increased interagency operations as a prerequisite for addressing fragmented technology and data needs. Findings emphasized the importance of homeless health-specific CDC partnerships first and foremost with HUD, and secondarily with stakeholders including the Substance Abuse and Mental Health Services Administration (SAMHSA), Department of Education (ED), Department of Justice (DOJ), and the Department of Labor (DOL).

Any proposed work based on the sub-task recommendations (Options 1A-2D) found within this report will build towards this larger joint platform; the success of any given sub-task will support the success of a multi-agency platform to reduce the complexity of collecting and sharing data at the CBO level. This would provide an invaluable resource to all local organizations regardless of their budgetary constraints.

CDC and HUD both have a history of interagency collaborations that support the potential success of this proposal. One example of CDC's prior collaborations include the North Star Architecture which is a joint investment between CDC and the Office of the National Coordinator of Health IT (ONC) to design a cloud-oriented environment to support efficient integration of public health data systems using modern technologies, data governance, and infrastructure management approaches.[6]

Recommendations by Strategic Objective

This strategic recommendation is delivered alongside two strategic objectives and accompanied options for CDC action.

How to Navigate this Section: For each option, the "Specific Considerations" section is supporting evidence derived from literature, interview, and expert findings. The "Relevant Applications in the Field" section provides resources for lessons learned, case studies, or examples of related successful efforts, and how to use them in the development of CDC courses of action; this sub-section may not be available for all recommendation options. The “Perceived Effort & Impact” section describes the TEP’s estimated level of effort required to develop the Option and its potential impact, as perceived by members of the TEP during Session 3. These effort and impact scores attempt to capture discussion around what’s needed to support CDC’s pursuit of a given Option. It does not, however, reflect a current evaluation of CDC’s internal capacities and constraints governing the feasibility of each Option. Each option also indicates its “Traceability” throughout the course of the project, including its aligned thematic finding, and proposed solutions by the TEP.

STRATEGIC OBJECTIVE 1:

Support CBO data collection by providing technical assistance and resources.

Goal: Provide CBOs with trusted technical coordination and assistance to facilitate adequate data collection and sharing.

OPTION 1A

Support jurisdictions to develop data warehouses that integrate data infrastructure for homelessness and health implemented by studying the cost-effectiveness of “innovator” and “early adopter” jurisdictions.

Desired Outcome:	Enhanced evidence of public health value, utility, cost, and process to support states’ decision-making regarding the feasibility of a data warehouse.
Specific Considerations:	▪ Validate study design with both field experts operating existing data warehouses and at CoCs, homeless prevention services, street outreach services, permanent housing interventions, and vendors . ▪ Jurisdictions at different readiness levels for adopting a data warehouse model may require individualized courses of action, communication plans, and resources based on current and projected capacity (e.g., budget, buy-in); examining states with more limited capacity to operate a data warehouse, and with more limited success, may provide useful insight.

Relevant Applications in the Field:	▪ CDC can leverage guidelines on how to conduct ethical big data governance from the Public Health Data Warehouse maintained by the Massachusetts Department of Public Health for the opioid epidemic. ▪ CDC can review successful data warehouses including the Ohio Human Services Data Warehouse, a multi-phase project to develop a holistic picture of homelessness in Ohio. Efforts involve capturing statewide data elements (e.g., HMIS, health, corrections), and sustaining existing partnerships with the Ohio Development Services, Ohio Housing Finance, and Mental health & Addiction Services.[7]
Perceived Effort & Impact:	Based on a preliminary assessment by the TEP, Option 1A would require a medium-level effort to implement and may result in a medium-level of impact.
Traceability:	Maps to Proposed Solution(s): ▪ Study of utility and cost-effectiveness of state data warehouses to improve data and evidence-based interventions. Original Theme and Finding(s) that prompted TEP discussion: Data Sharing: “Data is siloed by category (school, justice, physical health, mental health, homelessness, etc.);” AND “Organizations are all collecting the same data about the same people versus sharing data with each other.”

OPTION 1B

Increase community-based organizations’ ability to access available and appropriate regional- and national-level support by disseminating a directory of technical and skill-building resources.

Desired Outcome:	Increased capacity of organizations to collect and make use of client data, and improved relationships with individual clients, the community, and public health agencies.

Specific Considerations:	▪ Desired resources span health education, integration solutions, cultural and linguistic competence, organizational sustainability, interoperability and standards, billing practices and financing, communications, and human resources. ▪ Research and crowdsourcing efforts are needed to identify existing resources as well as gaps where resources do not currently exist. ▪ Access to direct technical assistance enables organizations to implement data integration efforts quickly, and complements the benefits of a learning collaborative ▪ A concerted effort is required to improve culturally competent data collection techniques for capturing meaningful behavioral and mental health characteristics. ▪ A nationally available online training library that provides resources for HMIS and data quality improvement could be made available, featuring data use templates, guidelines, legal consideration and resources to enhance availability and usability of technology software and hardware.
Perceived Effort & Impact:	Based on a preliminary assessment by the TEP, Option 1B would require a high-level effort to implement and may result in a medium level of impact.
Traceability:	Maps to Proposed Solution(s): Standard, technical guidance and assistance for CBOs to collect accurate data. Turn-key templates, tools, and guidelines outlining data sharing agreements and processes for bi-directional sharing. Improvement in the collection of behavioral and mental health related data. A nationally available training library providing resources for HMIS and data quality improvement Original Theme and Finding(s) that prompted TEP discussion: Data Collection: CBOs align their data and quality controls around grant reporting requirements, AND HUD requirements and HUD's universal data elements are the primary focus in HMIS data capture and sharing while niche/specialized elements become isolated in custom systems; Data Sharing: There is minimal data sharing between public health agencies and CBOs.

STRATEGIC OBJECTIVE 2:

Enhance housing and health data interoperability by strengthening interagency partnerships and collaboration.

Goal: Improve the quantity and quality of engagements between siloed government agencies to address the nation's complex health and housing data needs.

OPTION 2A

Support state, tribal, local, and territorial bodies to receive impactful, aggregated housing and health data by providing resources to engage across jurisdictional lines and with federal grantors.

Desired Outcome:	Broader access to aggregated data reports with increased geographic coverage, and enhanced data sharing between CBOs and grantors.
Specific Considerations:	▪ Identify the feasibility and potential incentives for federal, state, and local-level agencies to share aggregated data back to CBOs. ▪ Providing consistent, useful data about people experiencing homelessness and services utilized within a grantor's programs (e.g., clients who remain in supportive housing on a 30-, 60-, and 90- day basis) provides value to CBOs and incentivizes CBOs to submit more accurate data. ▪ Consider establishing a standardized reporting schedule for grantors to send aggregated reports back to CBOs, on a quarterly or semi-annual frequency based on administrative constraints. ▪ An effort to map which data elements are requested by which grantors will support more streamlined data reporting. ▪ Consider surveying CBOs about data elements critical to CBOs' knowledge and provision of services that are not currently supported by data standards and reporting requirements.
Relevant Applications in the Field:	▪ There may be value in modeling these data feedback efforts after existing cross-jurisdictional sharing efforts, such as funding opportunities to share services among jurisdictions and grantees, sharing of collaboration tools including through CDC-supported projects, and partnering with national organizations supporting cross-jurisdictional sharing (e.g., Center for Sharing Public Health Services).[8]
Perceived Effort & Impact:	Based on a preliminary assessment by the TEP, Option 2A would require a medium-level effort to implement and may result in a high-level of impact.
Traceability:	Maps to Proposed Solution(s): ▪ Regular data feedback from public agencies to community-based organizations. ▪ Mapping of information type from CBOs to appropriate data receivers (e.g., grantors). ▪ Establish a clear set of data elements desired by CBOs that are missing from current reporting requirements. Original Theme and Finding(s) that prompted TEP discussion: Data Collection: Data gaps and data quality are negatively impacted by outdated and costly technology, non-technical administrators, insufficient and rapid turnover of staff, and fragmented data systems; Data Sharing: Data is siloed by category (school, justice, physical health, mental health,

	homelessness, etc.) and organizations are all collecting the same data about the same people versus sharing data with each other.

OPTION 2B

Break down data siloes by strengthening federal partnerships with the HUD, SAMHSA, ED, DOJ, and DOL.

Desired Outcome:	Improved partnerships and opportunities for integration of health and housing data across federal agencies.
Specific Considerations:	• A concerted effort to develop a validated, standardized instrument to capture housing and homelessness status with review and awareness across relevant agencies is needed. • Creation of data standards related to housing and homelessness (e.g., United States Core Data for Interoperability (USCDI) standards) is critical to data harmonization.
Relevant Applications in the Field:	CDC can leverage existing partnerships between HHS and HUD, including Health Surveys Data Linkages, Department Cross-trainings, and the United Stated Interagency Council on Homelessness.[9]
Perceived Effort & Impact:	Based on a preliminary assessment by the TEP, Option 2B would require a high-level effort to implement and may result in a high-level of impact.
Traceability:	Maps to Proposed Solution(s): 1. Services to assist CBOs with data sharing (e.g., legal guidance). 2. Validated and standardized instrument to capture housing and homelessness status. 3. Concerted interagency effort between CDC and HUD to support technology and training Original Theme and Finding(s) that prompted TEP discussion: Data Collection: CBOs align their data and quality controls around grant reporting requirements; Infrastructure: Data gaps and data quality are negatively impacted by outdated and costly technology, non-technical administrators, insufficient and rapid turnover of staff, and fragmented data systems; Data Sharing: Perceived value to data sharing including potential cost sharing in non-duplication of efforts and direct impact to organization mission and the individual, AND There is minimal data sharing between public health agencies and CBOs.

OPTION 2C

Aid existing and new CoC-level learning collaboratives to improve operations in focused topic areas (e.g., outreach and enrollment data standardization) by studying learning collaboratives' educational approaches, leadership structure, costs, and tools.

Desired Outcome:	Increased engagement and buy-in from a wide range of partners (e.g., federal agencies, state and local health departments, private, academic, information exchanges), and more efficient completion of data integration efforts.
Specific Considerations:	• Each learning collaborative, or network of collaboratives focused on a specific topic area, should consider using human-centered design approaches such as use-cases and personas to visualize specific data users, their characteristics, needs, and interactions with data.
Relevant Applications in the Field:	Leverage previous CDC evaluations of statewide learning collaboratives. Related efforts from other divisions of CDC include the publication of "Recipes for Public Health: Implementing a Statewide Learning Collaborative to Support Clinical Quality Improvement" by CDC Division for Heart Disease and Stroke Prevention.[10]
Perceived Effort & Impact:	Based on a preliminary assessment by the TEP, Option 2C would require a medium-level effort to implement and may result in a high-level of impact.
Traceability:	Maps to Proposed Solution(s): ▪ Convene a learning collaborative to establish data-sharing best practices (e.g., data use agreements). Original Theme and Finding(s) that prompted TEP discussion: Data Collection: CBOs align their data and quality controls around grant reporting requirements; Data Sharing: There is minimal data sharing between public health agencies and CBOs.

OPTION 2D

Improve data quality on homelessness, including the interoperability of systems between community-based organizations, healthcare, and public health, by assembling a committee of stakeholders across federal organizations including HUD and HHS.

Desired Outcome:	A plan for operationalized data interoperability through the establishment of government rules and agreements.
Specific Considerations:	• A common language and data dictionary for housing classifications is a prerequisite for investments in interoperable systems. • A list of requirements, resources, and other considerations that could facilitate providing a continuum of pre-implementation preparation,

	implementation support, and continuity of post-implementation support to community-based organizations to manage interoperable data systems is a frequently expressed need.
Perceived Effort & Impact:	Based on a preliminary assessment by the TEP, Option 1C would require a high-level effort to implement and may result in a high-level of impact.
Traceability:	Original Theme and Finding(s): Infrastructure that prompted TEP discussion: Data gaps and data quality are negatively impacted by outdated and costly technology, non-technical administrators, insufficient and rapid turnover of staff, and fragmented data systems, AND Data is siloed by category (school, justice, physical health, mental health, homelessness, etc.) and organizations are all collecting the same data about the same people versus sharing data with each other. Maps to Proposed Solution(s): A common data dictionary (standardized definitions across state, federal, and local agencies) and common data model, defined as a uniform set of metadata and standardized data schemes.

Recommendations Prioritization

The MITRE team recommends CDC to first consider Options 2A, 2B, and 2C. These Options are restated below:

Option 2A: Support state, tribal, local, and territorial bodies to receive impactful, aggregated housing and health data by providing resources to engage across jurisdictional lines and with federal grantors.

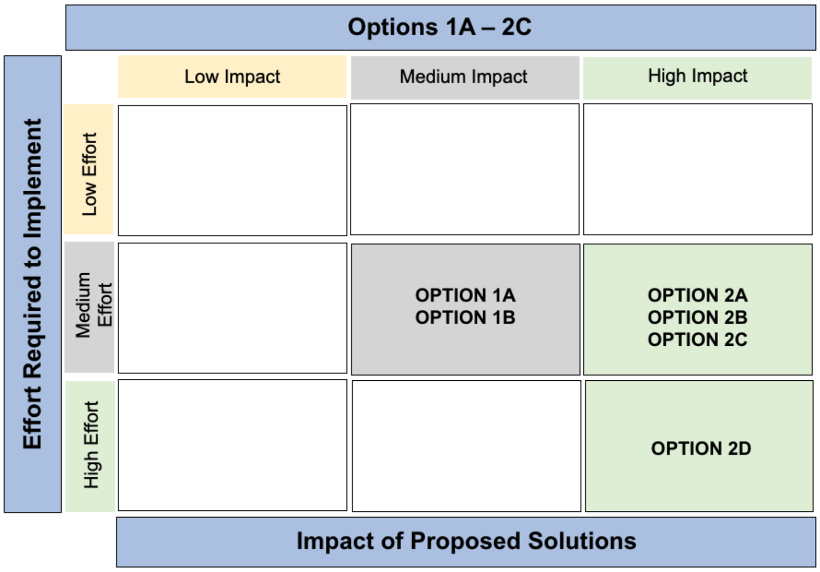
Option 2B: Break down data siloes by strengthening federal partnerships with HUD, SAMHSA (ED), (DOJ), and (DOL).

Option 2C: Aid existing and new CoC-level learning collaboratives to gain quality improvements in focused topic areas (e.g., outreach and enrollment data standardization) by studying learning collaboratives' educational approaches, leadership structure, costs, and tools.

This prioritization considers the TEP's estimated level of effort required to develop each Option, its potential impact, and the specific considerations derived from the ES and TEP.

Of note, the TEP's discussion regarding impact and effort was focused on the resources needed to support CDC's pursuit of a given Option but does not reflect a current evaluation of CDC's internal capacities and constraints governing the feasibility of each Option. The TEP's initial assessment of each option's effort required to implement, and potential impact are displayed in **Figure 3. Options Effort Impact Matrix**. CDC may use this initial assessment to guide further deliberation. Figure 3 categorizes recommendation options based on level of effort (low, medium, high) versus level of impact (low, medium, high) with the most impactful options being highlighted in green (Options 2A, 2B, 2C, and 2D).

Figure 3. Options Effort Impact Matrix



Options 1A – 2C

Effort Required to Implement

	Low Impact	Medium Impact	High Impact
Low Effort			
Medium Effort		OPTION 1A OPTION 1B	OPTION 2A OPTION 2B OPTION 2C
High Effort			OPTION 2D

Impact of Proposed Solutions

Conclusion

CDC is uniquely positioned to bring together key stakeholders to address the challenges faced by CBOs supporting people experiencing homelessness.

By piloting Options 1A-2D, CDC has the opportunity to spearhead and enhance collaboration between federal agencies to address issues of homelessness and health. The success of each potential pilot effort then paves the way to achieving the proposed strategic recommendation and associated objectives.

A joint working group between CDC and HUD would enable key resource sharing for CBOs to address local challenges with speed and agility, facilitate improved utility of federal resources, as well as enhance the flow of data between multiple levels of organizations and government.

Appendix A. Glossary & Acronyms

Term	Definition
Community Based Organization (CBO)	A CBO is an organization that can be non-profit, non-governmental or charitable and that represents community-based needs often associated with a specific area of concern or segment of the community
Continuum of Care (CoC)	A CoC is a regional planning body that coordinates housing and services funding for homeless families and individuals.
Electronic Case Reporting (ECR)	ECR is the automatic real time electronic data sharing of case report information between EHRs and public health authorities for disease tracking.
Electronic Health Records (EHR)	An EHS is an electronic version of a patient's medical history.
Environmental Scan (ES)	An ES is the identification of factors from in and outside organizations that impact an operations long term viability. The ES is a development of "the big picture" of an organization or ecosystem.
Department of Health and Human Services (HHS)	HHS is a cabinet-level executive branch department of the U.S. government created to protect the health of all Americans and providing essential human services.
Homeless Management Information System (HMIS)	An HMIS is a local information technology system used to collect client-level data and data on the provision of housing and services to homeless individuals and families and persons at risk of homelessness. Each CoC is responsible for selecting an HMIS software solution that complies with HUD's data collection, management, and reporting standards.
Department of Education (ED)	ED's mission is to promote student achievement and preparation for global competitiveness by fostering educational excellence and ensuring equal access.
Department of Housing and Urban Development (HUD)	HUD's mission is to create strong, sustainable, inclusive communities and quality affordable homes for all. HUD is one of the executive departments of the U.S. government. It administers federal housing and urban development laws.
Department of Justice (DOJ)	The mission of the Department of Justice (DOJ) is to uphold the rule of law, to keep our country safe, and to protect civil rights.

Term	Definition
Department of Labor (DOL)	The DOL's mission is to foster, promote, and develop the welfare of the wage earners, job seekers, and retirees of the United States; improve working conditions; advance opportunities for profitable employment; and assure work-related benefits and rights.
Key Informant Interview (KII)	Key informant interviews are qualitative in-depth interviews with people who know what is going on in the community.
Memorandum of Understanding (MOU)	An MOU is a document that describes the outlines of an agreement that two or more parties have reached.
NEDDS Base System	The NBS integrates data from many sources on multiple public health conditions to help local, state, and territorial public health officials identify and track cases of disease over time.
National Electronic Disease Surveillance System **(NEDDS)**	A CDC-developed integrated information system that helps local, state, and territorial public health departments manage reportable disease data and transmit notifiable disease data to CDC
Office of the National Coordinator of Health IT (ONC)	ONC is the principal federal entity charged with coordination of nationwide efforts to implement and use the most advanced health information technology and the electronic exchange of health information.
Substance Abuse and Mental Health Services Administration **(SAMHSA)**	SAMHSA is the agency within the U.S. Department of Health and Human Services that leads public health efforts to advance the behavioral health of the nation. SAMHSA works to reduce the impact of substance abuse and mental illness on America's communities.
Technical Expert Panel (TEP)	A TEP is a group of people that share ideas, expertise, and opinions to help develop a quality measure or address another quality topic.
United States Core Data for Interoperability (USCDI)	The USCDI is a standardized set of health data classes and constituent data elements for nationwide, interoperable health information exchange.

Appendix B. TEP Member List

Member	Organization
Bobby Watts (Co-chair)	National Healthcare for the Homeless Council (NHHC)
Sara Black (Co-chair)	National Association of County and City Officials (NACCHO)
Suma Nair	Health Resources and Services Administration
Chau Nguyen	Health Resources and Services Administration (HIV/AIDS Bureau)
Amy Griffin	Health Resources and Services Administration (HIV/AIDS Bureau)
Donald Whitehead	National Coalition for the Homeless
Denise De Las Nueces	Boston Health Care for the Homeless
Ted Henson	National Association of Community Health Centers
Katie Yorick	Baltimore City Mayor’s Office of Homeless Services
Sharon McDonald	National Alliance to End Homelessness
Jillian Weber	Department of Veterans Affairs
Dina Hooshyar	Department of Veterans Affairs
Leeanne Sacino	Florida Coalition to End Homelessness
April Emory	The Boulevard of Chicago
Camey Christenson	Community Information Exchange San Diego
Katie Jennings	United States Interagency Council on Homelessness
Katie Haverly	Everyone Home
Socrates Aguayo	NCCARE 360 (Unite Us)
Stephanie Savard	New Hampshire Coalition to End Homelessness
Beth Sandor	Community Solutions

Appendix C. Stakeholders

Organization	Relationship to CBOs	Level of Influence
Community Based Organizations (CBO)	Can include public HUD funded and private non-HUD funded organizations.	Local
People Experiencing Homelessness	The clients that CBOs serve.	Local
Continuum of Care (CoC)	A local collection of CBOs that coordinate services throughout the CoC area (county, region, state). The CoC lead is typically the data lead and responsible for reporting to funders.	Local
Physical Health Providers	Providers assist people experiencing homelessness with any medical needs such as substance use, dentistry, vaccinations. These services are either provided directly or are coordinated through the CBO.	Local
Mental Health Providers	Therapy and behavior health services are provided to people experiencing homelessness, especially to those that have a mental disorder or past trauma. These services are either provided directly or are coordinated through the CBO.	Local
Health Information Exchange (HIE)	Some regions share information across hospitals using HIEs that CBOs can access as a data source for new people experiencing homelessness entering their care.	Local
School Districts	Families experiencing homelessness are still required to send kids to school as part of their care. School districts may also identify possible people experiencing homelessness through interactions with the kids for CBOs to follow up with.	Local
Local Justice Department	Some CBOs provide legal services or are supporting people experiencing homelessness with criminal records that requires information sharing. CBOs also provide services to people experiencing homelessness transitioning from prison or found from law enforcement that requires coordination.	Local

Organization	Relationship to CBOs	Level of Influence
Homeless Management Information System (HMIS) vendors	HMIS systems are the main data repository for CBOs and is used for reporting to funders. In order to be classified as an HMIS system, HUD has a set of requirements that vendors must meet in their system. The requirements change yearly, which limits how many HMIS vendors CBOs can choose from.	Local
Public Health Agencies (PHA)	CBOs are required to report disease surveillance and other pandemic related data (for COVID-19) to their local PHA. There are also special programs related to people experiencing homelessness with HIV/AIDs that need to be reported on.	Local/State
Local Government	CBO must report data to either the city or state government department in charge of managing people experiencing homelessness for their region. Policies and mandates are also handed down to CBOs that they must adhere to.	Local/State
Department of Housing and Urban Development	HUD is the federal agency in charge of managing people experiencing homelessness and gives most of the funding that CBOs use to provide services. CBOs are required to report Universal Data Elements and program specific data elements up to HUD regularly as a condition of the funding.	National
HUD's Special Needs Assistance Programs (SNAPS)	SNAPS is the office within HUD that CBOs interact with as part of their grant funding.	National
Centers for Disease Control and Prevention	Provides guidance to PHAs on how to conduct disease surveillance on people experiencing homelessness, especially during pandemics like COVID-19.	National
Department of Education	Utilizes the local school districts to collect data on people experiencing homelessness students independently from CBOs, which causes a duplication of data collection.	National
Department of Justice	Provides guidance to local justice departments and law enforcement on how to support people experiencing homelessness. This support requires collecting information on the people experiencing homelessness that is not always shared with CBOs.	National

CMS Alliance to Modernize Healthcare (Health FFRDC)

Organization	Relationship to CBOs	Level of Influence
Department of Veterans Affairs	Any people experiencing homelessness veterans qualify for additional programs funding through Veterans Affairs. These programs have additional reporting requirements specific to their service history.	National
The Administration for Children and Family (ACF)	Families or youth experiencing homelessness that have recently left the foster program can utilize additional support programs through ACF. These programs have additional data that needs to be reporting to ACF.	National
National Homelessness organizations (e.g. National Health Care for the Homeless Council)	Large organizations that work across the nation to support CBOs with training, research, and advocacy (e.g. lobbying government for new laws/policies to assist CBOs).	National
Health Resources and Services Administration (HRSA)	The HIV/AIDS Bureau of HRSA administers the Ryan White HIV/AIDS Program, which provides a comprehensive system of care for people with HIV that CBOs can utilize for their people experiencing homelessness.	National

Endnotes

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[2] State of Homelessness: 2021 edition. National Alliance to End Homelessness. (2021, August 16). Retrieved May 10, 2022, from https://endhomelessness.org/homelessness-in-america/homelessness-statistics/state-of-homelessness-2021/

[3] National Coalition for the Homeless. (2018, December 21). REMEMBERING THOSE LOST TO HOMELESSNESS. National Coalition for the Homeless. Retrieved May 10, 2022, from https://nationalhomeless.org/category/mortality/#:~:text=People%20who%20experience%20homelessness%20have,mental%20health%2C%20and%20substance%20abuse.

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[5] Wilson, M. G., Lavis, J. N., & Guta, A. (2012). Community-based organizations in the health sector: a scoping review. Health research policy and systems, 10, 36. https://doi.org/10.1186/1478-4505-10-36

[6] Centers for Disease Control and Prevention Public Health Surveillance and Data. (July 22, 2022). Advancing Interoperability for Public Health. Retrieved July 25, 2022, from https://www.cdc.gov/surveillance/policy-standards/interoperability.html#:~:text=Our%20goal%20with%20data%20modernization,make%20the%20data%20more%20interoperable.

[7] Ohio Human Services Data Warehouse (2022). “The Data Warehouse - Statewide Data Consolidation, Reporting, Creating Linkages.” Retrieved July 21, 2022 from https://ohiohome.org/research/documents/ODW_brochure.pdf

[8] Centers for Disease Control and Prevention Public Health Professionals Gateway (August 21, 2018). “CDC Activities & Resources.” Retrieved July 27, 2022 from https://www.cdc.gov/publichealthgateway/cjs/activities.html

[9] Bipartisan Policy Center (June 2018). “HUD-HHS Partnerships: A Prescription for Better Health.” Retrieved June 20, 2022 from https://bipartisanpolicy.org/download/?file=/wp-content/uploads/2019/03/HUD-HHS-Partnerships-A-Prescription-for-Better-Health.pdf

[10] Centers for Disease Control and Prevention (June 20, 2018). “Implementing a Statewide Learning Collaborative to Support Clinical Quality Improvement.” Retrieved July 13, 2022 from https://www.cdc.gov/dhdsp/evaluation_resources/maryland.htm

H-CAP
HEALTHCARE CAREER
ADVANCEMENT PROGRAM

October 3, 2022

Denice Ross
U.S. Chief Data Scientist
White House Office of Science and Technology Policy (OSTP)

RE: Engagement and Accountability RFI - Advancing Equity with Community Data Partnerships

Dear Chief Data Scientist Ross,

The Healthcare Career Advancement Program (H-CAP) welcomes the opportunity to respond to this Request for Information by the White House Office of Science and Technology Policy. H-CAP is a national labor-management organization of SEIU locals and healthcare employers that partner on developing high-quality and innovative workforce solutions, including with nursing home employer partners and SEIU-represented nursing home workers. Our labor-management partnerships span 16 states plus D.C. and cover more than 1,000 employers and 550,000 workers, enabling front-line healthcare workers access to training benefits through collective bargaining.

We would like to focus our comments on Question 7 of the RFI: **"In which agencies, programs, regions, or communities are there unmet needs, broken processes, or problems around participation and accountability that could be remedied through stronger collaborations and transparency around equitable data?"** We would particularly like to bring to your attention the importance of advancing equitable data in the direct care workforce system.

Background

At H-CAP, we are proud that the majority of healthcare workers covered under our labor-management partnerships are primarily women and women of color, traditionally marginalized workers who face high levels of occupational segregation and limited access to career advancement. The frontline direct care workers (primarily home care aides and nursing assistants) covered under our labor-management agreements face particularly challenging working conditions that are exacerbated by structural racism and sexism: 86 percent of direct care workers women and 59 percent of direct care workers are people of color.[1] Direct care workers have long dealt with poor job quality—including minimum or unlivable wages, few to no benefits, inconsistent schedules and part-time hours forcing caregivers to work multiple jobs, limited career advancement options, and more—that were exacerbated and illuminated by the COVID pandemic. These untenable working conditions have led to unprecedented staff turnover rates in nursing homes and ever-increasing demand for home care workers. Direct care workers are essential workers whose physical and emotional labor as home care workers, personal care aides, and certified nursing assistants supports older adults and people with disabilities living with dignity.[2] Yet data collection on the direct care workforce has not kept up with the pace of the care crisis.

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[1] Stephen Campbell et.al, "Caring for the Future: The Power and Potential of America's Direct Care Workforce," PHI, 1/12/21. Available at: https://www.phinational.org/resource/caring-for-the-future-the-power-and-potential-of-americas-direct-care-workforce/

[2] Scales, K. (2021). It Is Time to Resolve the Direct Care Workforce Crisis in Long-Term Care. The Gerontologist, 61(4), 497–504. https://doi.org/10.1093/geront/gnaa116

Accurate, robust, and accessible disaggregated national and regional workforce data (i.e., labor and job quality data broken down by worker demographics) does not exist, leaving policymakers, government officials and employers largely unequipped to target the unique challenges facing direct care workers and improve care quality for consumers, especially BIPOC older adults and people with disabilities. The longstanding limitations of data on the direct care workforce that persist today are no surprise. American labor laws intentionally excluded the majority BIPOC women and immigrant direct care workforce from the benefits and protections afforded whiter, more male workforces.[3] Structural systems of racism and sexism institutionalized data inequity, and those systems must be confronted to envision an equitable national workforce data system.

We believe that your administration is uniquely positioned to lead on remediating this equitable data issue because low quality direct care jobs are largely financed by public dollars. In 2020, over 72 percent of long-term services and supports (LTSS) provided by direct care workers were paid for by a mix of federal and state government funds.[4] To address the care crisis, federal government agencies—especially since Medicaid is the primary payer of direct care workers' wages—could lead the way to create a workforce data system that works with workers and communities to ensure necessary information on the essential workforce of caregivers is centralized and disaggregated for the first time ever. By envisioning data systems that promote dynamic workforce development program design and assessments, the government can maximize the impact of public funding, ensure public dollars are spent on good quality, family-sustaining jobs, and support states in course-correcting on the racist, sexist legacy of care work in America.

Summary of Problems in the Current Direct Care Workforce Data System

The below summary of the problems in the current data system for direct care workers are well-documented by several sources, including the U.S. Government Accountability Office[5] in 2016, and the National Direct Service Workforce Resource Center[6] in a 2009 report ordered by the Center for Medicare and Medicaid Services, respectively.

- **There is no federal hub for consistent, reliable information about all aspects of the direct care workforce:** Instead, three main federal datasets are available: The Census Bureau's American Community Survey, the Bureau of Labor Statistics (BLS)' Occupational Employment Statistics, and BLS' National Compensation Survey. These are typically cross-referenced by researchers and analysts to attempt to build an aggregate, or summary, picture of the national workforce based on relatively small samples.[7] The only publicly accessible federal data on basic direct care working conditions and compensation, such as wages and benefits, is limited to averages across the sectors of samples of workers employed in covered industries, rather than individual workers' actual compensation. Covered industries include home health

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[3] "The Racial Equity and Job Quality Crisis in Long-Term Care." (2021, May). The Center for Advancing Racial Equity and Job Quality in Long-Term Care. https://centerforltcequity.org/wp-content/uploads/2021/06/CFE-Framework7.pdf

[4] Colello, K. (2022, June). Who Pays for Long-Term Services and Supports? Congressional Research Service: IF10343, Version 9. Available at: https://crsreports.congress.gov/product/pdf/IF/IF10343#:~:text=Each%20state%20designs%20and%20admini

[5] "Long-Term Care Workforce: Better Information Needed on Nursing Assistants, Home Health Aides, and Other Direct Care Workers." (2016, August). United States Government Accountability Office (GAO), GAO-16-718. https://www.gao.gov/products/gao-16-718

[6] Edelstein, S., & Seavey, D. (2009). The Need for Monitoring the Long-Term Care Direct Service Workforce and Recommendations for Data Collection. National Direct Service Workforce Resource Center. pp. 8. https://phinational.org/resource/the-need-for-monitoring-the-long-term-care-direct-service-workforce-and-recommendations-for-data-collection-2/

[7] Ibid.

agencies and nursing homes but leaves the hundreds of thousands of direct care workers who are independent home care providers out. Since federal data is available for the sector, not individual workers, disparities in wages and benefits across different race, gender and other identifying demographics of workers are obscured within the same sector.

- **Many workers are not counted or are undercounted:** Direct care workers who work as independent providers in private homes whose clients take on all employer-related roles including pay and tax reporting, as well as those employed in the “gray market” (i.e., are paid cash or “off the record” in private households), are often not counted at all.[8] The very job titles that are considered direct care occupations are not standardized across the three federal datasets, and do not encompass the full picture of caregivers employed to provide LTSS. For example, the U.S. Government Accountability Office (GAO) states in its 2016 review that the federally available data’s inclusion of independent providers employed directly by consumers to provide personal care services through state-administered Medicaid programs is “unclear” and varies by state.[9]
- **The lack of a federal mandate and designated funding for comprehensive data collection and maintenance on the workforce leaves states to piece together what they can with limited resources:** The lack of a comprehensive federal dataset leaves a gap for states to fill (or not) with their own workforce data collection systems. As the National Direct Service Workforce Resource Center found in 2009 in a report documenting workforce data gaps that remain today:

  > “[T]he vast majority of states do not have access to basic quantitative information that describes the state of the workforce in place to deliver services and supports to people with various kinds of disabilities. Nor do they have the data needed to support a comprehensive workforce strategy across service settings. Instead, various program, agency, and departmental ‘silos’ collect their data independently, and even then, workforce data is rarely a dedicated focus, contributing to an ad hoc or disjointed approach.”[10]

- **Gaps in demographic data and inconsistencies across how datasets account for workers’ identities makes understanding how to address the labor market issues through targeted, equity-based policymaking challenging:** Broadly, there is no one centralized national data system that enables equity-focused analysis. The direct care workforce is one of the most diverse workforces in the country. Direct care workers’ experiences vary within the same job classifications and settings of direct care, in similar geographic areas regionally and across states, based on their intersectional identities—race, gender, sexual orientation, immigration status and country of origin, age, disability, and more—impacts the different wraparound supports that workers need to stay in emotionally and physically grueling frontline care jobs, such as reliable transportation, child care, mechanisms to prevent and respond to harassment and discrimination, and culturally responsive management. Yet the lack of demographically disaggregated data hamstrings policy and program efforts to address the challenges that workers of different identities may face, and particularly obscures inequities within the workforce, such as access to opportunities for higher wages, better benefits, career mobility, advancement, and paid training in the field.

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[8] U.S. GAO, (2016), https://www.gao.gov/products/gao-16-718
[9] U.S. GAO, 2016. https://www.gao.gov/products/gao-16-718
[10] Edelstein, S., & Seavey, D. (2009). https://phinational.org/resource/the-need-for-monitoring-the-long-term-care-direct-service-workforce-and-recommendations-for-data-collection-2/

Key Recommendations to Advance Equitable Data in Caregiving

A wholesale redesign of the fragmented LTSS workforce system is beyond the scope of this Request for Information. However, there is much in terms of data collection, transparency, and maintenance that would improve some of the current challenges around participation and accountability tremendously. We recommend that the federal government leverage its position as the majority payer of LTSS to implement a "floor" of direct care workforce data collection standards by tying public investments to equitable, worker-centered data system requirements and incentives in the states in the following ways:

1) **Create a federal standard dataset of direct care workforce data which sets a "floor" for states to build upon:** A reimagined direct care workforce system would rely on the national dataset as a floor that could be tailored on a state-by-state basis to the needs of specific communities of workers and their families by seeking robust input from impacted stakeholders, including local workers, consumers, caregiver unions, employers and providers. In establishing a federal standard dataset of workforce information about providers, payers, residents and consumers, worker characteristics, and job quality information, the federal government can at last create a repository of information that policymakers, advocates, employers—and importantly, workers and communities—can access to make informed, successful policy and program decisions.

   Creating a federal standard direct care workforce dataset is deeply aligned with Executive Order 13985 (January 20, 2021) and so-ordered Recommendations from the Equitable Data Working Group. A foundational step in creating the federal standard dataset will be establishing a standard definition of direct care and the direct care worker job classification, to align the lack of standardization in job titles across the three existing federal datasets as described above in the discussion of problems in the data system. This would create a single job classification for data management purposes that captures information about home health aides, personal care aides, and nursing assistants providing LTSS across differing state programs. The new direct care worker job classification would be used as the least specific category in the federal standard dataset for understanding data across the workforce, and more specific job titles such as CNA could still be included for analysis if desired.

2) **Coordinate the national data collection effort:** Addressing decades and decades of neglecting to document direct care workers' experiences will require a coordinated national effort. The workforce data housed in the federal standard dataset recommended in this framework will need to be collected and tracked by the states due to our nation's fragmented LTSS system and myriad of different programs across the states. To standardize the data system, all federal agencies that touch direct care workforce issues, including Health and Human Services Agency (HHS), Center for Medicare and Medicaid Services (CMS), the U.S. Department of Labor (U.S. DOL), and the Administration for Community Living (ACL), should create regulatory "strings" to tie public investment to and federal matching and reimbursement dollars to states' implementation of equitable data systems. Tying public investment would include both incentivizing states and providers to participate in data systems reforms through increased federal Medicaid matching rates, for example, and penalizing those who do not comply. These regulatory strings should include requiring standardized collection of basic workforce data, race, gender and other worker demographic data, and data on indicators of job quality, such as job stability, wages and benefits as compared to cost of living, and more.

3) **Recommend to Congress and administrative agencies that designated federal funds should be appropriated to equitable data collection and system maintenance:** Mandating data collection in standard categories will require collecting data from many actors in the workforce system, including governments acting as employers of record in LTSS systems, fiduciary management systems handling payroll for independent providers, managed LTSS health plans, and employers/ service providers who are licensed by federal and/or state government agencies or are reimbursed with any public funds or through public insurance programs. To ensure that comparable data is collected across the workforce and that this significant administrative and labor-intensive data collection process is thorough, designated federal funds to on-ramp new data collection and support ongoing data management should be appropriated through HHS, CMS, U.S. DOL, and ACL in a coordinated manner. States and providers face over-stretched capacity and budgets, so it is crucial that additional federal funds that are carved out for data collection and maintenance to prevent shrinking the funds available to pay direct care workers' wages and benefits in an already under-resourced LTSS system—and large-scale investment in the direct care workforce and Medicaid LTSS on the scale of the original "Build Back Better" plan will be key to overarching system reform.

4) **Collect robust demographic data in standardized categories and disaggregate the federal standard dataset to facilitate cross-referencing and equity assessments:** Currently, limited raw data on the direct care workforce is collected on a national basis containing sufficient demographic indicators for analysts and policymakers to parse out inequities experienced by people with intersecting marginalized identities, particularly women and people of color.[11,12] A federal standard dataset should include collecting individualized, raw data on race, ethnicity, gender, sexuality, age, immigration status, disability status, and any additional identity categories that workers and stakeholders determine to be relevant, alongside basic job quality data on compensation rates, benefits, service duration and turnover, etcetera. Standardizing the demographic categories according to direct care workers' preferences is critical to ensure that the resulting data collected from workers across the country, in states with different demographic population distributions and divergent ways of talking about their preferred identity and can be analyzed.

   One international example to look to in doing this is the recent national effort in Canada to consult the public on statistical standards being developed for data collection on gender and sexual diversity to allow for the reporting of statistically diverse groups of the population in a consistent manner nationally that better reflected how Canadians describe themselves. The responses from the public consultation on preferred self-identification resulted in a range of standardized categories to be used in data analysis, from "LGBTQ2+" as the "least detailed" category level to support comparison across the largest available sample size, to more detailed standardized categories that reflect higher specificity but comprise of smaller sample sizes. In effect, people who reported their gender or sexuality in a "less common" manner of self-identifying can be counted at scale under the LGBTQ2+ umbrella yet also be counted in their preferred self-identification category in the raw data.[13]

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[11] We All Count. "The Data Equity Framework." N.d. https://weallcount.com/the-data-process/

[12] D'Ignazio, C. and Klein, L. "Introduction: Why Data Science Needs Feminism." (2020). 19-20. In Data Feminism. Retrieved from https://data-feminism.mitpress.mit.edu/pub/frfa9szd

[13] "Participate in the consultation on gender and sexual diversity statistical metadata standards." (29 January 2021). Statistics Canada. https://www.statcan.gc.ca/en/concepts/consult-variables/gender

To assist policymakers in developing and implementing policy solutions that will truly advance equity and address the job quality issues contributing to worker recruitment and retention issues, the raw data included in the federal standard dataset should be able to be disaggregated by as many identity categories as possible (with individuals de-identified for privacy). The disaggregated categories and measures in the federal dataset can be cross-referenced to identify targeted solutions, such as how caregivers' earnings or poverty status differs depending on intersecting identities.

5) **Mandate meaningful worker engagement and participatory, community-led data collection, and utilize a Black Women Best model and "data feminism" framework:** A truly equitable data framework for the direct care workforce requires intentional engagement with workers themselves, with an emphasis on consulting workers from a wide range of identities. A participatory data collection process would include designing and conducting surveys and any other data collection methods with workers, rather than "about" workers, such as conducting Feminist Participatory Action Research (FPAR). These methods center workers as "experts by experience," with external researchers sharing power equally with workers, and ensures workers maintain ownership over their personal information and are compensated accordingly for their expertise and labor.[14] Collection should also require informed consent from participants about what the data will be used for and culturally responsive, respectful question-asking in the respondents' preferred language and utmost consideration for workers' privacy and security. The resulting de-identified dataset should be accessible and publicly available to all.

   Furthermore, equitable direct care worker engagement means centering women and nonbinary people, particularly Black, indigenous, and women of color, who disproportionately make up the backbone of the caregiving workforce, in data collection, analysis, and any policy decisions implemented using the data. Black women are overrepresented in the direct care workforce and often endure the worst of its inequities. "Black Women Best" is a foundational economic framework that says when Black women's economic well-being is centered in policy, everyone's well-being is better off, and the entire economy ultimately thrives. The federal standard dataset and worker engagement strategy should be designed to ensure Black women are set up to succeed and be counted.

6) **Center workers in their own words by designing and implementing the first national worker-centered survey of direct care workers:** Centering direct care workers' lived experiences and position as the true policy experts in their own lives is another key component of solving the care crisis. In addition to standardizing data collection on quantitative and demographic indicators, a comprehensive workforce data equity strategy would include developing a national workforce experience survey to administer to workers across the country on a regular basis, for example, biannually. By engaging workers and stakeholders in developing such a survey, rich experience data can be collected on a large scale for the first time to better understand the challenges facing BIPOC and women direct care workers in their own

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[14] U.K.-based organization FLEX documented a detailed overview of applying a worker-centered FPAR approach: https://www.labourexploitation.org/publications/experts-experience-conducting-feminist-participatory-action-research-workers-high-risk

words and support the advancement of equity and job quality through targeted policy changes and investments.[15]

7) **Pursue additional policy avenues to increase data collection on direct care workers employed in private homes in "off-the-record," or "gray market" employment arrangements**: While collecting comprehensive data on the home care workers employed in the "gray market" in private homes is outside of the scope of the federal standard dataset suggested in this framework given that the requisite data must be provided by government agencies and providers that are already "on record" as a part of the workforce system, other available pathways to count gray market workers should be pursued. Government agencies should spearhead this effort, especially since gray market workers are disproportionately immigrants who face isolating and unprotected working conditions. As PHI (2021) argues, BLS, the U.S. Census Bureau, and other agencies should integrate additional questions related to immigrants in relevant federal surveys, and HHS should also fund new studies on immigrants working in the gray market, with ethical standards for conducting this research without threatening the safety and security of respondents.[16]

H-CAP applauds the Office of Science and Technology Policy for taking bold steps to advance equitable data initiatives that will benefit Americans in communities across our country. At H-CAP, we believe that data matters, and equitable data systems (or the lack thereof) showcase our nation's values. The United States should collect robust, worker-centric data on the essential direct care workforce because caregivers matter, as do the millions of people with disabilities, older adults, and families who rely on LTSS each day. We must create a just data system to assess the current challenges facing the direct care workforce and equip leaders with the information needed to design caregiving systems to advance equity and job quality and benefit everyone. We appreciate the opportunity to share our thoughts on ways to advance equitable data in one of our nation's most vital and vulnerable workforces.

We would be happy to continue to communicate with OSTP as the Administration's equitable data initiatives continue to move forward in the coming months and years. If you have any questions or feedback about this comment letter, please contact Breanna Betts, Policy Analyst, a [redacted]

Sincerely,

Daniel Bustillo
Executive Director
Healthcare Career Advancement Program (H-CAP)

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[15] The California Health Interview Survey (CHIS) offers an example of a comprehensive, disaggregated population-based survey: https://healthpolicy.ucla.edu/chis/about/Pages/about.aspx. It is the largest state health survey in the nation in which more than 20,000 Californians in each county are interviewed each year to provide robust data that is statistically representative of the state's diverse population, and renowned for its data on ethnic subgroups and gender & sexual orientation.

[16] Federal Policy Priorities for the Direct Care Workforce. (2021). PHI. https://www.phinational.org/resource/federal-policy-priorities-for-the-direct-care-workforce/

OPRE Report Number 2022 214 | September 2022

Applying Human-Centered Design to Human Services: Pilot Study Findings

Desiree W. Murray, Kristina Rosinsky, Maggie Haas, Asaph Glosser, and Suzanne Boyd

Applying Human-Centered Design to Human Services: Pilot Study Findings

OPRE Report Number 2022-214
September 2022

Desiree W. Murray, Kristina Rosinsky, Maggie Haas, Asaph Glosser, and Suzanne Boyd

Submitted to:
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Office of Planning, Research, and Evaluation
Administration for Children and Families
U.S. Department of Health and Human Services

Contract Number: HHSP233201500034I

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Suggested citation: Murray, D.W., Rosinsky, K., Haas, M., Glosser, A., & Boyd, S. (2022). *Applying Human-Centered Design to Human Services: Pilot Study Findings*, OPRE Report 2022-214, Washington, DC: Office of Planning, Research, and Evaluation, Administration for Children and Families, U.S. Department of Health and Human Services.

This report and other reports sponsored by the Office of Planning, Research, and Evaluation are available at http://www.acf.hhs.gov/opre.

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Acknowledgements

The authors thank the staff at each of the three agencies that participated in the pilot study for their time and feedback:

- Denver Human Services
- Santa Clara County Social Services Agency
- Washington State Division of Child Support, Department of Social and Health Services

In addition, the authors thank the following individuals from the Administration for Children and Families, Office of Planning, Research, and Evaluation (OPRE) for their significant contributions to this project:

- Valeria Butler
- Erin Cannon
- Kathleen Dwyer

The authors also thank staff from the Administration for Children and Families Office of Child Support Enforcement, Office of Head Start, Office of Family Assistance, and Office of Child Care for their input on this project and/or review of this report.

Finally, the authors thank their colleagues who contributed to this project:

- **Aesha Bhattacharya, Taylor Collins, and Tori Leonard** from Anthro-Tech
- **Jennifer Cleveland, Asiya Kazi*, Kerensa Nagle*, Jenita Parekh, Sara Shaw*,** and **Lauren Supplee*** from Child Trends (an asterisk indicates the individual is a former Child Trends staff member)
- **Marisa Putnam** from MEF Associates

The views expressed in this publication do not necessarily reflect the views of these individuals or organizations.

Please note that some content presented in this report has been taken verbatim from another product produced as part of the Human-Centered Design for Human Services (HCD4HS) project: Rosinsky, K., Murray, D.W., Nagle, K., Boyd, S., Shaw, S., Supplee, L., & Putnam, M. (2022). *A Review of Human-Centered Design in Human Services*, OPRE Report 2022-78, Washington, DC: Office of Planning, Research, and Evaluation, Administration for Children and Families, U.S. Department of Health and Human Services.

Expert Advisory Group Members

The authors thank the following members of the Human-Centered Design for Human Services (HCD4HS) expert advisory group. These individuals were selected for their expertise in the implementation and/or study of human-centered design. Selections were made collaboratively between the Office of Planning, Research, and Evaluation (OPRE) at the U.S. Department of Health and Human Services' Administration for Children and Families (ACF), Child Trends, Anthro-Tech, and MEF Associates. The views expressed in this publication do not necessarily reflect the views of these members.

- **George Aye,** Greater Good Studio
- **Blair Corcoran de Castillo**, Fannie Mae
- **Emily Ianacone**, Mayor's Office of Innovation, Baltimore
- **Tracy Johnson Messinger**, Bill and Melinda Gates Foundation
- **Anne LaFond**, John Snow Inc.
- **John Nash**, University of Kentucky
- **Jodi Sandfort**, University of Washington

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Overview

Human-Centered Design (HCD) is a process and a mindset for addressing complex problems by designing solutions with those who will ultimately use the solution (i.e., end users). Because of its inherent focus on end users or recipients of services, HCD appears to have potential for promoting effective, efficient, and compassionate service delivery that is aligned with the mission of the U.S. Department of Health and Human Services' Administration for Children and Families (ACF). Despite this appeal, the implementation of HCD within human services is relatively novel.[1,2] There has been little empirical work to date on how HCD might be used to improve outcomes of interest to ACF programs.

Project Goals and Research Questions

In 2018, ACF's Office of Planning, Research, and Evaluation (OPRE) initiated the Human-Centered Design for Human Services (HCD4HS) project to explore the viability of HCD in addressing the complex problems facing public sector human services programs. The HCD4HS project team was comprised of Child Trends, Anthro-Tech, and MEF Associates. This project included a review of the knowledge base to define HCD and describe how it has been used and evaluated in the human services context, and a pilot study to evaluate the implementation of HCD, with a focus on assessing its evaluability.

This pilot study sought to answer the following research questions:

1. What types of challenges within ACF programs are best suited for an HCD approach?
2. What resources are required to implement HCD approaches in ACF programs?
3. What systemic or cultural barriers may make implementation a challenge, and can those be mitigated?
4. What does HCD implementation look like?
5. How can the HCD approach be evaluated in order to better understand outcomes of interest to ACF? Can HCD be evaluated to determine whether or not this approach is more or less successful than traditional approaches?
6. What criteria are defined as successful outcomes when evaluating this process?
7. Were improvements observed on outcomes of interest for end users?
8. Were improvements observed within the organization?

Methods

The HCD4HS project selected three human services agencies that administer different ACF-funded programs, have different end users, and are likely to successfully implement HCD based upon their readiness, including need, fit, resources, and capacity: Denver Human Services, Santa Clara County Social Services Agency, and Washington State Division of Child Support. These sites were identified through a structured recruitment process and were selected from 32 human services agencies or programs across the country that self-nominated.

The pilot study implemented a capacity-building approach in which HCD consultants from Anthro-Tech provided ongoing HCD training and coaching to a team of staff at each agency (the "design team") who carried out the HCD activities. Training began with an introductory workshop in January 2021; Design

Thinking Workshops were held in the summer of 2021; and coaching occurred from February through December 2021. Design teams received an average of 7-9 hours of coaching support per week. Evaluation data were collected throughout most of the implementation period, beginning in February 2021 and ending in November 2021.

The HCD4HS pilot study used a mixed methods evaluation approach in which similar questions were asked of different individuals participating in the pilot study, in different formats. For example, some data were collected as weekly and monthly logs to assess the consistency of implementation experiences across time. To address the research questions, the project developed of a suite of measures for use in this evaluation based on the literature, which included:

- Design Team Logs,
- HCD Consultant Logs,
- Content Expert Logs,
- Interview protocols for design teams and HCD consultants, and an
- Implementation Assessment tool (a semi-structured group interview assessing key aspects of implementation in a manner that is quantifiable).

Key Findings and Discussion

This project contributes to current understanding of how HCD can be evaluated within a human services context by:

- Formalizing a Theory of Change,
- Developing new evaluation tools and testing methods, and
- Identifying key findings regarding implementation of a capacity-building approach for HCD in this context.

Responses to the initial research questions for the pilot study are provided below. Of note, not all the questions could be fully addressed.

- All three sites appeared to make good progress in addressing very disparate challenges: Temporary Assistance for Needy Families (TANF) cliff effect, staff engagement, and completion of child support order modifications. However, given that there were only three sites, we cannot fully address which types of challenges within the broad range of ACF programs may be *best* suited for HCD.
- Design teams identified project management, leadership support, and incentives for end user participation as critical resources for implementation of HCD, similar to implementation of other change initiatives.
- Design teams identified primary barriers as time and capacity, recruitment of end users, getting incentives in place to encourage end user participation, and organizational structures and processes.
- Using a capacity building approach, all design teams participated in an initial HCD Primer workshop (24 hours) followed by 11 months of training and coaching from an HCD consultant (average of 5 hours/week) and content expert (average of 2-4 hours/week). All training and coaching were provided virtually.

- Design teams clearly demonstrated HCD principles related to empathy and collaboration. Demonstration of some principles varied across site, time, and reporter. The evaluation timeline precluded full assessment of all principles.
- Given limitations of existing measures, this project developed tools including weekly and monthly logs of HCD activities, interviews, and an Implementation Assessment assessing HCD principles, process, and mindset. However, the project timeline precluded evaluation of solutions, including outcomes for end users. In order to compare HCD to other approaches, different tools would likely be needed.
- Given that design teams did not get to the HCD phase where they would implement their solution, outcome improvements for end users could not be assessed.
- All design teams demonstrated an HCD mindset by demonstrating empathy; openness to the opinions and perspectives of end users and others; and adopting new ways of identifying challenges, brainstorming, and trying different ideas. They also demonstrated a bias toward action.

Additional key findings also emerged that supplement the initial research questions, as follows:

- HCD can be evaluated systematically in human services programs with a variety of theoretically-driven data collection tools, although more work is needed in measure development.
- With expert training and coaching, design teams demonstrated HCD principles and implemented a range of HCD techniques with different challenges, end users, and contexts.
- From early in the evaluation, design team members demonstrated an HCD mindset, including empathy for end users, openness to different opinions and perspectives, and new ways of identifying challenges and brainstorming.
- Design teams demonstrated capacity for HCD through using strategies competently, building confidence, developing processes to support sustainability, and addressing challenges that arose.
- HCD was found to be useful and relevant in addressing disparate challenges across three sites, and each site had interest in continuing to use HCD in some ways.

Executive Summary

Human services programs address complex social issues ranging from supporting healthy relationships, child welfare, and economic mobility, to providing high-quality, accessible early childhood programs. Because of its inherent focus on end users or recipients of services, human-centered design (HCD) appears to have potential for promoting effective, efficient, and compassionate service delivery that is aligned with the mission of the U.S. Department of Health and Human Services' Administration for Children and Families (ACF).[3] HCD also can be used to spark innovation to address the myriad challenges faced by human services programs. Despite this appeal, the implementation of HCD within human services is relatively novel.[4,5] There has been little empirical work to date on how HCD might be used to improve outcomes of interest to ACF programs. A priority for ACF is to explore the potential for HCD in human services—whether it is feasible for human services programs to implement, what implementation might look like in human services, what resources are required, and how HCD implementation could be evaluated in this context.

In 2018, ACF's Office of Planning, Research, and Evaluation (OPRE) initiated the Human-Centered Design for Human Services (HCD4HS) project to explore these topics. The HCD4HS project team was comprised of Child Trends, Anthro-Tech, and MEF Associates. This project included a review of the knowledge base to define HCD and describe how it has been used and evaluated in the human services context, and a pilot study to evaluate the implementation of HCD, with a focus on assessing its evaluability.

This pilot study sought to answer the following research questions:

1. What types of challenges within ACF programs are best suited for an HCD approach?
2. What resources are required to implement HCD approaches in ACF programs?
3. What systemic or cultural barriers may make implementation a challenge, and can those be mitigated?
4. What does HCD implementation look like?
5. How can the HCD approach be evaluated in order to better understand outcomes of interest to ACF? Can HCD be evaluated to determine whether or not this approach is more or less successful than traditional approaches?
6. What criteria are defined as successful outcomes when evaluating this process?
7. Were improvements observed on outcomes of interest for end users?
8. Were improvements observed within the organization?

The HCD4HS pilot study built on current knowledge of HCD in human services, including the definition and principles in the box below that were developed by the HCD4HS project team.

What is HCD?

The HCD4HS project defines HCD as:

A process and a mindset for addressing complex problems by designing solutions with those who will ultimately use the solution (i.e., end users). HCD is guided by key principles that promote empathy for end users and the generation of new and creative solutions by taking into account behaviors, ways of thinking, needs, and aspirations. A design team comprised of individuals from multiple perspectives engages both end users and stakeholders (such as partners, community organizations, staff from other departments, etc.) throughout an iterative process that tests proposed solutions and refines them based on feedback. Ideally, the intensive involvement of end users and stakeholders will help ensure solutions are both easily adopted and effective.[6]

HCD is also characterized by the following six principles:[7]

Principle 1: Understand end users and stakeholders. The design solution is rooted in explicitly understanding the needs, tasks, and environments of these individuals.

Principle 2: Engage with end users and stakeholders throughout. These individuals are meaningfully engaged throughout the design process (i.e., from helping define the problem to brainstorming and testing potential solutions).

Principle 3: Test and revise solutions based on end user and stakeholder feedback. The design is created and revised based on feedback from these individuals.

Principle 4: Iterate. The process may not be linear, meaning the team revisits prior steps to ensure the final solution best meets the needs of the end user.

Principle 5: Consider entire experience. The design solution considers the contexts in which end users live and the solution operates.

Principle 6: Collaborate across disciplines. The team of individuals collaborating to design solutions (i.e., design team) should represent varied skillsets, areas of expertise, and perspectives to promote cross-learning and understanding.

Pilot Study Overview

Three human services agencies participated in the HCD4HS pilot study: Denver Human Services, Santa Clara County Social Services Agency, and Washington State Division of Child Support (see below for descriptions of each agency). Site selection considerations included representation from a breadth of ACF-funded programs and end users (e.g., customers, staff), and an assessment of a site's readiness for successful implementation, including need, fit, resources, and capacity. These sites were identified through a structured recruitment process and were selected from 32 human services agencies or programs across the country that self-nominated. The project team reviewed applicants for alignment with the site selection criteria, including further conversations with a subset of sites. The pilot study implemented a capacity-building approach in which HCD consultants from Anthro-Tech provided ongoing HCD training and coaching to a team of staff at each agency (the "design team") who carried out the HCD activities. Each design team was also provided with support from a content expert from MEF or Child Trends. The content expert for each design team provided expertise and guidance in the substantive area each agency was focused on (e.g., how child support works, etc.). Training began with an introductory workshop in January 2021; Design Thinking Workshops were held in the summer of 2021; and coaching occurred from February through December 2021. Design teams received an average of 7-9 hours of coaching support per week. Evaluation data were collected throughout most of the implementation period, beginning in February 2021 and ending in November 2021.

Denver Human Services

Denver Human Services (DHS) operates federal, state, and locally funded services to support children, older adults, and families. For the HCD4HS pilot study, DHS sought to focus efforts on supporting individuals exiting the county's Temporary Assistance for Needy Families (TANF) program. They wanted to help families experiencing the consequences of what is known as "benefits cliffs," or the "cliff effect." This phenomenon occurs when an increase in earnings results in an individual or family exceeding an income eligibility threshold for a given benefits program, but the amount of the new earnings does not replace the cumulative value of the assistance they had been receiving while on public benefits.[8] The goal was to support these end users—families exiting TANF—and to reduce the number of them who returned to TANF after exiting the program.

Santa Clara County Social Services Agency

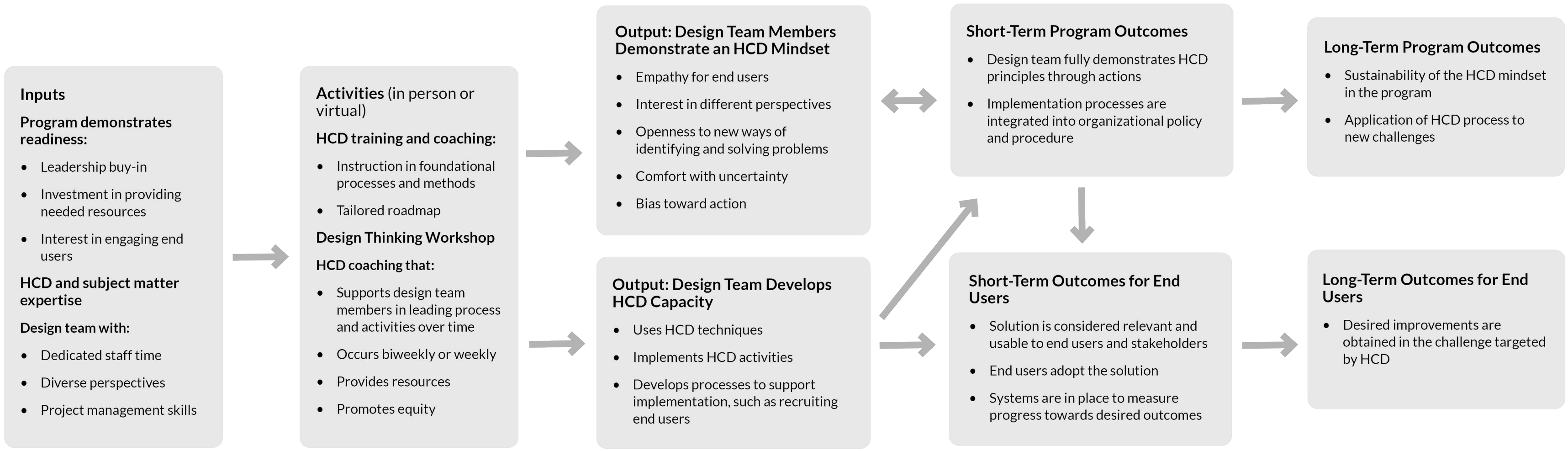
The Santa Clara County Social Services Agency (SSA) provides safety net services to children, families, and adults. With multiple operational divisions providing direct services to community members, SSA sees staff wellness and engagement as critical to providing high-quality services to the families and individuals it serves. Prior efforts to measure staff engagement by SSA underscored the opportunity to improve in this area. For the HCD4HS pilot study, SSA sought to build on prior county efforts to increase engagement and well-being of agency employees (the end users).

Washington State Division of Child Support

The Washington State Division of Child Support (DCS) is housed within the state's Department of Social and Health Services. DCS operates the state's child support program. A core responsibility of child support programs is establishing monthly support orders. These orders can be changed when the circumstances of a parent change (e.g., getting or losing a job). For the HCD4HS pilot study, DCS sought to improve the order modification process for families to ensure child support payments reflected the most up-to-date circumstances of the family. The order modification process can be daunting for parents. It entails filling out multiple complex forms and often requires the provision of detailed financial information. DCS sought to use the HCD4HS pilot study to increase the percentage of these end users—parents who requested a modification—who successfully complete the application for a modification.

Theory of Change

A Theory of Change is a model that specifies the critical components, activities, and/or processes hypothesized to produce specific changes (outcomes). A Theory of Change was developed to guide this pilot study. The Theory of Change was informed by a review of the knowledge base on the use of HCD in human services conducted as part of the HCD4HS project.[9] Over the course of the pilot, the Theory of Change was revised based on what was learned. The figure below shows how inputs and activities (such as readiness, HCD expertise, and coaching) are expected to change the way organizations approach problem-solving and ultimately, improve outcomes for end users.



Inputs

Program demonstrates readiness:

- Leadership buy-in
- Investment in providing needed resources
- Interest in engaging end users

HCD and subject matter expertise

Design team with:

- Dedicated staff time
- Diverse perspectives
- Project management skills

Activities (in person or virtual)

HCD training and coaching:

- Instruction in foundational processes and methods
- Tailored roadmap

Design Thinking Workshop

HCD coaching that:

- Supports design team members in leading process and activities over time
- Occurs biweekly or weekly
- Provides resources
- Promotes equity

Output: Design Team Members Demonstrate an HCD Mindset

- Empathy for end users
- Interest in different perspectives
- Openness to new ways of identifying and solving problems
- Comfort with uncertainty
- Bias toward action

Output: Design Team Develops HCD Capacity

- Uses HCD techniques
- Implements HCD activities
- Develops processes to support implementation, such as recruiting end users

Short-Term Program Outcomes

- Design team fully demonstrates HCD principles through actions
- Implementation processes are integrated into organizational policy and procedure

Short-Term Outcomes for End Users

- Solution is considered relevant and usable to end users and stakeholders
- End users adopt the solution
- Systems are in place to measure progress towards desired outcomes

Long-Term Program Outcomes

- Sustainability of the HCD mindset in the program
- Application of HCD process to new challenges

Long-Term Outcomes for End Users

- Desired improvements are obtained in the challenge targeted by HCD

Methods

The HCD4HS project used a mixed methods approach including quantitative and qualitative data that were integrated in generating findings. In order to inform questions about HCD evaluation approaches, we asked similar questions of different individuals participating in the pilot study, in different formats. In addition, some log data were collected weekly and monthly to assess implementation experiences across time. To address the research questions, the project included the development of a suite of measures for use in this evaluation based on the literature, which included:

- Design Team Logs,
- HCD Consultant Logs,
- Content Expert Logs,
- Interview protocols for design teams and HCD consultants, and an
- Implementation Assessment tool (a semi-structured group interview assessing key aspects of implementation in a manner that is quantifiable).

To analyze quantitative data from the logs and Implementation Assessment, we used descriptive statistics, including counts, averages, and ranges. We then triangulated data across measures and methods, noting any similarities and differences between raters, across agencies, and across time. Thematic analysis was used to summarize open-ended responses on the logs and in interviews.

Findings

Evaluation findings provide important lessons about HCD implementation for practitioners. The findings also provide lessons for researchers on how they can approach theory-driven evaluations of future HCD efforts in public human services settings. Responses to the initial research questions for the pilot study are provided below. Of note, not all the questions could be fully addressed.

Research question	Finding
Research Question 1: What types of challenges within ACF programs are best suited for an HCD approach?	All three sites appeared to make good progress in addressing very disparate challenges: TANF cliff effect, staff engagement, and completion of child support order modifications. However, given that there were only three sites, we cannot fully address which types of challenges within the broad range of ACF programs may be best suited for HCD.
Research Question 2: What resources are required to implement HCD approaches in ACF programs?	Design teams identified project management, leadership support, and incentives for end user participation as critical resources for implementation of HCD, similar to implementation of other change initiatives.
Research Question 3: What systemic or cultural barriers may make implementation a challenge, and can those be mitigated?	Design teams identified primary barriers as time and capacity, recruitment of end users, getting incentives in place to encourage end user participation, and organizational structures and processes.

Research question	Finding
Research Question 4: What does HCD implementation look like?	Using a capacity building approach, all design teams participated in an introductory training (24 hours) followed by 11 months of training and coaching from an HCD consultant (average of 5 hours/week) and content expert (average of 2-4 hours/week). All training and coaching were provided virtually. Design teams clearly demonstrated HCD principles related to empathy and collaboration. Demonstration of some principles varied across site, time, and reporter. The evaluation timeline precluded full assessment of all principles.
Research Question 5: How can the HCD approach be evaluated in order to better understand outcomes of interest to ACF? Can HCD be evaluated to determine whether or not this approach is more or less successful than traditional approaches?	Given limitations of existing measures, this project developed tools including weekly and monthly logs of HCD activities, interviews, and an Implementation Assessment assessing HCD principles, process, and mindset. However, the project timeline precluded evaluation of outcomes for end users. In order to compare HCD to other approaches, different tools would likely be needed.
Research Question 6: What criteria are defined as successful outcomes when evaluating this process?	Criteria that could be used to define successful implementation based on the Theory of Change developed for this study include: demonstration of an HCD mindset, development of HCD capacity, demonstration of HCD principles in action, integration of HCD implementation into organizational policies and procedures, and development of relevant and usable solutions that end users adopt and for which progress is monitored on an ongoing basis.
Research Question 7: Were improvements observed on outcomes of interest for end users?	Given that design teams did not get to the HCD phase where they would implement their solution, outcome improvements for end users could not be assessed.
Research Question 8: Were improvements observed within the organization?	All design teams demonstrated an HCD mindset by demonstrating empathy; openness to the opinions and perspectives of end users and others; and adopting new ways of identifying challenges, brainstorming, and trying different ideas. They also demonstrated a bias toward action. All teams expressed interest in continuing their HCD capacity building efforts.

Additional key findings also emerged that supplement the initial research questions, as follows:

HCD can be evaluated systematically in human services programs with a variety of theoretically-driven data collection tools, although more work is needed in measure development. Data collected through multiple methods yielded largely similar findings, supporting the validity of our tools. Reliability was supported by the consistency of ratings repeated by several respondents. Discrepancies between reporters may reflect important differences in perspectives and inform which measures may be more useful for assessing different types of information. Future measurement work is also needed to clearly distinguish HCD principles (which we suggest may be best defined as actions) and an HCD mindset (thoughts, perceptions, and beliefs). The theoretical model and measures used in this project may be useful for developing more rigorous HCD evaluation studies in the future and for identifying key components and mechanisms of change to strengthen impact.

With expert training and coaching, design teams (i.e., staff at human services agencies) demonstrated HCD principles and implemented a range of HCD techniques with different challenges, end users, and contexts. Design teams received approximately 7-9 hours per week of consultation and direct support from an HCD consultant and a content expert over the course of 11 months, in addition to three full days of initial HCD training. With this capacity-building support, design teams demonstrated HCD principles and appeared to use HCD techniques effectively as evidenced by (1) high HCD consultant and design team ratings on relevant log questions (such as, "Our team demonstrates empathy for end users" and "The design team effectively uses HCD techniques"), (2) the use of various HCD techniques over the course of the pilot study, and (3) Implementation Assessment scores for several of the HCD principles.

From early in the evaluation, design team members demonstrated an HCD mindset, including empathy for end users, openness to different opinions and perspectives, and new ways of identifying challenges and brainstorming. The mindset was underscored across multiple data collection approaches across time and agency. However, aspects of this mindset were apparent at the beginning of the pilot study, suggesting that design teams at the selected agencies came to this work with a strong initial HCD mindset, rather than developed it through the pilot study.

Design teams demonstrated capacity for HCD through using strategies competently, building confidence, developing processes to support sustainability, and addressing challenges that arose. HCD consultants rated design teams' use of HCD techniques highly and there was evidence of an increase in design team confidence in and capacity for HCD across the evaluation period. Design teams also developed capacity by creating new processes to support HCD implementation and addressing challenges.

HCD was found to be useful and relevant in addressing disparate challenges across three sites, and each site had interest in continuing to use HCD in some way. Design team members were optimistic about the viability of the solutions they were creating. They also consistently indicated that HCD was relevant for their agencies' specific challenges, as did the HCD consultants. There was also evidence that design teams were utilizing an HCD mindset and principles in other aspects of their work and were taking action to enable continuation of HCD, although concerns about the time commitment for full implementation were noted.

Discussion

This project contributes to current understanding of how HCD can be evaluated within a human services context. It formalized a Theory of Change, developed new evaluation tools and tested methods, and identified key findings regarding the value of building capacity for HCD implementation.

Evaluation tools and methods. Data collection tools and methods were developed for use in this project and were grounded in the current literature and a theoretical model using a systematic evaluation approach. Formalization of these and other HCD evaluation tools is not only useful for research, but may help shift organizational priorities, and even metrics, for success.[10] There may be particular value to assessing the HCD principles and mindset through a facilitated interview with key design team members (similar to the Implementation Assessment tool developed for this project). Moreover, the work suggests the need to further refine measures in a manner that can better distinguish a design team's HCD mindset (their thoughts, perceptions, and beliefs) from their demonstration of principles (their actions).

Implications of findings for HCD implementation. This project provides valuable lessons for other human services programs interested in implementing HCD.

- Readiness, including leadership support and adequate staff capacity and resources, appeared to be a critical component for successful implementation of HCD in this project.
- Fully virtual training and coaching were viable and effective based on feedback from design team members and HCD consultants.
- Training human services staff new to HCD to implement the full process takes time and requires ongoing support and coaching from experts. However, this capacity-building may be an important outcome in and of itself since it may promote an HCD mindset that could benefit any number of change initiatives. To support capacity building, it may be helpful to train design teams by working on a smaller, more manageable challenge before using HCD for complex challenges.
- Equity can be integrated within HCD via the use of specific strategies. Equity is also promoted when design teams include individuals with diverse perspectives, backgrounds, skills, expertise, and roles within the organization or community. However, human services programs may also experience challenges fully engaging some individuals (e.g., end users and stakeholders) throughout the project, an important area for future initiatives to prioritize.

Conclusion

The HCD4HS project developed an approach for evaluating capacity-building to support HCD implementation within three organizations addressing different challenges related to human services delivery. This project provides valuable insights about the capacity-building process for HCD within human services programs that demonstrate interest in and readiness for engaging in this type of change initiative. It also demonstrates the importance of using a theoretical model, highlights the value of different assessment approaches, and identifies specific areas for future research, including work to further operationalize the HCD principles and mindset, and to validate research tools.

Introduction

Human services programs address complex social issues ranging from supporting healthy relationships, child welfare, and economic mobility to providing high-quality, accessible early childhood programs. Because of its inherent focus on end users or recipients of services, human-centered design (HCD) appears to have potential for promoting effective, efficient, and compassionate service delivery aligned with the mission of the U.S. Department of Health and Human Services' Administration for Children and Families (ACF).[11] HCD also can be used to spark innovation to address the myriad challenges faced by human services programs. Despite this appeal, the implementation of HCD within human services is relatively novel.[12,13] There has been little empirical work to date on how HCD might be used to improve outcomes of interest to ACF programs.

The HCD4HS Project

Given the lack of research on the use of HCD in human services, in 2018, ACF's Office of Planning, Research, and Evaluation (OPRE) contracted with Child Trends and its partners Anthro-Tech and MEF Associates to conduct the Human-Centered Design for Human Services (HCD4HS) project to explore the viability of HCD in addressing the complex challenges facing public sector human services programs. This project includes two major activities: 1) a review of the knowledge base to define HCD and describe how it has been used and evaluated in the human services context, and 2) a pilot study including 11 months of training and coaching for three human services agencies and a mixed methods evaluation of the HCD implementation at these agencies. The latter is the focus of this report. These two research activities were complementary. In particular, the review of the knowledge base informed how HCD training was delivered, the development of a Theory of Change, and the data collection approaches used.

The pilot study aimed to describe implementation of HCD in human services with a particular focus on assessing its evaluability. HCD experts from Anthro-Tech trained and provided coaching to a group of staff at three human services agencies (i.e., the "design teams"). Child Trends and MEF Associates provided consultants with policy and subject matter expertise matched to the challenge being addressed to assist with implementation. Child Trends also collected data to explore the implementation, feasibility, and evaluability of HCD.

From the outset of the project, OPRE placed specific emphasis on developing an evaluation approach to assess implementation of HCD in a manner that can inform future evaluation efforts. Although individuals at agencies without prior experience with HCD were trained and coached during a relatively short period of time, this approach provides a model that future evaluators of HCD implementation can build upon in an array of different policy and implementation settings.

What is Human-Centered Design?

As part of this work, the HCD4HS project included a review of the knowledge base about the use of HCD within human services (see Box 1 for a summary of themes from this review). Through this review, it became clear that there is no one universally accepted definition of HCD. Therefore, the HCD4HS project developed the following definition of HCD:

> A process and a mindset for addressing complex problems by designing solutions with those who will ultimately use the solution (i.e., end users). HCD is guided by key principles that promote empathy for end users and the generation of new and creative solutions by taking into account behaviors, ways of

> thinking, needs, and aspirations. A design team comprised of individuals from multiple perspectives engages both end users and stakeholders[a] (such as partners, community organizations, staff from other departments, etc.) throughout an iterative process that tests proposed solutions and refines them based on feedback. Ideally, the intensive involvement of end users and stakeholders will help ensure solutions are both easily adopted and effective.[14]

In addition, the HCD4HS project identified six principles that capture the essence of HCD, which are based closely on standards from the International Organization for Standardization (ISO Standard No. 9241-210:2019):

Principle 1: *Understand end users and stakeholders*: The design solution is rooted in explicitly understanding the needs, tasks, and environments of these individuals.

Principle 2: *Engage with end users and stakeholders throughout*: These individuals are meaningfully engaged throughout the design process (i.e., from helping define the problem to brainstorming and testing potential solutions).

Principle 3: *Test and revise solutions based on end user and stakeholder feedback*: The design is created and revised based on feedback from these individuals.

Principle 4: *Iterate*: The process may not be linear, meaning the team revisits prior steps to ensure the final solution best meets the needs of the end user.

Principle 5: *Consider entire experience*: The design solution considers the contexts in which end users live and the solution operates.

Principle 6: *Collaborate across disciplines*: The team of individuals collaborating to design solutions (i.e., design team) should represent varied skillsets, areas of expertise, and perspectives to promote cross-learning and understanding.[15]

The pilot study used this definition and these principles to help guide the way design teams were trained and coached in HCD. Data collection tools were also developed to be in alignment with these definitions and principles (for more, see Methods, below).

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[a] While some scholars have expressed concerns about the term "stakeholder," because of its connotation and potential to obscure power dynamics,[16] we use it here for clarity due to its unique meaning within the HCD field. Where it is possible to replace “stakeholder” with a more specific term, we do so.

Box 1. Other Key Findings From Review of Knowledge Base[17]

- There are five HCD phases: Research and Discover, Synthesize and Generate Solutions, Conceptualize and Prototype, Test and Iterate, and Implement and Refine.
- HCD is being utilized for many challenges across a range of human services programs.
- HCD is being implemented primarily at a local level, often with government or philanthropic support, and in consultation with a design firm or institute that provides training and expertise.
- Most human services organizations using HCD are in the early stages of implementation. An HCD mindset develops over time through engagement with the HCD process and could be thought of as a long-term outcome of the process. Given the novelty of HCD within human services, at this time there are more resources available on the process of HCD than on the HCD mindset.
    - Organizations implementing HCD are utilizing a variety of methods across all phases of the HCD process, such as interviews, observation, design workshops, and pilot studies.
    - Human services organizations report the process of obtaining input directly from end users is quite valuable, and often leads to new, unexpected solutions.
    - Organizations implementing HCD have reported positive changes in the design team's mindset, exemplified through increased empathy, innovation, community engagement, and collaboration.
    - HCD implementation studies suggest that important facilitators include 1) strong leadership; 2) buy-in from stakeholders; 3) a design team with a strong facilitator, diversity of perspectives, and shared language; and 4) ongoing coaching. Successful implementation also requires time, effort, and collaboration.
- HCD's sustainability in human services is unclear. HCD processes have been sustained within some organizations, particularly where there is strong support from leadership. However, resource and time constraints are key barriers to sustaining HCD within an organization.
- Although evaluations of HCD are largely descriptive, several efforts have been made to advance the measurement of HCD activities, implementation quality, and organizational outcomes. Lack of validated measures of the HCD process has limited progress in this area.
- Much remains to be learned about if and how HCD actually improves the challenges being addressed in human services.

Evaluating Human-Centered Design in the Context of Human Services

A priority for ACF is to explore the potential for HCD in human services – whether it is feasible for human services programs to implement, what implementation might look like in human services, what resources are required, and how HCD implementation could be evaluated. In a review of the knowledge base, the HCD4HS project team found few examples of rigorous evaluations of HCD interventions, particularly in the public sector.[18] Prior evaluations of HCD interventions have had limited scope and have generally relied on a case study approach to evaluation. These case studies describe how HCD was implemented in a particular place, and identify facilitators of the process, challenges, and/or lessons learned.[19,20,21,22,23] The case study approach, which often places a heavy emphasis on engaging end users and stakeholders in the study design and implementation, provides rich information on a specific implementation effort in a given locale. However, case studies are not well suited to support generalizable findings or to understanding the impact of the HCD process.

The individual case study approach has also limited the development of valid and reliable tools specifically aimed at measuring HCD implementation, despite growing recognition of the need to document and evaluate HCD.[24,25,26,27] Nearly all measures used in the HCD implementation studies identified appear to have used investigator-designed measures, such as unique surveys and interview guides. In addition to the emergent nature of the HCD field, this may also reflect challenges in measuring amorphous concepts like the extent to which people demonstrate an “HCD mindset.”[28]

Prior evaluations have also not typically used a formal Theory of Change to design or select methods and measures. A Theory of Change is a model that specifies the critical components, activities, and/or processes hypothesized to produce specific changes (outcomes). Without a Theory of Change, it is not clear how or why the HCD process is believed to create desired changes. Similarly, the core components of HCD that might be generalizable across HCD interventions have not been identified. The absence of a recognized theoretical framework in the field makes it difficult to measure the implementation of HCD and its outcomes with standardized measures that are comparable across programs or implementation efforts. Moreover, grounding evaluation efforts in a clear Theory of Change can support evaluation designs that assess overall impact, the degree to which the intervention was implemented as designed, and the influence contextual factors have on implementation and impacts.

This Report

Subsequent sections in this report summarize the evaluation approach, implementation of the pilot study, and our findings. First, the report presents the research questions that grounded the pilot study work and describes the three agencies that participated in the pilot study and the approach to their selection. Then, the report presents the initial Theory of Change. It then provides a description of HCD implementation and the data collection and analytic approach, followed by a presentation of the evaluation findings as organized by the Theory of Change.

The report concludes with a discussion of the strengths and limitations of the study, presentation of a revised Theory of Change based on study findings, and lessons for future studies of HCD and implications for HCD implementation. Several appendices accompany this report: a glossary of terms (Appendix A), supplemental figures (Appendix B), detailed findings for each of the study’s research questions (Appendix C), the data collection measures used and recommended modifications for future use (Appendix D), as well as the references used throughout this report.

Research Questions

The pilot study addressed eight main research questions, which were further refined and operationalized by the evaluation team (described in Methods, see below):

- **Research Question 1:** What types of challenges within ACF programs are best suited for an HCD approach?
- **Research Question 2:** What resources are required to implement HCD approaches in ACF programs?
- **Research Question 3:** What systemic or cultural barriers may make implementation a challenge, and can those be mitigated?
- **Research Question 4:** What does HCD implementation look like?
- **Research Question 5:** How can the HCD approach be evaluated in order to better understand outcomes of interest to ACF? Can HCD be evaluated to determine whether or not this approach is more or less successful than traditional approaches?
- **Research Question 6:** What criteria are defined as successful outcomes when evaluating this process?
- **Research Question 7:** Were improvements observed on outcomes of interest for end users?
- **Research Question 8:** Were improvements observed within the organization?

While these research questions specifically focus on ACF programs, the findings from this work apply to human services programs more broadly.

Pilot Study Site Recruitment and Selection

The HCD4HS project involved a structured recruitment process to identify three sites for the pilot study. The recruitment process aimed to identify a range of ACF-funded programs that had the capacity to implement HCD and a willingness to be active participants in the pilot study. In this section we describe the site recruitment and selection process, criteria for selecting the programs for the pilot study, and the characteristics of the sites themselves. This section provides important context for the study that must be considered when interpreting findings.

The recruitment, selection, and engagement process occurred as follows:

- **Recruitment.** Information about the opportunity to participate in the pilot study was disseminated through OPRE's newsletter, discussions with ACF program offices, and social media. The announcement described the pilot study, emphasizing both the potential for program improvement and the opportunity to inform the broader field about HCD, and it provided instructions for nominating a human services program to be considered for the study. Applicants were asked to provide a brief narrative that described their agency or program, along with the challenge they would like to solve with HCD.
- **Review and assessment.** The HCD4HS project received 32 self-nominations from human services agencies or programs across the country. This included state and county human services programs, as well as other ACF-funded programs (e.g., Head Start grantees). The self-nominations were

reviewed and assessed for alignment with the selection criteria (see Table 1). Following this initial review, a small subset of applicants was interviewed to further assess fit with the selection criteria.

- **Selecting and securing sites**. The HCD4HS project team had conversations with the identified subset of sites to help prioritize those that best aligned with the selection criteria. These conversations included helping the applicants better define their problem statement, as well as determine the composition of their design team (a group of approximately five people collaborating to design a solution). During this process, each applicant was rated on the degree to which there was demonstrated alignment with each selection criterion in Table 1, and that information was used to recommend sites to OPRE for inclusion in the pilot study.
- **Finalizing terms of participation**. Following OPRE approval, each prospective site was engaged in further conversations to finalize the terms of participation in the pilot study. A memorandum of understanding (MOU) clearly laid out the responsibilities of the participating agency and the HCD4HS project team. These MOUs described the key project phases and timeline, the anticipated level of effort of the design teams associated with participation (minimum of 30 hours per week over five months,[b] spread across the approximately five design team members), and the training, coaching, and financial supports to be provided by the HCD4HS project. Supports offered were distributed equally across the three participating sites.

Each site was assessed using specific selection criteria informed by the National Implementation Research Network's (NIRN) Hexagon Tool[29] and input from the HCD4HS project's expert advisory group (listed at the beginning of this report). The advisory group reviewed the selection criteria to help apply categories from the Hexagon Tool to the HCD implementation context. Table 1 summarizes the primary criteria used to identify programs that were likely to be the best fit for the pilot study. There was substantial variation across the applications, as well as the three agencies that were ultimately selected, in terms of the degree to which they fully met the below criteria. The selection process resulted in the identification of three agencies with strong leadership buy-in, adequate resources, and interest/alignment with an HCD approach.

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[b] As described later, the initial five-month term was extended during the course of the pilot study.

Table 1. Selection criteria

Need

- Identification of a challenge that can likely be addressed by HCD
- Clear identification of the end user
- Identification of a challenge that can be realistically improved within the pilot study period

Fit

- Not currently using an HCD process in the organization
- Alignment with ACF programmatic areas (e.g., economic security, early childhood, and healthy marriage/responsible fatherhood programming)
- Contribution to geographic diversity in the pilot study

Resources

- Materials and facilities available to support the HCD process
- Data systems in place to measure program outcomes/outputs
- Available program funds to support implementation of solution

Evidence

- Clear description of the challenge of interest
- Clear description of program's goals for participating in the process
- Availability of data tied to stated challenge

Readiness

- Interest in learning more about HCD through training and coaching
- Both executive leadership and supporting staff buy in
- Openness to end user perspectives and willingness to involve end users in the problem-solving process
- Comfort with iterative processes
- Comfort and use of data-driven decision making
- Openness to new potential interpretations about the origins and definitions of the challenge and openness to new potential solutions to the challenge

Capacity to implement

- Number of staff members available to participate in the process (target of five)
- Ability to commit time to pilot study activities

We recognize that the selection process resulted in the identification of organizations with strong readiness and capacity for implementing HCD. This decision was made so it would be possible to fully evaluate HCD implementation. We also explicitly chose to work with programs without prior HCD experience to represent the broader field of human services organizations that do not have HCD expertise.

The three human services agencies selected to participate in the pilot study represent a range of ACF-funded programs with varied challenges and end users. Below, we provide an overview of each agency, as described by agency staff, including the programmatic area, the challenge they sought to address, the targeted end user, and strengths identified through the selection process.

Denver Human Services

Denver Human Services (DHS) operates federal, state, and locally funded services to support children, older adults, and families. For the HCD4HS pilot study, DHS sought to focus efforts on supporting individuals exiting the county's Temporary Assistance for Needy Families (TANF) program.

In Colorado, each individual county administers its own TANF program under the supervision of the state Department of Human Services. States and counties have substantial discretion in how they use TANF funds to best meet the needs of families with low incomes. Along with direct cash assistance, TANF programs provide a variety of services to promote the main goals of TANF, which include the reduction of dependence on government benefits through job preparation, employment, marriage, and the formation and maintenance of two-parent families.

DHS leadership wanted to use HCD to support the transition of individuals exiting TANF. Specifically, they wanted to help families experiencing the consequences of what is known as "benefits cliffs," or the "cliff effect." This phenomenon occurs when an increase in earnings results in an individual or family exceeding an income eligibility threshold for a given benefits program, but the amount of the new earnings does not replace the cumulative value of the assistance they had been receiving while on public benefits.[30] DHS wanted to use the HCD4HS pilot study to improve supports for families during this transition. The goal was to support these end users—families exiting TANF—and to reduce the number of them who returned to TANF after exiting the program. DHS's interest in participating in this HCD pilot built on their "Human Together" initiative, a strategic framework the county is using to advance organization-wide goals through engagement with their staff and clients.

With regard to selection criteria detailed in Table 1 above, Denver had a clearly defined challenge (need and evidence) as well as considerable resources like a dedicated data and technology team, prior experience with process improvement efforts, and a previously identified team and champion for the work (resources). They expressed high interest and openness to an HCD approach (readiness), and wanted to learn about how to engage differently with clients to ensure the centrality of client voice and experience.

Santa Clara County Social Services Agency

The Santa Clara County Social Services Agency (SSA) provides safety net services to children, families, and adults. With multiple operational divisions providing direct services to community members, SSA sees staff wellness and engagement as critical to providing high-quality services to the families and individuals it serves. Prior efforts to measure staff engagement by SSA underscored the opportunity to improve in this area. For the HCD4HS pilot study, SSA sought to build on prior county efforts to increase engagement and well-being of agency employees (the end users).

SSA leadership saw the pilot study as an opportunity to design new methods of employee engagement that were directly responsive to the needs of SSA staff, particularly client-facing staff, as end users. Data collected from employee surveys before the HCD pilot study suggested that client-facing staff benefited the least from employee engagement and well-being efforts, likely due to the nature of their work. For example, client-facing staff expressed their strong commitment to prioritize serving their clients, often at the expense of participating in agency-sponsored engagement efforts, such as virtual road shows or newsletters where important updates, communications, and celebrations are shared with SSA staff. Data collected from annual surveys also suggested that two-way communication was a driver of engagement. While over half of client-facing staff agreed or strongly agreed that communications from agency leaders have improved and that they provide opportunities for staff to give feedback, share ideas, or raise concerns, there was no mechanism for staff to hear the responses to their suggestions or comments from leadership. SSA leadership wanted to use the HCD pilot study to learn about the barriers that client-facing staff face in participating in employee engagement activities and to design a prototype that increased this engagement.

With regard to selection criteria detailed in Table 1 above, SSA provided strong evidence of need with data and a literature review (need, evidence). In addition, they had various levels of staff engaged in addressing their challenge and an identified champion for the work (capacity). However, there were some questions about ongoing labor issues in the county which were thought to have the potential to create challenges in engaging employees as end users (readiness).

Washington State Division of Child Support

The Washington State Division of Child Support (DCS) is housed within the state's Department of Social and Health Services. DCS operates the state's child support program, including locating noncustodial parents, establishing paternity, establishing and enforcing child support orders, modifying these orders when circumstances warrant it, and collecting and disbursing child support payments. For the HCD4HS pilot study, DCS sought to improve the order modification process for families.

A core responsibility of child support programs is establishing monthly support orders. Child support orders, the amount a noncustodial parent is required to pay to the custodial parent, are set based on the financial and social circumstances of the parents. Child support programs typically take into consideration factors such as the income of each parent and parenting time arrangements.[31] In Washington State, child support orders can be established through administrative processes or through the court system. In either case, either the custodial or noncustodial parent has the right to request a modification to their child support order if their financial or social circumstances change. For example, if a noncustodial parent loses their job, they might request a downward modification to their monthly support order amount to reflect their decreased ability to pay support. This modification process can be daunting for parents. It entails filling out multiple complex forms and often requires the provision of detailed financial information. DCS sought to use the HCD4HS pilot study to increase the percentage of these end users—parents who requested a modification—who successfully complete the application for a modification. Their participation in this pilot builds on the agency's longer-term efforts to improve the order modification process. This includes developing messaging and processes that increase the opportunity for parents to request and receive order modifications that align with the financial and family circumstances of the two parents. This includes involvement in a prior OPRE-funded behavioral science-informed intervention that resulted in a significant increase in the number of parents who were incarcerated who received modifications to their child support order.[32]

With regard to selection criteria as detailed in Table 1 above, DCS had a clearly defined challenge (need), availability of relevant data (evidence), a pre-existing workgroup (capacity), previous participation in related change initiatives, and clear understanding of the value of the client perspective (readiness).

Table 2. Summary of pilot agency challenges, end users, and design team composition

	Denver	Santa Clara	Washington
Challenge to be addressed	Easing the abrupt end of benefits when individuals are no longer eligible for TANF (commonly referred to as the "cliff effect")	Improving employee engagement	Increasing the completion of child support order modifications
End users	Program clients	Human services agency staff	Program clients
Design team composition	Strategic planning staff, TANF caseworkers, eligibility specialist	Leadership, representation from across departments and job functions at SSA	Child support supervisor, leadership, strategic planning staff

Source: HCD Consultant Log, Weekly Design Team Log, HCD Consultant and Design Team Interviews

Initial Theory of Change

A Theory of Change was developed to guide the evaluation (see Figure 1 below), and was informed by a review of the knowledge base on the use of HCD in human services conducted under the HCD4HS project.[33] A Theory of Change is a model that specifies the critical components, activities, and/or processes hypothesized to produce specific changes (outcomes). Our proposed Theory of Change specifies key concepts related to how HCD is expected to aid problem solving and make improvements for end users. This model also reflects a capacity-building approach to HCD implementation in a human services agency. Specifically, human services agency staff (design teams) were trained and coached by HCD professionals who are external to the agency. The proposed Theory of Change specifies key concepts related to capacity-building activities and their expected outcomes for the design teams, and ultimately, the broader human services program or agency. Thus, a Theory of Change may look different for other implementation approaches, such as those in which the implementation of HCD is led by an external HCD consultant or those in which organizations have devoted full-time HCD professionals who conduct the HCD activities using their own in-house expertise.[34]

We organize the Theory of Change by inputs (e.g., resources and characteristics brought to the work), activities (e.g., tasks engaged in as part of HCD implementation), outputs (e.g., the presumed direct results of implementing the activities well), short-term outcomes (e.g., the most immediate impact of the work), and long-term outcomes (e.g., impacts of the work expected in the more distant future).

In this Theory of Change, we identify three inputs: (1) a program meets selection criteria (i.e., demonstrates readiness and capacity), (2) the program's own resources, policies, and leadership support to implement and ultimately sustain the HCD approach,[35,36,37] and (3) the expertise brought by the HCD consultants and content experts to guide each program through HCD implementation. In reality, these inputs may not be fully demonstrated (i.e., a program may not have these inputs), but for the purpose of this Theory of Change, we are hypothesizing that having all inputs would lead to the greatest likelihood of achieving the outputs and outcomes.

These inputs are needed for ideal implementation of three main activities described in more detail in the Methods section below: (1) initial HCD training (referred to as the HCD Primer), (2) a workshop with end users where research findings are synthesized and solutions brainstormed (referred to as a Design Thinking Workshop), and (3) ongoing training and coaching. Participation in all three activities was theorized to result in the following implementation outputs at each program:

- The design team effectively uses HCD techniques to address the challenge they have identified;
- The design team demonstrates HCD principles defined above;[38,39] and
- The design team implements HCD activities, such as doing research to better understand end users, generating solutions, prototyping, testing, etc.

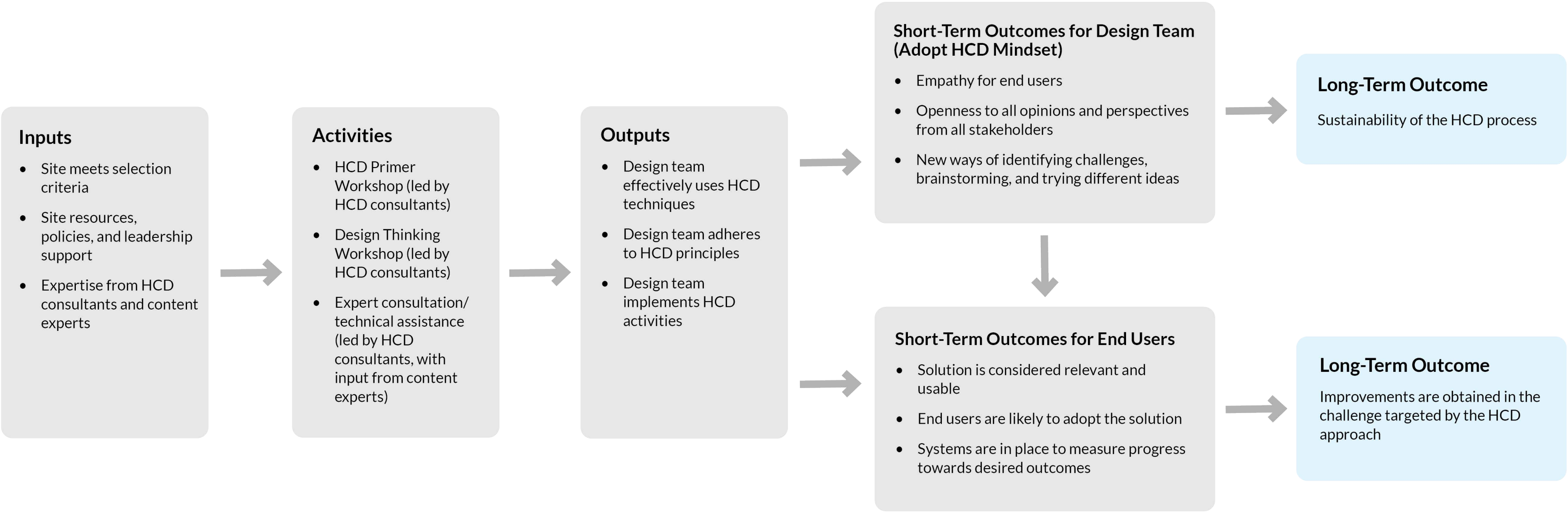
The literature suggests that implementing HCD can lead to a number of short-term process outcomes for a design team. The three components of an "HCD mindset" with the strongest evidence from the literature are:

- Increased empathy for end users[40,41,42]
- Increased value of listening to all opinions and perspectives from all stakeholders;[43,44] and
- Increased innovation through new ways of identifying challenges, brainstorming potential solutions, and trying different ideas.[45,46,47]

Based on evidence provided from the review of the knowledge base, we hypothesized that having an HCD mindset contributes to sustainability of HCD practices by promoting the use of HCD in solving other challenges an organization may face (although this pilot study was not designed to assess this hypothesis).[48,49,50] In addition, we hypothesized that a team of individuals who have adopted an HCD mindset will generate novel solutions that address a targeted challenge. In particular, we expect that having an HCD mindset will lead to solutions that end users and stakeholders consider relevant and usable, an increased likelihood of users adopting the solution that is created, and the development of systems to measure progress toward desired outcomes.[51,52,53,54,55] When implemented effectively, we hypothesize that HCD results in solutions that meet the needs of end users and stakeholders and solve the challenge the design team initially set out to solve.[56] The pilot study included a pre-registered plan to measure the solution-specific long-term outcomes, however, solutions were not yet implemented at the time the evaluation ended.

Findings in this report are organized by the components of the Theory of Change to help tell a story that flows from inputs to outcomes. This Theory of Change was revised based on what was learned through this pilot study, which is reviewed in the Discussion section later in this report.

Figure 1. Original Theory of Change[c]



Inputs

- Site meets selection criteria
- Site resources, policies, and leadership support
- Expertise from HCD consultants and content experts

Activities

- HCD Primer Workshop (led by HCD consultants)
- Design Thinking Workshop (led by HCD consultants)
- Expert consultation/ technical assistance (led by HCD consultants, with input from content experts)

Outputs

- Design team effectively uses HCD techniques
- Design team adheres to HCD principles
- Design team implements HCD activities

Short-Term Outcomes for Design Team (Adopt HCD Mindset)

- Empathy for end users
- Openness to all opinions and perspectives from all stakeholders
- New ways of identifying challenges, brainstorming, and trying different ideas

Short-Term Outcomes for End Users

- Solution is considered relevant and usable
- End users are likely to adopt the solution
- Systems are in place to measure progress towards desired outcomes

Long-Term Outcome

Sustainability of the HCD process

Long-Term Outcome

Improvements are obtained in the challenge targeted by the HCD approach

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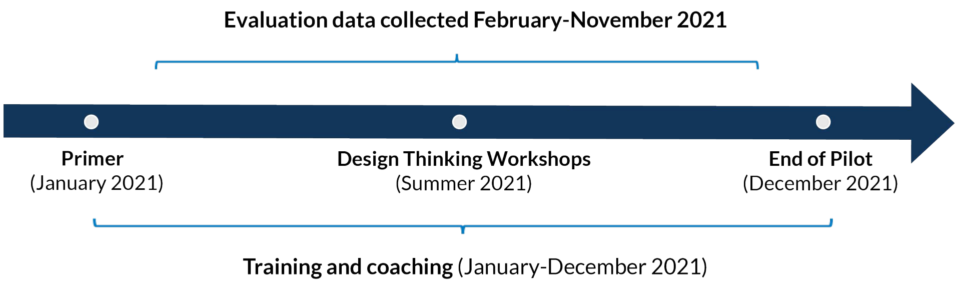
[c] The pilot study did not intend to measure the long-term outcome of sustainability. The pilot study included a pre-registered plan to measure the solution-specific long-term outcomes (i.e., measurable improvements in the challenges targeted by the design teams), however, solutions were not yet implemented at the time the evaluation ended. Therefore, the long-term outcome boxes are in a different color than the other boxes.

Methods

To address the research questions, the HCD4HS project included a pilot study that encompassed both implementation and evaluation of HCD at three agencies. HCD was implemented with a capacity-building approach in which HCD consultants from Anthro-Tech provided ongoing training and coaching to a design team at each agency that implemented the HCD process. The pilot study began with the HCD Primer, or introductory training, in January 2021, and coaching ended in December of 2021. Data related to implementation, feasibility, and evaluability of HCD were collected throughout this period beginning after the Primer through November 2021. Coaching continued after data collection at the request of the agencies, as seen in a timeline for the project in Figure 2.

Of note, the HCD activities were planned to occur over five months, with data collection activities occurring throughout and after the training and coaching ended. However, due to complications presented by the COVID-19 pandemic, discussed further in Box 4 below, agencies progressed through the HCD process more slowly than anticipated, and coaching was extended to 11 months (February through December of 2021).

Figure 2. Pilot study timeline



HCD Implementation

The pilot study used a capacity-building model of HCD implementation. HCD professionals external to the organizations provided training and coaching to the agency staff, who then learned HCD through the process of implementing it. This model was selected to support the agencies' desire to increase their staff's knowledge and skills related to HCD, and to help standardize the HCD process for the purpose of the pilot study. This approach has advantages for sustainability and in the long term may be less costly than approaches that rely on external consultants to complete the HCD work for the agencies. Other approaches such as external consultant implementation or having programs build their own in-house capacity without external expertise would likely result in different evaluation findings.

The training and coaching included the following activities described below in more detail:

- A three-day virtual workshop about the core principles and techniques of HCD (HCD Primer);
- Virtual training and coaching from an HCD consultant throughout the pilot study to provide guidance and feedback to the design teams as they practiced HCD techniques and activities, as well

as ongoing support from a content expert with knowledge of the challenge the design teams were trying to solve; and

- A virtual Design Thinking Workshop with design team members, stakeholders, and end users to synthesize the research findings, brainstorm solutions, and work toward a prototype.

Each agency was paired with its own HCD consultant from Anthro-Tech who had at least 7 years of experience in HCD implementation. The HCD consultants were overseen by an individual with 20 years of experience in HCD and who is an affiliate assistant professor at the Department of Human Centered Design and Engineering at the University of Washington. The HCD consultants met and communicated with each other regularly (at least 30 minutes per week) about their work with each agency to promote consistency across the design teams. These consultants led the HCD Primer and Design Thinking Workshops, and provided virtual training and coaching.

Each agency was also provided the support of a human services content expert from MEF or Child Trends. The content expert for each agency provided expertise and guidance in the substantive area each agency was focused on (e.g., how child support works, etc.). The content expert role was designed to supplement the expertise already present in each agency, for instance, by sharing innovative ideas from other locales, best practices, common challenges, and other knowledge that could have helped the agency address the challenge they identified. Denver and Washington were assigned the same content expert from MEF Associates; Santa Clara was assigned a different content expert from Child Trends, each with relevant content expertise.

HCD Primer

The purpose of the HCD Primer was to introduce design teams to the project, to teach them about the HCD process and key activities, and to lay out a customized roadmap for each design team's challenge area. The Primer, which totaled 24 hours over three days, was conducted virtually using Zoom and Miro as collaboration platforms. At the time (January 2021) these were new platforms for the design teams, who used them for later activities as they implemented HCD at their agencies. The first two days of the HCD Primer were attended by all three pilot design teams, together. The third day of the Primer was conducted separately for each pilot agency.

The first two days of the HCD Primer provided foundational training, including an introduction to the HCD process and mindset along with benefits, critiques, and several case studies of successful HCD implementation. Following this overview, participants learned about each of the phases of the HCD process (see Box 2) and practiced key techniques such as user research methods, defining their challenge, ideation, prototyping, and evaluating prototypes with end users (see the glossary in Appendix A for definitions of HCD-related terms used throughout this report).

Box 2. HCD Phases

1. **Research and Discover.** The goal of the Research and Discover phase is to learn about the lives of end users to understand their needs, constraints, motivations, and context free of prior assumptions and without jumping to solutions. The perspective of key stakeholders is also considered and assessed during this phase.
2. **Synthesize and Generate Solutions.** The primary goal of this phase is to synthesize the research findings to fully understand the problem from the perspective of the end users and generate insights that can lead to new or creative solutions. Toward the end of this phase, ideas are often narrowed down through prioritization exercises, the consolidation of ideas, and by evaluating what is feasible, viable, and desirable according to both end users and stakeholders.
3. **Conceptualize and Prototype.** During this phase, design teams move from prioritized ideas and insights into prototypes (i.e., possible solutions) that visualize the design solution to make it more tangible. The goal is to create rough (or “low-fidelity”) design solutions that can be tested with end users before a prototype is perfected.[57]
4. **Test and Iterate.** The goal of the Test and Iterate phase is to evaluate low-fidelity prototypes to determine what is working well, what needs improvement, and why. During testing, the design team gathers data on end users’ ability to understand and use the solution, end users’ satisfaction and likelihood to adopt the solution, and other metrics. The team may need to circle back to earlier steps to generate additional ideas (enacting the “iterate” principle).
5. **Implement and Refine.** This phase is about implementing the design solution and planning for ways to continue to get feedback after starting implementation. Depending on the type of solution, this step may include developing the solution (through coding, building, writing, programming), developing an implementation plan (what will be implemented and when), piloting the solution on a small scale, developing communication and marketing plans, developing governance frameworks, and planning end user feedback loops.[58]

One criticism of HCD is that it does not explicitly promote equity because it does not take into account power dynamics between various individuals that are involved (or not involved) in the design process.[60] In this pilot study, the curriculum included a focus on the importance of considering equity throughout all HCD phases. For example, participants were trained in how to take “equity pauses” to reflect on shared goals, take stock of assumptions, and to name what they might do better in support of equity and inclusion (see Box 3). Participants were also encouraged to consider whose perspectives they were hearing and those they were not hearing, and how the proposed solutions could positively or negatively impact different groups.

Box 3. Equity Pause

An “equity pause” is a pause in the design or planning process to reflect, remind ourselves of our goals, and name what we might do better in support of equity and inclusion.[59]

The third day of the HCD Primer was tailored to each agency’s needs. Participants reflected on take-aways about the HCD process, further explored the challenge they wanted to address, and worked with their HCD consultant to draft a roadmap. The roadmap included team roles and responsibilities, stakeholder engagement plans, proposed HCD activities, and timelines. These roadmaps effectively became the plan for the rest of the implementation.

Training and Coaching

After the HCD Primer, each of the three HCD consultants trained and coached the design teams on a regular weekly basis during 60-to-90-minute virtual meetings. As needed, additional check-ins with the entire team or the lead of each design team (“design team lead”) were held. As discussed above, the approach to coaching was focused on supporting design team members to be actively engaged in building their HCD capacity and applying HCD processes and strategies. The HCD consultants provided space, trust, knowledge, and confidence, and asked thoughtful questions while letting the design teams learn how to resolve any challenges themselves.

Each of the HCD consultants worked most closely with the design team leads. These were the individuals with the primary responsibility for moving forward the HCD process in their agency and coordinating with the rest of the design team. HCD consultants met with their respective design team lead to co-create weekly meeting agendas. Often, meetings focused on planning for HCD activities, applying findings from research and data, and strategic and emergent project planning based on the HCD principles. The HCD consultants also provided templates for HCD activities, such as user interviews, brainstorming workshops, concept posters, and usability test scripts, and they helped the design teams create custom versions tailored to their agency and project. When a certain topic required a more hands-on instructional approach, the HCD consultants provided short workshops with models and exercises to practice. For example, before one design team conducted interviews, their HCD consultant provided a thorough training on interviewing, along with a workshop to detail and finalize their interview goals.

The HCD consultants compiled learnings, progress, innovative solutions to challenges, and advice and provided that information to all of the design team members in a monthly newsletter.

Design Thinking Workshop

Approximately six months after the HCD Primer, each HCD consultant facilitated a virtual Design Thinking Workshop with their pilot agency. The workshops were attended by the design team members, additional subject matter experts or stakeholders from the community, content experts, and end users. The goals for the Design Thinking Workshop were to:

- Review the user research conducted to date to distill a problem statement;
- Ideate and brainstorm ideas for how to solve the challenge;
- Prioritize the ideas based on co-created evaluation criteria from the research, and then vote on solutions; and
- Prototype and usability test the solutions.

As with the HCD Primer, the Design Thinking Workshops combined instructional activities with hands-on collaborative exercises. For example, the HCD consultants facilitated activities to brainstorm many ideas, followed by using criteria to narrow down their ideas to the most feasible, desirable, and useful solutions. Each of the design teams concluded their Design Thinking Workshop with a prototype that had been usability tested by end users. Training and coaching continued after the Design Thinking Workshop through the end of December 2021.

Box 4. Context

The preparation for this pilot study began in the months immediately preceding the start of the COVID-19 pandemic in the United States. The HCD4HS project had not finalized agreements with any of the three agencies by March 2020, when governors across the country began issuing stay at home orders and most public sector agencies either went fully remote or paused operations.

The pandemic clearly necessitated a shift in the pilot study, and it specifically contributed to delays and a change of focus during the selection phase. There were multiple programs the HCD4HS project had engaged as potential pilot study sites that did not have the capacity to participate once the severity of the pandemic became clear. In some cases, this was a result of substantial budget reductions of public programs or temporary reductions in work hours out of concern for the economic shocks of the pandemic. The HCD4HS project was engaged in conversations with multiple state and local early care and education programs as part of this process. Though all public sector programs experienced dramatic disruptions in the spring of 2020, these providers were particularly strained. In several cases, applicants that had expressed strong interest in participating indicated that they were no longer able to proceed. All three of the agencies that ultimately participated in the pilot study were able to make relatively rapid shifts to remote work and had the capacity to engage in restructured pilot study activities in a virtual environment.

The effects of COVID-19 on the project persisted beyond the recruitment phase, as well. The initial design of the project anticipated substantial in-person interaction between design teams and the HCD consultants. All of these activities shifted to a virtual format for the entirety of the project. Moreover, HCD is heavily dependent on hearing directly from end users, and the operational status of each of the three agencies also reduced the ease with which they could engage end users. More specifically, the end users in one agency were human services agency staff who were overloaded with more work than during pre-pandemic times. In the other two agencies, which had program clients as their end users, design teams faced challenges with recruiting and engaging clients via virtual means.

Despite these challenges, the pilot study implemented a model aligned with the core goals of the project and the principles of HCD. Design teams were actively engaged throughout the pilot study period. The work conducted throughout this pilot study underscores the flexibility of the agencies and demonstrates the ability to implement HCD in a remote context. At the same time, the COVID-19 pandemic is an important contextual factor for interpreting findings.

Data Sources, Measure Development, and Analytic Approach

Research Questions

The pilot study initially proposed eight main research questions (see Table 3). Within these questions, more specific sub-questions were developed to help clarify each and ensure the pilot study focused on the areas of greatest interest to OPRE. The sub-questions are presented in the second column of Table 3, along with data sources used in the third column.

Table 3. Research questions and data sources

Research question	Sub questions	Data sources
Research Question 1: What types of challenges within ACF programs are best suited for an HCD approach?	• What types of challenges did programs want to address with an HCD approach? How were these similar/different across programs? • What progress did programs show in addressing challenges they identified?	• Design Team Logs • HCD Consultant Logs • Interviews
Research Question 2: What resources are required to implement HCD approaches in ACF programs?	• What resources did programs use to implement HCD? • Which specific resources were perceived as necessary for facilitating HCD implementation? Which were helpful (but not necessarily critical)? Which were not helpful? • To what extent did HCD design team members experience support from executive leadership and buy in from other relevant staff? • How were resources similar or different across programs?	• Design Team Logs • HCD Consultant Logs • Content Expert Logs • Interviews
Research Question 3: What systemic or cultural barriers may make implementation a challenge, and can those be mitigated?	• What barriers made HCD implementation a challenge and how did programs address those barriers? • How did barriers to implementation differ across the participating programs?	• Design Team Logs • HCD Consultant Logs • Content Expert Logs • Interviews
Research Question 4: What does HCD implementation look like?	• What HCD activities did the design teams complete during implementation? • How did implementation of the HCD process differ across the participating programs? • How did the HCD training and coaching inform HCD design team's HCD mindset? • How helpful was the HCD training and coaching? • To what extent did design teams effectively use HCD techniques? • To what extent did each design team demonstrate the HCD principles? Which principles were more and less difficult to demonstrate?	• Design Team Logs • HCD Consultant Logs • Content Expert Logs • Implementation Assessment • Interviews

Research question	Sub questions	Data sources
Research Question 5: How can the HCD approach be evaluated in order to better understand outcomes of interest to ACF? Can HCD be evaluated to determine whether or not this approach is more or less successful than traditional approaches?	• What tools did the HCD4HS pilot study use to evaluate the HCD process? Which ones seemed most valuable for future evaluations?	• Design Team Logs • HCD Consultant Logs • Content Expert Logs • Implementation Assessment • Interviews
Research Question 6: What criteria are defined as successful outcomes when evaluating this process?	• What objective measure of success did design teams identify for their challenge? • How did they track these outcomes? By the end of the study, were systems in place to measure progress toward desired outcomes? • Is the solution considered relevant and usable? • Are end users likely to adopt the solution? Why or why not?	• Interviews • Implementation Assessment
Research Question 7: Were improvements observed on outcomes of interest for end users?	• Were improvements observed on the outcomes of interest? If so, what factors seemed to be associated with this improvement? • Did improvements on outcomes of interest vary by program? If so, how? What contributed to any variation?	• Design Team Logs • HCD Consultant Logs • Interviews
Research Question 8: Were improvements observed within the organization?	• To what extent did design team members adopt an HCD mindset? • Did programs notice unexpected improvements in outcomes?	• Design Team Logs • HCD Consultant Logs • Implementation Assessment • Interviews

To address the research questions, a suite of measurement tools was developed for use in this evaluation (see Appendix D), which included:

- Design Team Logs (weekly and monthly),
- HCD Consultant Logs,
- Content Expert Logs,
- Interview protocols for HCD consultants and design team members, and an
- Implementation Assessment tool.

Table 3 indicates the data sources used to answer each research question. As noted in the review of the literature on evaluation of HCD implementation and outcomes in human services, measures with well-established reliability and validity are lacking.[61] Thus, the pilot study adopted some of the most commonly used approaches to HCD evaluation, including the use of multiple perspectives and in-depth interviews.[62] New measurement tools were also developed for key constructs identified as critical to the HCD implementation process, including empathy for end users and innovative thinking. The pilot study used a mixed methods approach that asked similar questions of different individuals (e.g., design team members and HCD consultants) and in different formats (e.g., monthly logs with ratings reflecting HCD principles, interviews, etc.). This mixed methods approach is particularly useful for an emerging area of research like the evaluation of HCD in human services programs because it provides an opportunity to identify new or unexpected findings while also obtaining information that can be summarized numerically. In addition, the pilot study used a repeated measures format for some data collected weekly and monthly to assess the consistency of implementation experiences across time.

Tools and specific measures were designed to align with the Theory of Change and to answer the research questions. Best practices in measure development were used, drawing from the authors' prior experience developing and validating measures,[63,64,65] including implementation tools. For the rating scales, we identified each construct or domain to be assessed based on the Theory of Change, confirmed there were no existing measures, specified and defined the dimensions of each construct, and created items to assess each dimension and construct based on the literature review or related measures (a process described as "deductive generation").[66] To ensure the items measured the intended constructs (i.e., content validity), HCD expert advisory group members reviewed the items and suggested edits. In-depth semi-structured interview guides were developed for HCD consultants and design team members in alignment with the research questions and recommendations for qualitative research on implementation.[67]

All data collection tools were developed to be administered virtually. The study was preregistered with the Center for Open Science to enhance transparency and objectivity.[d]

Table 4 summarizes the constructs measured by each tool. Details about the analytic approach used for each data source are described below. Copies of all tools are available in Appendix D.

Table 4. Constructs measured by each tool

	Demonstration of HCD principles	Having an HCD mindset	Activities	Type and amount of training and coaching	Barriers and facilitators	Outcomes
Design Team Logs	X	X	X		X	X
HCD Consultant Log	X	X	X	X	X	X
Content Expert Log			X	X	X	
Interviews	X	X	X	X	X	X
Implementation Assessment	X	X	X			

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[d] Please refer to https://osf.io/kyqru.

Design Team Logs

Design teams completed both weekly and monthly logs (see Appendix D). Logs were expected to provide a more accurate and precise way to track the activities and work each agency was doing throughout the process, rather than relying on interviews at the end of the pilot study. The logs asked design team members to indicate the types of HCD activities they engaged in (e.g., surveys, interviews, etc.), rate their demonstration of the HCD principles (e.g., degree to which the team demonstrated empathy, was collaborative, etc.), the impact of barriers, and team progress. The weekly and monthly logs also provided respondents the opportunity to provide comments about their experiences. Design teams selected one person to fill out the weekly log and selected three people to each fill out a monthly log (such as the design team lead, an administrator, and an additional team member).

Information was collected about HCD activities weekly to promote accurate data reporting, although the need for this frequency was an aspect of the approach that was evaluated. Information about the demonstration of HCD principles and progress was asked of three individuals in each design team, given expected variability in any one individual's perspective. These questions were asked monthly because they were broader in scope and weekly changes in perceptions were not anticipated.

To analyze the Weekly Design Team Log data, the HCD activities were counted and the most frequent activities were summarized in a table. There were several instances where respondents did not complete a log for a given week or month.[e] When responses were missing, available data were analyzed, with missing data points omitted and findings presented in terms of averages or percentages, rather than raw counts. The open-ended data in all logs were analyzed for themes (via content analysis), with attention to changes in themes over time (e.g., whether a challenge in the beginning was present later) or differences by agency.

For Monthly Design Team Logs, an average score was computed across the three reporters from each design team and ratings of each item were examined separately. Analysis involved noting any similarities and differences between raters, across design teams, and patterns across time. These data (both open-ended responses and ratings) were referenced in the interview guide for design teams, so that interviewees were able to elaborate further on their ratings, and so that interviewers could ask questions about trends they saw over time.

On these logs, respondents were given the option to indicate whether a question was "not applicable." "Not applicable" was presented as an option because some HCD principles asked about on the logs were only applicable once a design team got to a particular step in the HCD process. For example, the item "Our team generates, tests, and revises potential solutions, going back to earlier steps as often as needed (i.e., uses an iterative process)" is only relevant after the Research and Discover phase.

HCD Consultant Logs

The three HCD consultants each completed a monthly log (see Appendix D) that captured the activities the design teams completed, how they provided support to their assigned site, the amount of support they provided, the design teams' demonstration of HCD principles and use of HCD techniques, and the design teams' progress towards solving their identified challenge. Although design team members were asked about their activities weekly, similar questions were only asked of HCD consultants monthly to limit response burden.

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[e] Response rates for the Weekly Design Team Logs ranged from 66 to 97 percent, depending on the site. The response rate for Monthly Design Team Logs was 92 percent.

Log data from HCD consultants were analyzed in the same way as the Monthly Design Team Logs. Level of support provided to design teams was averaged across months (to understand average level of support across the pilot study period) and across design teams (to understand average support provided to a team). HCD consultants' responses were compared with those collected from design team members and any similarities or differences were noted through visual inspection of the quantitative data summaries. On these logs, respondents were provided an option to indicate whether a question was "not applicable" for the same reasons mentioned above.

Content Expert Logs

The two content experts from MEF and Child Trends completed a monthly log that captured their experience providing support to their assigned agency(ies), including the type and amount of supports they provided. Data were analyzed using the same approach used for the other monthly logs.

Interviews

Individual interviews were conducted with each of the HCD consultants and three HCD design team members at each agency.[f] Similarly to the extant HCD evaluation literature, in-depth semi-structured interviews were used to enrich our understanding of quantitative data and obtain a more nuanced understanding of their experiences.[68] The goal of the interviews with HCD consultants was to understand the types of supports they provided to the design teams, gather their perspectives on how the HCD design teams functioned and changed over time during the pilot study process, and discover barriers and facilitators to HCD implementation in the agency they worked with. The goal of the design team interviews was to gather information on their experiences and insights from participating in the HCD process to answer each of the broad research questions. The design team interviews also provided insight into the extent to which equity was considered throughout the pilot study.

All interview recordings were transcribed and reviewed for completeness before being analyzed for themes. Initially, two trained researchers with qualitative analysis experience read and re-read each set of transcripts and took notes about potential themes related to each research question, as well as additional important themes that emerged through the interviews using a process informed by the Framework Method.[69,70] The two researchers compared their notes and came to a consensus on key themes. Next, the full evaluation team met to review the themes and identify any patterns. A set of consistent and coherent themes derived from this process were presented to the broader implementation team for interpretive analysis and refinement to generate a final set of themes to report. Representative individual quotes were also identified to highlight and contextualize specific themes.

HCD Implementation Assessment

Based on a validated assessment tool developed by Aldridge et al. (2016), which was derived from a similar tool created by NIRN, we developed a tool to systematically assess HCD implementation.[71,72] This tool was administered to three design team members from each agency (including the design team lead) through a semi-structured facilitated group interview and yielded data regarding the extent to which each item measured by the tool is "in place," "partially in place," or "fully in place." This tool assessed the extent to which the team was doing the following:

- Demonstrating each of the six HCD principles,

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[f] Some, but not all, of these individuals responded to the Monthly Design Team Logs.

- Implementing HCD activities specific to each phase, and
- Demonstrating an HCD mindset.

A group format was used to account for variation in perspectives and interpretations from different design team members. A "modified consensus" process (i.e., where all participants were comfortable moving forward with a particular rating even if they disagreed) allowed for the three design team members to accept the group agreement without every individual agreeing on every rating. The facilitator—a researcher from Child Trends—provided clarification on assessment items when needed and reflected on similar and discrepant information previously shared in the interview.

For each of the three areas noted above (e.g., HCD mindset), an average score was calculated to indicate the extent to which it was considered to be present in the design team. This was summarized in a percentage (i.e., average of .5 on a 0-2 scale = 25%; average of 1.5 = 75%)[g] and depicted graphically for each agency, as is consistent with Aldridge et al. (2016)'s established scoring approach.[73] Although all design teams participated in the Implementation Assessment, some data from Washington are missing due to inadequate time to fully complete the assessment with their team.

Synthesis Across Data Sources

After each of the data sources was analyzed separately, they were reviewed in relationship to each other and to each of the research questions. Data were integrated across raters, time, and data collection tool by visual inspections of descriptive data, graphs, and review of interview themes addressing similar questions. First, we assessed whether findings were consistent or not. Where there were discrepancies, we examined the data further to explain them with additional context or generated hypotheses for differences in the data or in respondent perspectives. In some cases, it became clear that respondents misinterpreted the questions asked of them. In other instances, the differences seem to reflect different perspectives on the same issue. In the sections that follow, we indicate when any discrepancies arose and how we triangulated data to arrive at a conclusion. Once findings were identified, we shared them with the expert advisory group for further interpretive context (see the Acknowledgments for a list of experts consulted). Findings are presented in this report in a way that best captures the story the data are telling. Given the project goals and small sample size of the study, our analyses were descriptive (not inferential).

Findings

This section presents the findings of the evaluation, organized according to the Theory of Change. Findings related to the HCD activities (i.e., training and coaching activities) are presented first, followed by the outputs, and short- and long-term outcomes for the design team. Limited data are available for short- and long-term outcomes for the end users, but are addressed as possible. Throughout this section, the discussion of findings is focused on information obtained from each data source and how data were triangulated to produce the final takeaway findings that are presented in text boxes throughout this report.

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[g] The Implementation Assessment asked questions about the HCD principles, HCD phases, and the HCD mindset. Multiple questions were asked related to each principle, phase, and the overall mindset (i.e., "domains"). The Implementation Assessment ratings were on a scale of 0 to 2. A rating of 0 indicated that no activities or elements from the item were in place and/or the team had not yet started on this item. A rating of 1 indicated that the item in question was sometimes, or partially in place. A rating of 2 indicated that all dimensions of the activity or element were fully in place, and there is clear evidence to support this. Scores across all items for a given domain were averaged by site. The averages were converted into percentages by dividing the average by 2.

Box 5. Approach to Reporting Findings

Findings are presented in a way that best captures the story the data are telling. In some cases, the story is about how a particular data point changed over time in different ways in the three sites. In such a case, longitudinal data is presented by site. In other cases, each site's experiences over time were similar, so data are averaged across sites. And in some instances, where there is little change over time, data are averaged over time.

Further, while individual sites are named frequently, in some cases, the site's name is masked to protect the privacy of the respondent.

Finally, tables and figures are presented to provide key information for understanding the overall findings. Additional tables and figures that are less central to the overall story are presented in Appendix B.

Activities

To document the activities used to build HCD capacity in design teams, data were collected about (1) average number of hours of support provided by the HCD consultant and content expert, (2) types of support provided, as well as (3) perceived helpfulness of and satisfaction with the coaching. These findings inform the overarching feasibility of implementing HCD in human services.

Amount of Training and Coaching Provided

The HCD consultants spent an average of five hours per week providing support to the design teams (typically 3-6 hours/week with significant variability across design teams and months, suggesting coaching was tailored to the needs of the design teams).[h] See Box 6. This is inclusive of direct support, like calls and observing/participating in design team meetings, as well as indirect support, like preparing for meetings with agencies and reviewing deliverables or design solutions.

Content experts spent less time with each design team (2-4 hours/week), which was expected given their role was more narrowly defined than the role of the HCD consultant.[i] Again, this is inclusive of direct and indirect time spent supporting the design team and/or HCD consultant.

Box 6. Amount of Support Provided

HCD consultants provided an average of five hours of support per week per design team (range = 4.4 - 6.4).

Content experts provided an average of two to four hours of support per week per design team.

This information was corroborated by interview data. During the interviews, design team members were asked whether the amount of support they received was too much, too little, or just right. Several design team members described the amount of support they received from the HCD consultants and content experts as "just right."

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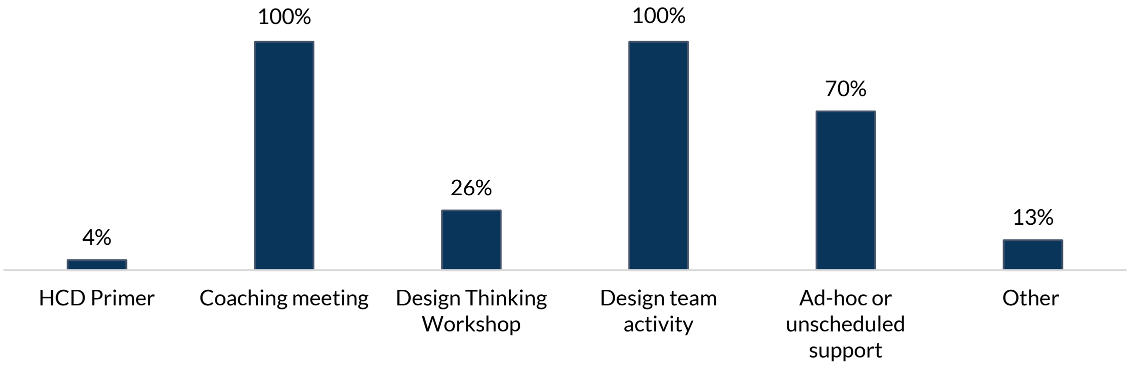
[h] Across sites, the lowest monthly average was 3 hours and the highest was 14 hours.

[i] Across sites, the lowest monthly average was 2 hours and the highest was 5 hours.

Types of Training and Coaching

Figure 3 shows the percentage of months during which HCD consultants provided particular supports to the design teams, averaged across sites to protect the privacy of the consultants. Although some supports occurred on a weekly basis, HCD consultants were asked about the types of supports they provided on a monthly basis. Consistent with the coaching plan developed for the study, HCD consultants led and/or participated in virtual coaching meetings and design team activities with each design team each month. Most months, HCD consultants also provided ad-hoc or unscheduled support, although this varied greatly across agencies (50%-100% of months). The HCD Primer and Design Thinking Workshops were time-limited activities, thus they occurred in fewer months.

Figure 3. Percentage of months HCD consultants provided specific supports, averaged across sites



Source: HCD Consultant Log

Notes: Multiple activities could occur each month. "Coaching meeting" corresponds to the "virtual technical assistance (TA) meeting" option on the HCD Consultant Log (which is a regular meeting where the HCD consultant provided coaching to the design team). "Design team activity" refers to an HCD activity the consultant participated in with the design team. Data are shown in terms of the percentage of months rather than a count because of missing data. The number of months an activity occurred was divided by the number of months for which data were available. Ranges by activity are as follows: HCD Primer (0-13%), coaching meeting (no variation), Design Thinking Workshop (14-38%), design team activity (no variation), ad-hoc or unscheduled support (50-100%), and other (0-25%).

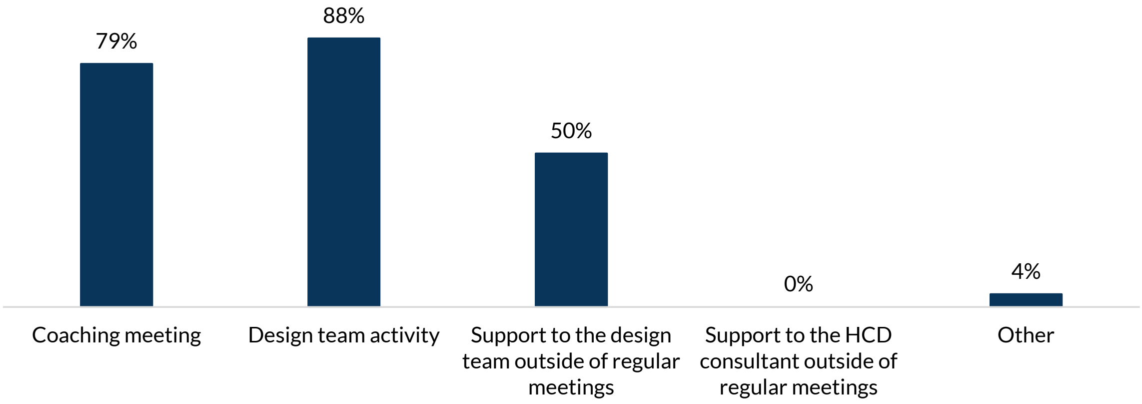
The interviews with HCD consultants and design teams confirmed the types of support described on the HCD Consultant Monthly Logs. In addition, interviewees described how HCD consultants:

- Helped the design teams with project management, especially at the beginning of the pilot study;
- Provided design teams with templates and examples from others that have implemented HCD; and
- Provided ongoing coaching that helped the design team members build skills (such as interviewing and effectively leading design team meetings) and take action.

Interviewees described HCD consultants as "coaching, not doing."

Similarly, content experts participated in design team activities and virtual TA meetings in most months. They also provided ad-hoc support to the design team in about half of the months, with some variation by site. However, they did not provide any support directly to the HCD consultants outside of regular meetings (see Figure 4). The greatest amount of variability across sites occurred in time spent providing consultation to the design team outside of regular meetings.

Figure 4. Percentage of months content experts provided supports, averaged across sites



Source: Content Expert Log
Notes: Multiple activities could occur each month. Data are shown in terms of the percentage of months rather than a count of months to be consistent with how HCD Consultant Log data are presented. Ranges by activity are as follows: virtual TA meetings (75-88%), design team activities (75-100%), support provided to the design team outside of regular meetings (38-75%), support provided to the HCD consultant outside of regular meetings (no variation) and other supports (0-13%).

The interviews with HCD consultants and design teams provided additional details to supplement the Content Expert Log data. Specifically, interviewees said content experts did the following:

- Provided resources and advice about the content area that was the focus of the design team, for example, sharing research articles with the team for them to read and discuss.
- Provided advice about user research practices, such as which research methods to use for which purpose.
- Asked questions and reflected back what they heard from design teams to help them clarify their thinking and address barriers.

The various data sources aligned with the type of supports the HCD consultants and content experts provided. HCD consultants and content experts provided direct support to each design team, mostly in the form of trainings, participation in design team activities (e.g., design team meetings), and virtual TA to build capacity within each agency. Based on the data collected, it is clear HCD consultants were focused on coaching design teams on the use of HCD while the content experts provided outside knowledge about the challenge design teams were trying to solve.

Training and Coaching to Build HCD Capacity

HCD Primer. In interviews, design team members acknowledged the value of the HCD Primer in terms of helping them understand HCD. One person mentioned often referring back to the materials shared during the Primer throughout their implementation of HCD.

Design Thinking Workshop. On the Design Team Logs, participants described the Design Thinking Workshop as "an eye opener," "fun," and "a beautiful experience." In interviews, one person noted that the Design Thinking Workshop represented a new approach to idea generation and that without the workshop, they likely would have landed on a different solution.

One HCD consultant likened the roles of HCD consultant and content experts to a pair of travel agents, with the HCD consultant providing information on how to get to the destination (i.e., using HCD to address the challenge), and the content expert providing information about local customs and other important context about the destination (i.e., what others have done in the content area, pitfalls to avoid).

Coaching. On the Monthly and Weekly Design Team Logs, respondents consistently indicated that the regular coaching sessions supported their learning of the HCD process and kept the work moving forward. The design team members expressed appreciation for the project management-related supports their HCD consultant provided, such as tracking next steps, taking notes, and facilitating meetings. A representative from one of the design teams shared how their HCD consultant coached them to take on more of the project management tasks over the course of the pilot study. Another design team member noted how the HCD consultant helped their team move forward when they got "stuck" (for instance, when developing interview questions and planning for focus groups). The respondents repeatedly noted the general helpfulness of the coaching they received (e.g., how the HCD consultants explained new concepts and helped the team get to consensus, and how the one-on-one guidance to support project management and leadership skills made design team meetings more effective). Respondents elaborated on these sentiments in interviews. Design team members noted how the HCD consultants coached them and did not "do" for them, which they saw as helpful in building their own capacity and supporting the team in taking action.

Design teams' reports of the content expert role in building an agency's capacity to implement HCD was mixed. On the Monthly and Weekly Design Team Logs, one respondent noted being unclear about the role of the content expert. In interviews, some individuals commented that they did not find the content expert role particularly helpful, saying they offered the wrong kind of support (e.g., the team wanted information about prior efforts to address the challenge they were focusing on, but did not receive it), or that feedback was not helpful as the content expert did not fully understand the organizational structure and climate. One of these individuals mentioned how they did not understand the content expert role since the design team members were experts themselves. In contrast, there were many other positive comments about the content expert. Design team members noted on the logs that their content expert helped them develop strong interview questions and/or noted the general helpfulness of the training and coaching they received from the content expert. In interviews, two people described the perspective the content expert brought as valuable in part because the content expert was not within their system. In one agency, all design team members interviewed described the content expert as invaluable, with specific comments indicating that the expert brought discussions to a new level, helped the team make time to read and discuss relevant articles, and helped them conceptualize their challenge more clearly. Therefore, opinions about the content experts varied by design team.

Box 7. Integrated Findings

Activities

HCD consultants

1. Served as a coach to build capacity in the agencies.
2. Helped with project management, especially at first, but transitioned this to design teams over time as they became the driver of the process.
3. Provided curated resources about HCD, like tools, templates, and example artifacts from others who have implemented HCD in the past.
4. Served as a catalyst for action—encouraging design teams to move from discussion to action and providing scaffolding to make them more comfortable with activities they were less comfortable with (like interviews and focus groups).
5. Provided supports primarily via virtual coaching sessions and participation in design team activities, with some additional ad hoc support as needed (average of 5 hours per week total for direct and indirect time).

Content experts

1. Provided consultation on the relevant content area.
2. Shared knowledge and provided resources about what others have done.
3. Provided advice about research practices.
4. Provided feedback to the design team and asked questions to help the team think through their ideas and any barriers.
5. Provided support primarily via virtual TA meetings and participation in design team activities, with some additional ad hoc support when requested (average of 2-4 total hours/week).

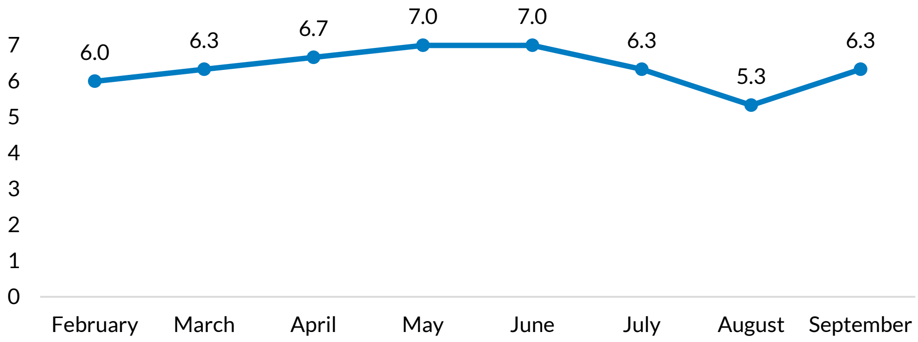
Outputs

As noted in the Theory of Change, Outputs include (1) effective use of HCD techniques, (2) demonstration of HCD principles, and (3) implementation of HCD activities, which are each addressed in this section.

Design Team Effectively Uses HCD Techniques

Two questions on the monthly logs provide insight into how effectively design teams used HCD techniques. Figure 5 shows that HCD consultant ratings of teams' perceived effectiveness increased steadily from the beginning of the pilot study through June, and decreased in July and August, before increasing again in September.

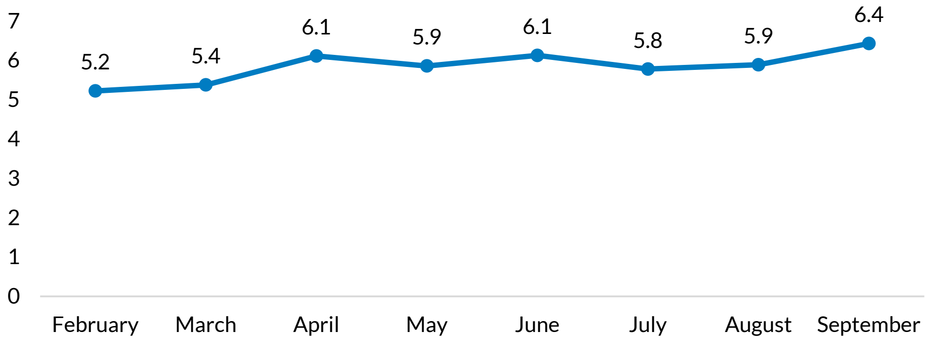
Figure 5. HCD consultant perceptions of whether design teams used HCD techniques effectively, averaged across sites



Source: HCD Consultant Log
Note: Scale is 1 (not at all); 4 (somewhat); 7 (a lot). Over time, the average site scores ranged from 5 to 7.

Design team members were also asked to reflect on the extent to which they felt confident about using HCD techniques. Design team ratings seen in Figure 6 show generally increasing confidence across time with relatively high levels of confidence from the very beginning. Findings are averaged across sites due to limited variation among sites.

Figure 6. Design team member rating of their confidence using HCD techniques, averaged across sites



Source: Monthly Design Team Log
Note: Scale is 1 (not at all); 4 (somewhat); 7 (a lot). Over time, the average site scores ranged from 4 to 7.

The interviews support these findings and provide important additional context that may not be reflected in the 7-point ratings on the logs. HCD consultants described design team members as becoming more confident in leading the work over time, as they shifted from providing a great deal of support to acting more like an advisor (e.g., someone to share ideas with) than a coach. An HCD consultant noted, “My role changed as their competency grew. I was able to add more nuance or bring them to the next level of detail.” The design team members echoed this point by emphasizing how the HCD consultants were helping them build new skills throughout the pilot study (such as learning how to conduct interviews or effectively lead design team meetings).

However, there were some instances where design teams had challenges with regard to HCD techniques. For instance, in two of the three sites, both HCD consultants and design team members noted how design team members had difficulty conducting interviews and/or summarizing findings early in the pilot study. For example, one design team found it difficult to distill the learnings from interviews with end users without injecting their own perspectives. At another site, a design team member shared how conducting interviews was new to them and initial training was necessary. One of the design teams often wanted to move straight to implementation after the Design Thinking Workshop before prototyping and testing, which does not align with the principles of HCD. Design team members from two agencies noted that it was difficult to determine how to move forward after the Design Thinking Workshop since there were so many options to pursue. This may explain why the log ratings suggest a dip in effective use of HCD techniques in the latter half of the summer, after the Design Thinking Workshops.

Box 8. Integrated Findings

Output: Design teams effectively use HCD techniques

HCD consultants and design team members reported high levels of perceived skill and confidence that improved over time. However, there were some setbacks, especially with research and synthesis and the period after the Design Thinking Workshop.

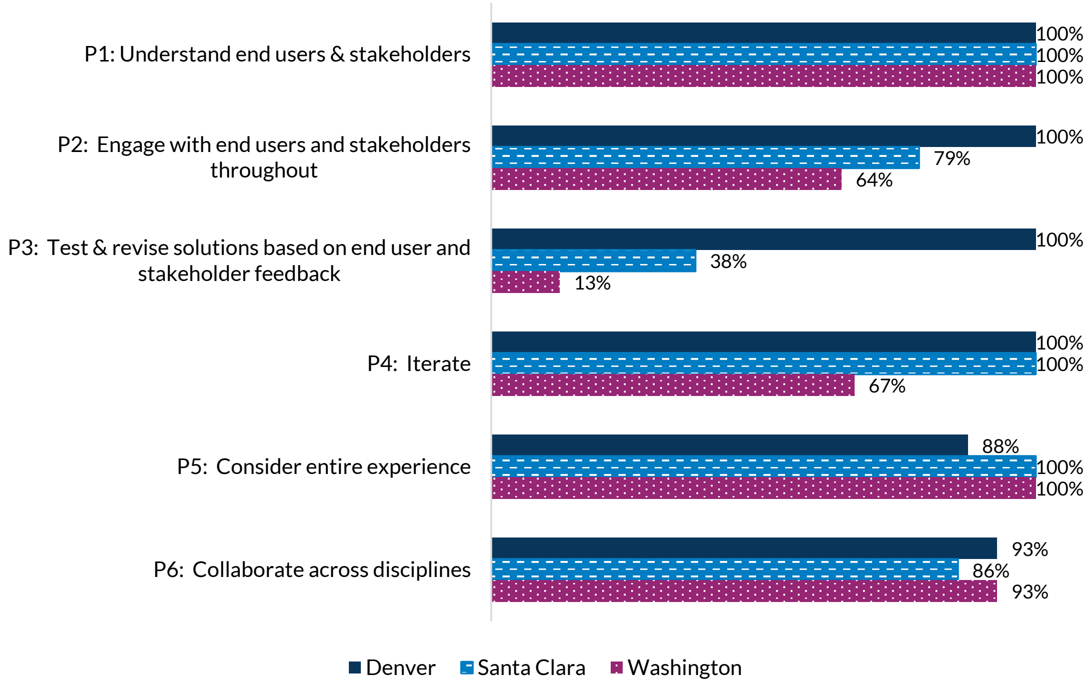
Design Team Demonstrates HCD Principles

Multiple data sources were used to assess the extent to which design teams demonstrated the six principles of HCD detailed earlier in the report, including the Monthly Design Team Logs, the HCD Consultant Logs, the Implementation Assessment, and the interviews. The specific wording of questions assessing the principles varied somewhat across measurement tools, but items were intended to directly reflect the key concept of each principle.

Overall, there was considerable variability across the different principles, as well as across agencies and across time, suggesting the importance of looking at these data in more detail. The first data source is the Implementation Assessment, which was administered to three design team members at each agency at the end of the evaluation period. Each principle was given a score based on multiple questions (see Appendix D) that used consensus ratings with facilitator clarification.

As seen in Figure 7, Principles 1 (understand end users and stakeholders), 5 (consider entire experience), and 6 (collaborate across disciplines) were scored as being fully demonstrated by all three design teams (using 75% as the threshold for “fully”).[74] Principles 2 (engage with end users and stakeholders throughout), 3 (test and revise solutions based on end user and stakeholder feedback), and 4 (iterate) were less fully demonstrated by design teams. Denver was scored as fully implementing all six principles; Santa Clara was scored as implementing five, and Washington was scored as implementing three. The extent of implementation of the principles is explained in part by how far along each site got in their implementation of HCD (discussed more below).

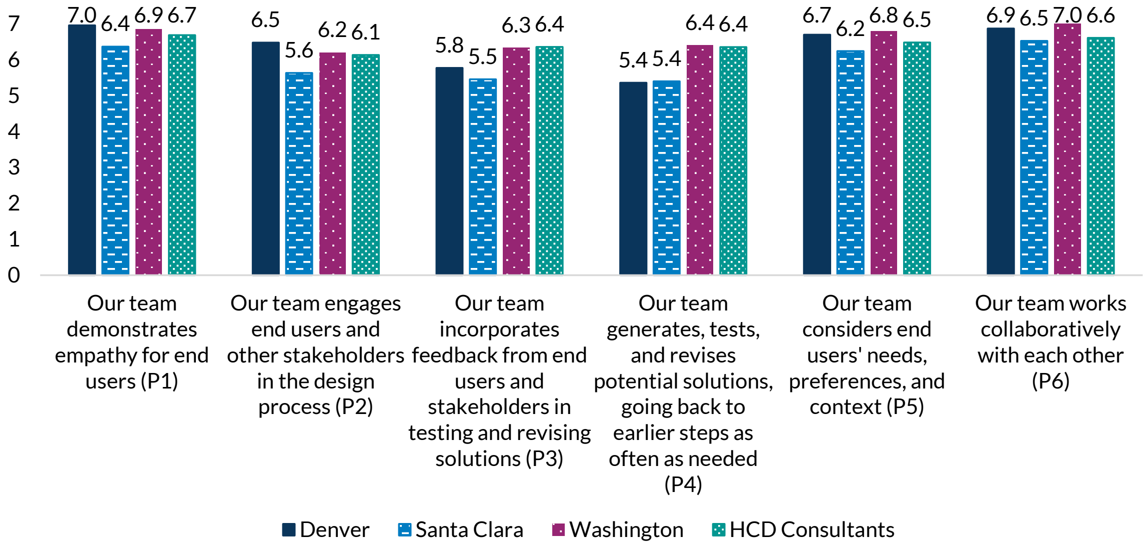
Figure 7. Extent of implementation of HCD principles



Source: Implementation Assessment

Information about demonstration of principles is also provided by monthly ratings of single-item questions about each principle by a sample of individuals on the design teams and by HCD consultants. As can be seen below in Figure 8, there is a similar story with Principles 1, 5, and 6 having the highest ratings, which are consistent over time. Consultant ratings, averaged across sites, are generally similar to those provided by design team members.

Figure 8. Design team and HCD consultant ratings on design team demonstration of HCD principles, averaged over time



Source: Monthly Design Team Log, HCD Consultant Log

Note: The log question text used in this graph reflects the text on the Monthly Design Team Logs. The HCD Consultant Logs used slightly adapted text such as "The design team demonstrates empathy for end users." Average HCD consultant ratings by agency ranged from 6.4 to 6.9 for Principle 1, 6.0-6.4 for Principle 2, 5.7 to 6.8 for Principle 3, 5.0-6.7 for Principle 4, 6.1-6.9 for Principle 5, and 6.3-6.9 for Principle 6.

Support for design teams' demonstration of HCD principles, such as focusing on end users and collaborative problem-solving, was also reflected in interviews. One design team member explained, "It's a valuable experience, even if there is no solution. It's having empathy. The HCD principles are valuable to know and practice." Evidence of collaborative teamwork can also be seen in this quote from an HCD consultant, "They're really achieving quite a lot in terms of new ways of working and new ways of collaborating, as well as learning the mindsets and principles and tools and techniques of HCD. That's on top of working together in a way that they usually don't in their organization, which is really exciting."

"Our organization is good at seeking feedback, but it's just that we had never co-created in the past. In the past, we just heard a problem and then decided on what we thought would be best for end users." They added, "We are well-versed in doing surveys and getting feedback from customers and clients, but we have yet to engage with them in co-creating a solution. Those two things are very different—hearing what the problem is versus hearing what they want as its solution." – Design Team Member

Variation across Principles

As noted, convergent evidence across multiple raters and data sources suggest that all three design teams were perceived as successfully demonstrating principles related to understanding end users, considering end users' entire experience, and working collaboratively in multidisciplinary teams. For principles demonstrated less fully, data from interviews and activity logs were used to facilitate understanding of the design teams' experiences.

As seen in Figure 7, according to the Implementation Assessment, Principle 2 (end user and stakeholder *engagement* throughout the process) was less fully implemented at two sites than Principle 1 (*understanding* end users and stakeholders). However, the monthly logs suggested high ratings (>6) on these principles at all but one agency. From the Weekly Design Team Logs, Denver and Santa Clara reported engaging end users during approximately 45 percent of the weeks, while Washington reported engaging end users during about 20 percent of the weeks. Design team ratings were generally higher during months when they were actively engaging with end users (e.g., "Research and Discover" in spring and the Design Thinking Workshop in the summer), which is to be expected. Interview data validate some of the challenges design teams had recruiting end users (described further below), despite the value many design team members placed on this engagement. Moreover, the HCD consultants gave design teams higher scores on end user and stakeholder engagement throughout the pilot study than did the design team members themselves. Assessment of this principle is further complicated by the fact that several design team members reported "not applicable" on their logs, especially at the beginning of the pilot study (see Table B-1 in Appendix B).

Principle 3 (incorporate feedback in testing and revising solutions) had relatively low scores for two design teams when compared to other principles on the Implementation Assessment, similar to the monthly log ratings. However, some design teams rated Principle 3 as not applicable until they were actually engaged in this activity during the summer, while others rated themselves lower because it had not happened yet (see Figure B-1 and Table B-2 in Appendix B). Interviews suggested that all design teams embraced the idea of testing and revising solutions based on the feedback they obtained (or would obtain) from end users and stakeholders, and there was enthusiasm for talking to more end users and testing the solutions with them. One HCD consultant reported that the design team became overly focused on implementation after the Design Thinking Workshop, although they were also excited about co-creating solutions with their end users.

Principle 4 is focused on the extent to which the design team uses an iterative and nonlinear problem-solving approach, going back to earlier phases as needed. Two of the three design teams had their lowest scores (5.4) on the monthly log ratings for this principle, although only one agency was considered to be implementing it less than fully on the Implementation Assessment. This discrepancy appears related, in part, to design teams' interpretation about when this principle was applicable (similarly to Principle 3) and numerous 'not applicable' ratings until they did the Design Thinking Workshops during the summer. Given this confusion, design teams' reports of when they worked on the different HCD phases across the study period were examined (See Table 5) as an indicator of how they iterated. As can be seen, Denver and Santa Clara revisited the Research & Discover and Synthesize & Generate Solutions phases throughout the pilot study. Washington, on the other hand, proceeded more linearly, although with some overlap between phases. However, the Washington design team described in interviews how they would refer back to the research they did earlier in the project, how they created low-fidelity prototypes before higher-fidelity ones, and were generally comfortable with a non-linear process. They indicated they had not designed, tested, and revised potential solutions as many times as needed, which lowered their score on the Implementation Assessment.

Table 5. Work on of phases by month and site reflecting iterative process

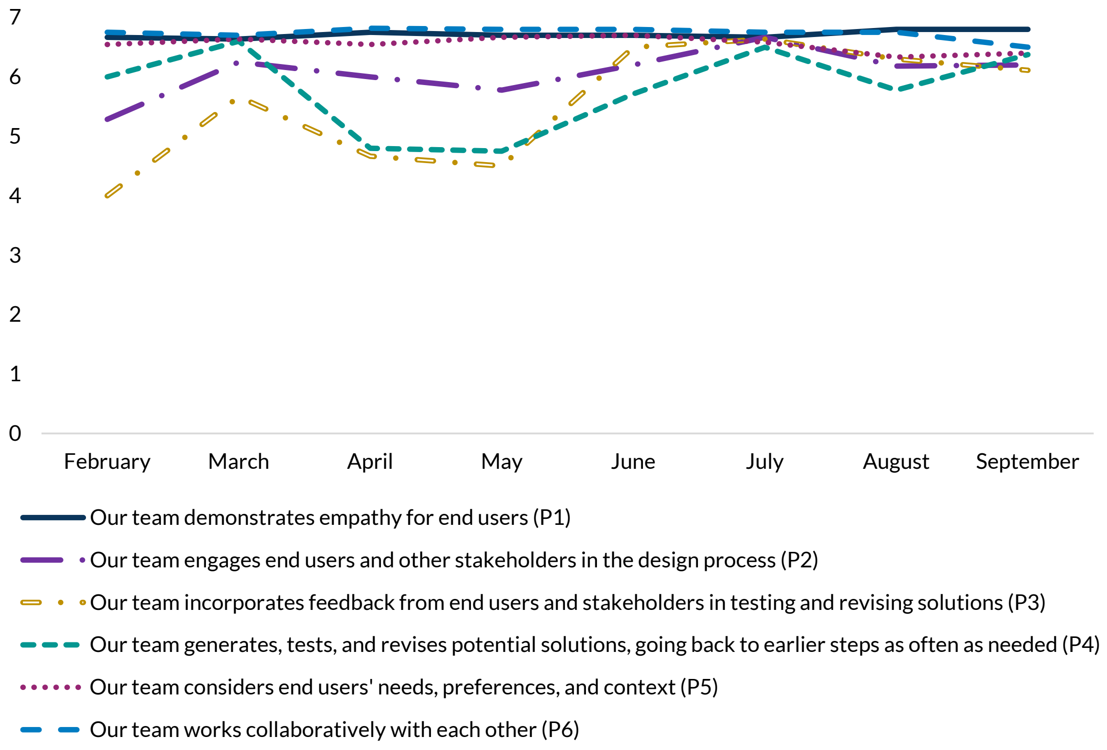
	February	March	April	May	June	July	August	September
Research and Discover	D S W	D S W	D S W	D S W	D* S W*	D* S	D S*	D*
Synthesize and Generate Solutions	S* W*	S*	D	D S W	D S W	D* S W	D* S W*	D* S*
Conceptualize and Prototype	S*				D*	D* S*	D S W	D S W
Test and Iterate					D*	D* S*	D S*	D W
Implement and Refine					D*			S*

*Indicates there were inconsistencies between the Weekly Design Team Log and HCD Consultant Log. This table shows all instances in which either a design team member or HCD consultant indicated the team worked on a particular phase. The asterisk (*) indicates when only one reporter (design team member or HCD consultant) said the team worked on a phase that month.
Source: HCD Consultant Log, Weekly Design Team Log
Note: For the Weekly Design Team Log, we marked an activity as occurring in a given month if the respondent indicated the activity occurred in any week of that month.
D=Denver, S=Santa Clara, W=Washington

Variation across Time

Data collected from monthly log ratings about demonstration of principles from HCD consultants and design teams provide additional nuance to interpretation. As seen below in Figure 9, ratings across principles converged over time around the Design Thinking Workshops when design teams were beginning to develop solutions to their challenges and share these with end users and other stakeholders. In particular, Principles 2, 3, and 4; which were rated lower overall across sites; improved after this time. Some of this variability may again have been related to differences in interpretation of whether all principles were applicable during earlier phases of the HCD work. For instance, some teams indicated "not applicable" early on, whereas others rated themselves more poorly early on, highlighting a measurement challenge.

Figure 9. Design team demonstration of HCD principles over time



Source: Monthly Design Team Log, HCD Consultant Log
Note: Ratings from design team members and HCD consultants were averaged together across sites.

Challenges in Assessing HCD Principles

There were a number of challenges related to assessing the HCD principles by design team member reports on the monthly logs that complicate interpretation of these data. First, design team members rated their demonstration of the HCD principles as they were learning HCD, and it was surprising to see that they reported relatively high ratings from early in the pilot project. This could be due to a number of factors, including having selected agencies that were well-prepared for this type of work, providing initial training before assessments started (i.e., lack of a true baseline), or lack of sensitivity in the measures. Second, it appears that the design teams interpreted questions about some of the principles differently than they were intended (e.g., providing responses of N/A when they were relevant). It may be that design team members did not fully understand the principles given that this was their first experience with the process. Although their ratings were generally similar to those provided by the HCD consultants (i.e., Figure 8), there were numerous discrepancies between design team and HCD consultant report of specific activities conducted each month (i.e., Table 5).

Finally, and perhaps most importantly with regard to the evaluability objective of this project, it may be that the measures of the principles were not reliable and/or that the principles themselves need further conceptual clarification. In designing a monthly rating of demonstration of principles, single items were created for each principle, which may not adequately represent each one. For example, Principle 1 was assessed by asking about empathy specifically, whereas the principle describes having a design solution rooted in explicitly understanding the needs, tasks, and environments of end users. The Implementation Assessment includes a broader assessment of each principle and provides an opportunity to clarify understanding of what is being asked, which may suggest that scores on this measure are more reliable. Thus, additional conceptual clarity for the purpose of measure development and refinement would be helpful. This issue is addressed further in the Discussion.

Equity in the HCD Process

As discussed above, HCD does not necessarily include an explicit focus on equity. In fact, equity-centered design was conceptualized to fill this gap.[75] However, intentional efforts to prioritize equity were made in this pilot study. In addition to teaching strategies for promoting equity within HCD practices, design teams worked to create teams with diverse perspectives, skills, and expertise and to be aware of power dynamics within the teams and broader agency in making task assignments. The various qualitative data sources provide information about the extent to which design teams demonstrated a focus on equity, even though it was not explicitly assessed in this project.

Respondents to the Weekly and Monthly Design Team Logs shared how they created diverse teams from across different departments, roles, and levels within their agencies. They discussed how team members shared work responsibilities and were respectful of team members' availabilities and skills. Santa Clara implemented a rotating project manager role to ensure the responsibility of leading meetings and moving the work forward did not fall disproportionally on one person. This division of labor allowed all team members the opportunity to guide discussions and contribute in varied ways throughout the project. These logs also provided information about how the design teams offered gift cards or other tokens of appreciation to end users who participated in the pilot study. These incentives were aimed at helping to reduce barriers to participation (such as through reimbursement for internet access and compensation for their time). Incentives were especially important for the design teams whose end users were clients; since when agency staff are end users, they are compensated for their time as part of their normal work responsibilities. Finally, design team members mentioned on these logs that they were trying to recruit end users from various backgrounds to help ensure they were hearing varied perspectives.

The HCD consultants also noted on the HCD Consultant Logs that the teams considered which voices and perspectives (from design team members to end users) they had not heard from when making decisions and gathering feedback. During the interviews, design team members from two agencies and their HCD consultants explicitly mentioned their use of equity pauses. For instance, one consultant said: "I think they also really benefited from the concept of the equity pause —a moment and a set of questions to pause and ask yourself throughout the project about whether or not you have the right people involved, who we are not hearing from, and what is the history here, those sorts of things. I think that clicked really well for them as a technique and a mindset to have when they are making decisions." This approach helps teams consider the implications of the decisions they are making on varied groups before the decision is made.

Interviewees also discussed how the teams focused on ensuring all voices were being heard. However, two of the three HCD consultants and one design team member mentioned how design teams struggled to identify a diverse group of end users with whom to speak. For instance, in Denver, the design team ended up only hearing from a subset of their end users because the department only served some TANF recipients (others were served by contracted agencies). In Washington, a large proportion of end users reached (interviewed) were military veterans; this encouraged the team to develop a process for providing incentives to encourage participation from more diverse end users.

From these data sources, it is clear that the design teams made efforts to consider equity both within their design team and among the end users they engaged. However, it was not clear if all important groups of end users were successfully engaged, despite reports of efforts to do so. This may be related to the time and resource constraints imposed by this pilot study. For instance, it may take more time to build trust with people from communities that may have had negative interactions with human services agencies in the past, or staff who have had negative workplace experiences for many years.

Box 9. Integrated Findings

Output: Design team demonstrates HCD principles

- Agencies demonstrated some HCD principles more than others.
- Demonstration of three principles appeared to improve over time.
- Demonstration of some principles varied across site, time, and reporter.
- Agencies took a number of actions to promote equity, although found engagement of a diverse group of end users to be challenging.
- There were several challenges in assessing principles as defined in this project.

Design Team Implements HCD Activities

As previously depicted in Table 5, the design teams varied somewhat in when they worked on the different HCD phases, and none of the design teams were able to complete all the phases during the time period of the study. Additional data on activities and phases collected on the weekly and monthly logs and the Implementation Assessment reflect a similar pattern and provide additional details.

Extent of Implementation of Each Phase

The Implementation Assessment assessed Denver and Santa Clara's implementation of each phase[j] (see Appendix D). Figure B-2 in Appendix B shows that both of these design teams fully (90-100%) implemented the first three phases: Research & Discover, Synthesize & Generate Solutions, and Conceptualize & Prototype phases. Denver also fully implemented the Test & Iterate phase (100%), while Santa Clara had not yet started that phase at the time of the assessment. Neither agency had implemented the Implement & Refine phase.

Activities and Time Implementing Each Phase

Design teams used a diverse array of HCD activities over the course of the pilot study, with the most commonly implemented activities indicated in Table 6 (see the glossary in Appendix A for definitions of each activity).

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[j] Some data from Washington were missing due to inadequate time to fully complete the implementation assessment with their team.

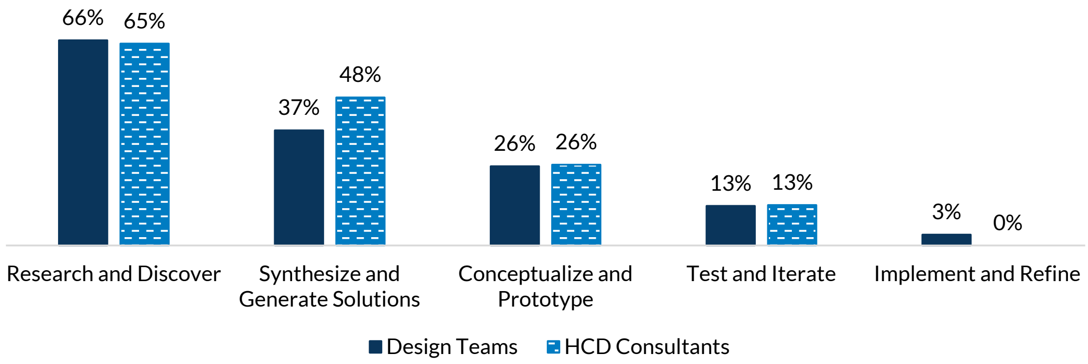
Table 6. Most frequently implemented activities, by phase of the HCD process

Phase	Most frequently implemented activities
Research and Discover	Interviews, data analysis
Synthesize and Generate Solutions	Design Thinking Workshops, brainstorm sessions, How Might We statements
Conceptualize and Prototype	Rapid prototyping, concept posters
Test and Iterate	Cognitive walkthroughs, usability testing
Implement and Refine	Development of the solution, governance planning

Source: HCD Consultant Log, Weekly Design Team Log
Note: Design Thinking Workshops were part of the prescribed implementation plan.

As seen in Figure 10 below, design teams spent most of their time on the Research and Discover phase, with decreasing amounts of time for each subsequent phase, including little to no time on the Implement and Refine phase. Although largely consistent in their ratings, the HCD consultants indicated that the teams spent more time synthesizing and generating solutions than design teams reported. Figures B-3 through B-7 in Appendix B provide additional details on the percentage of time spent on each activity within each phase as reported by the design teams and the HCD consultants.

Figure 10. Percentage of time spent on each phase, averaged across sites



Source: Weekly Design Team Log, HCD Consultant Log
Note: Time is expressed as a percentage due to missing data. The design team data is presented as a percentage of weeks; HCD consultant data are presented as a percentage of months and averaged across agency due to limited variability. Ranges of agency level HCD consultant averages by activity are as follows: Research and Discover (63-71%), Synthesize and Generate Solutions (38-57%), Conceptualize and Prototype (25-29%), Test and Iterate (0-25%), and Implement and Refine (no variation). Ranges of design team averages by activity are as follows: Research and Discover (62-72%), Synthesize and Generate Solutions (26-48%), Conceptualize and Prototype (13-35%) Test and Iterate (4-24%), and Implement and Refine (0-7%).

Box 10. Integrated Findings

Output: Design team implements HCD activities

- During the time period available for the study, design teams spent the most time on, and more fully implemented, the earlier HCD phases.
- While some activities occurred more frequently than others, design teams used a diverse array of HCD methods/activities over the course of the pilot study.

Barriers and Facilitators

Although barriers and facilitators of HCD implementation were not explicitly identified in the original Theory of Change, they were included in the evaluation and assessed in a number of ways, including interview questions and a checklist of common barriers (based on the HCD literature) on the HCD Consultant and Design Team Monthly Logs. There was also opportunity for design team members and HCD consultants to share open-ended comments about challenges and what was working well on both monthly and weekly logs (see Appendix D).

Facilitators

Resources and supports identified as helpful for HCD implementation in the Monthly Design Team Log included strong project management, leadership support, having diverse perspectives on the design team, collaborative and respectful team dynamics, technology resources (including resources used to facilitate virtual training and coaching and design team collaboration), and the alignment of the work with the culture and priorities of their organizations (i.e., the organization being open to change, or the support of HCD by the state's governor). Weekly Design Team Logs highlighted similar facilitators, but also reflected the importance of having a process for, and the ability to, distribute incentives. In addition to the aforementioned facilitators, the HCD Consultant Log also noted benefits of access to HCD expertise and tools, and the strategic engagement of stakeholders (including other relevant staff and IT support). Across reporters, the three facilitators identified as most critical were: strong project management, leadership support, and the ability to offer incentives to end users.

Interviews highlighted the importance of these three factors. For example, a design team member from Denver noted that, "A good lead or project manager is essential. It's hard to remember what's always due but having someone organizing and efficient kept the ball rolling and held us accountable." The HCD consultants described how they often had to serve in this role for the teams, especially at the beginning of the pilot study. Regarding leadership support, design teams emphasized the importance of frequent and open communication with leadership. In Washington, effective leadership and support from their finance team enabled the design team to distribute incentives to end users—something they previously were not able to do. A design team member from Santa Clara emphasized, "Leadership needs to set the tone and demonstrate the commitment. They also need to know what's going on so they can address barriers that we can't... This is essential to any systems change—you need leadership buy in ownership or else you'll be working in a house of cards—everything could come crumbling down fast."

Both HCD consultants and design team members also clearly communicated the importance of incentives for engaging end users. A design team member from Washington detailed how they did not offer incentives when they first held end user interviews, which they believe contributed to challenges with recruitment and participant no-shows. Learning from this experience they decided to offer $25 gift cards to participating end users for participation in the Design Thinking Workshop, and saw a boost in participation. Two of the three design teams were able to distribute monetary (i.e., gift card) incentives to end users that provided feedback and support to the teams. Santa Clara did not have the ability to provide incentives, but found creative ways to express appreciation to those who provided feedback and support (ex., thank you cards and “goody” bags). A design team member from Santa Clara highlighted the importance of finding ways to thank participants, “You need that community to participate—if you don’t get that you’re not getting anywhere.”

Box 11. Integrated Findings

Facilitators

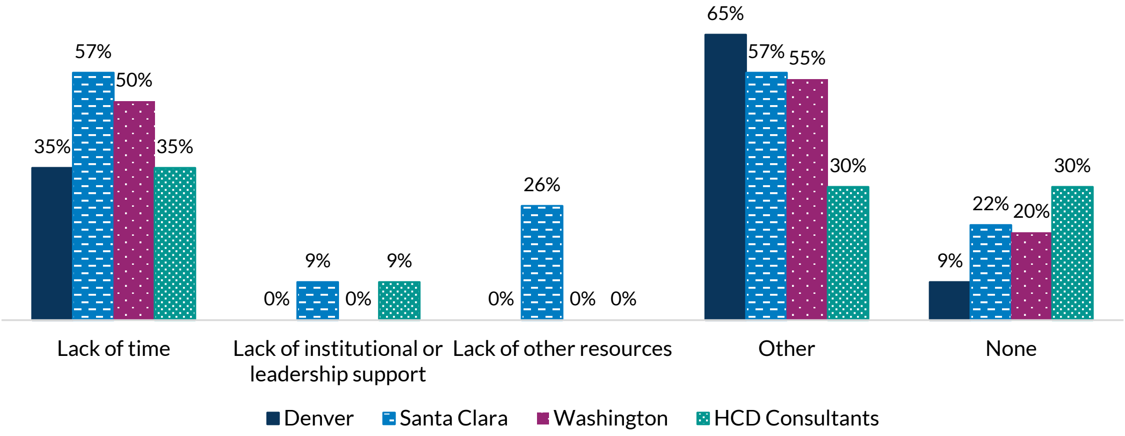
The most critical facilitators to the HCD process were:

- Strong project management,
- Leadership support, and
- A process for, and the ability to, distribute incentives.

Barriers

Each design team reported regular and ongoing barriers on the weekly and monthly logs, although design team members described these as more challenging than the HCD consultants did. Specific barriers assessed each month are depicted in Figure 11 below. In addition to lack of time, other barriers not identified in checklists were also quite common, including organizational/operational challenges and “red tape,” engaging and recruiting end users, balancing other work priorities with their HCD-related work, adapting to COVID-19 and design team members being deployed for disaster service, and challenges related to distributing incentives to end users participating in the design process. Interviews with design team members and HCD consultants identified the following barriers: the recruitment of end users, challenges related to distributing incentives, general constraints of operating in a government agency, challenges related to the COVID-19 pandemic, ensuring end user confidentiality and data security, and sustainability.

Figure 11. Percentage of months design teams encountered different barriers



Source: HCD Consultant Log, Monthly Design Team Log
Note: Months are presented in percentages, as opposed to counts, due to missing data. Ranges of site-level HCD consultant averages by challenge are as follows: lack of time (25-57%), lack of institutional or leadership support (0-25%), lack of other resources (no variation), other (0-63%), and none (13-50%).

A design team member from Santa Clara discussed the unique challenge of this pilot study taking place during the COVID-19 pandemic. They explained, “The context of COVID was a challenge and reward—it required us to be adaptive, which is a piece of HCD. That part also provided some challenges—we had to figure out how to be together and build trust in a virtual world.” That individual went on to discuss why building internal capacity was so critical. Another design team member from Santa Clara highlighted the importance of adequate staff time by stating, “If we want to have HCD live on past the [training and coaching] phase, we need to have a dedicated—at least one full time position—but more likely a team to be able to continue this type of work. It’s very time intensive, very resource intensive, and the design team is doing this in addition to the work they normally do.”

In addition to the types of barriers, the extent to which barriers interfered with HCD implementation at each agency was examined. Overall, the design teams experienced barriers as more impactful than the HCD consultants did, which is understandable given their difference in experience with HCD. Design team members also faced ongoing demands from competing work and organization priorities that the HCD consultants may not have observed. As seen in Figure 12, there is also variability in the impact of barriers across sites and across time, with design teams generally rating the impact as more than “somewhat.” Importantly, however, none of these barriers were described as

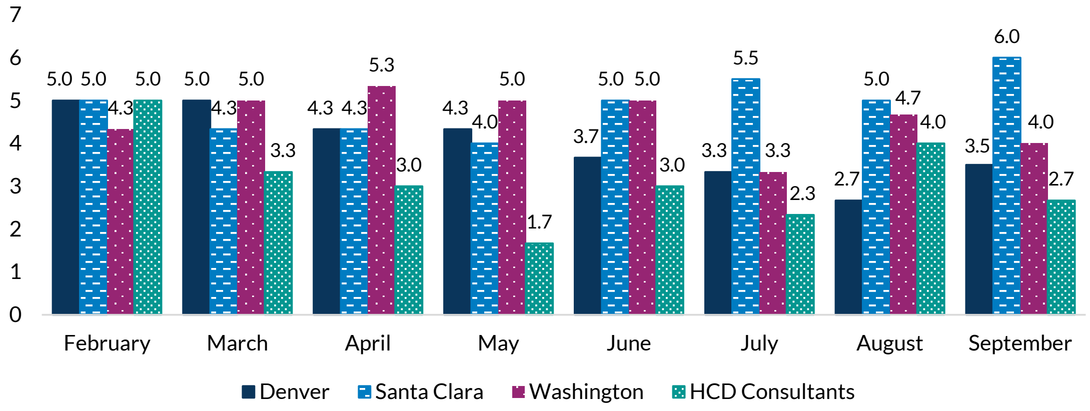
Box 12. Integrated Findings

Barriers

- Design teams faced barriers often, though no barrier was found to be insurmountable.
- Design teams reported barriers as more challenging than did HCD consultants.
- The experience of barriers varied across time and by site.

insurmountable. In fact, as can be seen in Table 7 below, there were many creative and purportedly effective ways in which each of these were addressed.

Figure 12. Perceptions of how much barriers interfered with implementation



Source: HCD Consultant Log, Monthly Design Team Log
Note: Scale is 1 (not at all); 4 (somewhat); 7 (a lot). Over time, the range of average HCD consultant ratings was 2.3-4.3.

Table 7. Types of barriers experienced by design teams and strategies used to address them

Barrier	How barrier was addressed
Time available for design team members to engage in the HCD work, which was exacerbated by the pandemic and staff time off	• Bringing in other team members • Rotating project management structure • Having HCD consultant help with project management • Shifting staff day-to-day responsibilities so design teams could dedicate time towards HCD work • Collaborative design teams with members who would pitch in when others were busy
Recruitment of end users, specifically having no-shows; recruiting a diverse pool of end users; lack of incentives; limited time to build trust with end users; end users' lack of time	• Incentives and wi-fi stipends for virtual meetings • Working with case workers to identify individuals who would be more likely to engage • Listening to end users and not being defensive • Using virtual platforms end users were more comfortable with
Incentives, specifically not having a process in place to administer gift cards	• Gift bags and other forms of appreciation used as an alternative • Building a new process to provide gift cards

Barrier	How barrier was addressed
Organizational structures and processes with many layers of approval needed	• Frequent communication and involvement with leadership and executive teams inside the organization
End user confidentiality, specifically around consultant participation in the Design Thinking Workshop, and issues related to file sharing with people outside of the organization (i.e., HCD consultants/experts)	• Creating separate locations for file storage for design team members and people outside the agency (i.e., HCD consultant) • Working with agency to explain project/get approval for HCD consultant and content expert participation in the Design Thinking Workshop
COVID-19, when people needed to be deployed as disaster service workers, other employees having increased workloads, having to do everything virtually	• Breaking up Design Thinking Workshop into multiple shorter virtual sessions • Use of technology (such as Teams, Zoom, Calendly, and Miro) to collaborate as a team and engage with end users and stakeholders virtually • Extension of training and coaching timeline

Outcomes

Short-Term Outcomes for Design Team: Adopt an HCD Mindset

As noted in the Theory of Change, an HCD mindset was operationalized as (1) empathy for end users, including working to understand the feelings and perspectives of end users; (2) openness to all opinions and perspectives from all stakeholders; and (3) new ways of identifying challenges, brainstorming solutions, and trying different ideas. To assess this construct, we used log ratings, the Implementation Assessment, and interviews.

Overall Mindset

The Implementation Assessment included the following three items that were averaged to assess the HCD mindset within each design team at the end of the evaluation:

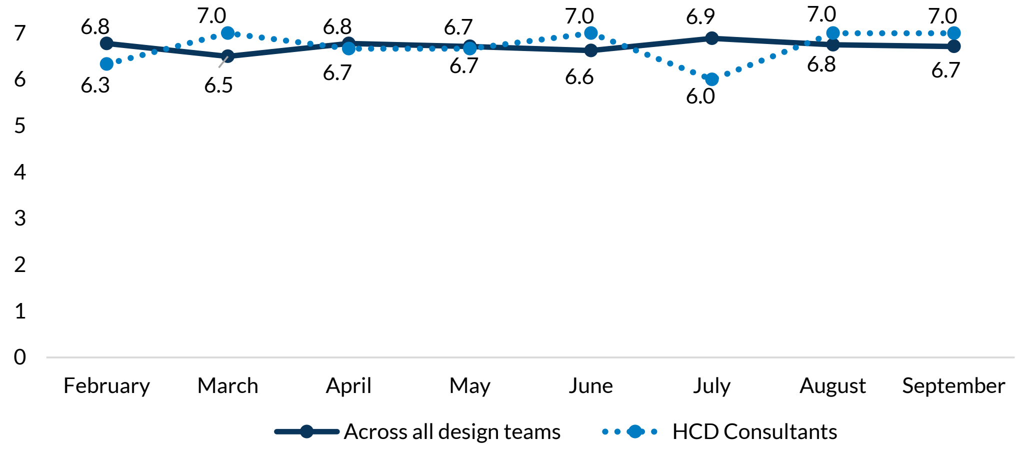
- The team truly understands the feelings and perspectives of the end users.
- The team is interested in and open to trying new and creative ideas.
- The team is comfortable with uncertainty about the challenge and solutions and avoids "jumping to conclusions."

Based on these items, one design team demonstrated 100 percent of an HCD Mindset, while the other two demonstrated 83 percent, each of which exceeds the 75 percent threshold for full demonstration of implementation. Of note, design team members had different interpretations of the first item, *understanding the feelings and perspectives of end users*. In interviews, HCD consultants were asked to what extent design team members adopted an HCD mindset. One noted that their team was "working together in a way that they usually don't in their organization, which is really exciting. It was just a very different mindset shift to be talking to [end users about their experiences]." A design team member from Santa Clara discussed how their design team has begun to think more creatively, and while at the beginning of the pilot study they had one solution in mind and wanted to "make it work," they are now open to new solutions and the idea of iteration. That individual went on to describe HCD, highlighting, "It's something that's going to make you think on your feet. Something that is going to give you a different way of thinking, and there's never a right or wrong answer to it."

Empathy for End Users

Although previously depicted in Figure 8, Monthly HCD Consultant and Design Team Logs assessed empathy, which can be interpreted both as Principle 1 (understand end users and stakeholders) and as part of an HCD mindset. Figure 13 shows data on empathy across time, which demonstrate high ratings from the first assessment that were relatively consistent across time and raters. HCD consultants generally agreed with design teams, with slight variation during July, coinciding with when the Design Thinking Workshops occurred. In interviews, design team members from Santa Clara indicated that they gained humility by talking to end users, and design team members from Washington said that engaging with clients reduced stereotypes they had about their clients.

Figure 13. Perceptions of how design teams demonstrate empathy for end users, averaged among raters



Source: HCD Consultant Log, Monthly Design Team Log
Note: Scale is 1 (not at all); 4 (somewhat); 7 (a lot). Over time, the range of average HCD consultant ratings was 6.4-6.9 and the range of design team ratings was 6.4-7.0.

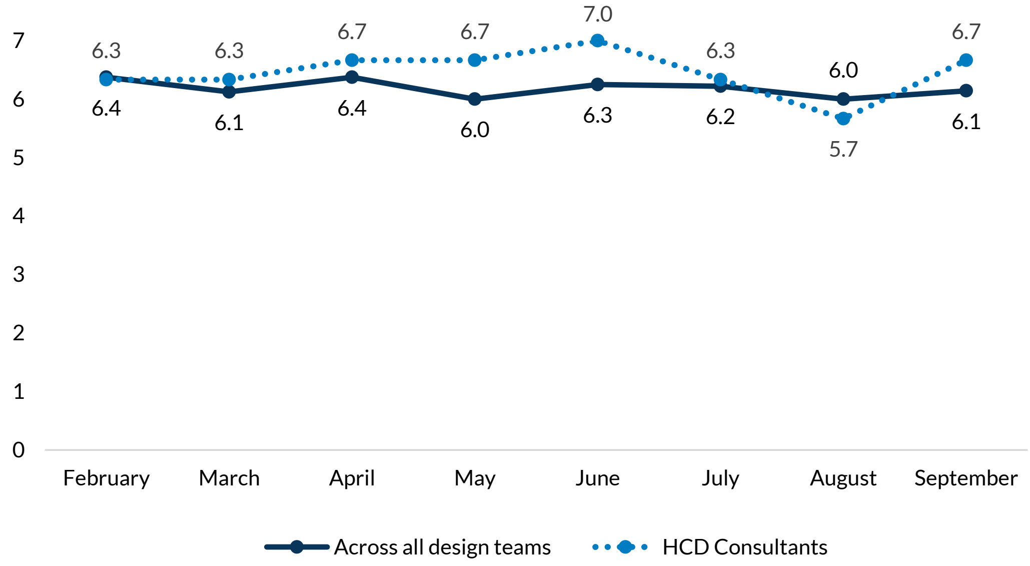
Openness to All Opinions and Perspectives of Stakeholders

HCD consultants provided evidence of openness in describing how design team members expanded their perspectives on stakeholder needs. For example, one noted that "talking to customers and partnering with vendors that [they] don't normally talk to about how their programs work were the most impactful things towards shifting [their] perspective toward iterating on designs and focusing on what customers actually needed or wanted." A design team member from Denver shared how they realized during the pilot study that they were missing an important voice on their design team, so they invited someone with that perspective to join. Design team members in Washington talked about engaging a variety of stakeholders to ensure that all of the stakeholders understood the goals of the video they were making about the child support order modification process. The stakeholders also reviewed the language being used so the video was as accurate as possible.

New Ways of Identifying Challenges, Brainstorming, and Trying Different Ideas

The HCD Consultant and Monthly Design Team Logs also assessed the extent to which design teams tried new ideas and new ways of identifying challenges and brainstorming solutions (Figure 14). As seen below, ratings were again largely high and consistent across time and raters, with the exception of one lower rating by the HCD consultants shortly after the Design Thinking Workshops when design teams were integrating a lot of feedback and deciding how to move forward with a solution. Again, this suggests evidence of an HCD mindset at the beginning of the evaluation (following the initial training).

Figure 14. Perceptions of how design teams tried new ideas and new ways of identifying challenges and brainstorming, averaged among raters



Source: HCD Consultant Log, Monthly Design Team Log
Note: Scale is 1 (not at all); 4 (somewhat); 7 (a lot). Over time, the range of average HCD consultant ratings was 6.0-6.9 and the range of design team ratings was 5.6-6.6.

In contrast to these ratings, interview data reflect that design teams learned new approaches to problem-solving during the pilot study. For example, a design team member from Denver described how they prioritized not getting too attached to an idea or solution. Instead, they chose to be led to solutions with input from end users, being willing to adapt and refine their prototypes based off of collected feedback. They described, "I've been a part of several process improvement efforts in the past, and I remember getting so attached to my ideas…The end user in mind when designing is huge and something I'll carry with me beyond this project." Another individual from Denver declared, "The success of what we've learned through this [pilot study] is because we were very open and ready." A Santa Clara design team member also discussed how the design team grew closer over the course of the pilot study, and they were able to "think outside the box" more than they could at the beginning of their work. On the other hand, one HCD consultant noted that their design team struggled with imagining something new. The same HCD consultant commented on how it was hard for their agency to make the shift from being organization/business-focused and more user-focused.

“Bias Toward Action”: An Emergent Indicator of an HCD Mindset

HCD consultants and design team members also described gaining a perspective that encourages action, rather than excessive thinking and planning (“bias toward action”). This perspective is consistent with the training provided and is commonly referenced in the field as part of a design thinking mindset,[76] although it did not emerge with strong evidence in the literature review discussed previously. One HCD consultant provided a helpful perspective on the novelty of this indicator for the design team they worked with: “I think they’re doing a good job with the bias toward action—I think it’s very new. I think the current way of doing things is to document a really well thought out, well-argued plan, approach, and budget for a solution all at once, get it approved and then make it happen. Instead of, you know, to try things out and see what works and define your solution before you ask for the budget and permission to sustain it afterwards. I think that’s been a reversal for them, but one they’ve adapted to well.” Two design team members from different agencies also appreciated how the HCD consultants helped them move toward action and test out their ideas.

Box 13. Integrated Findings

Short-term outcomes for design teams (developing an HCD mindset)

- All design teams clearly demonstrated an HCD mindset, with notable consistency across time and sites.
- Design teams demonstrated empathy for end users in multiple ways from early on in the project, including focusing on the “human side” of an issue.
- Design teams demonstrated openness to the opinions and perspectives of end users and others by seeking out their perspectives and incorporating end user feedback in other aspects of their work, outside the pilot study.
- Design teams adopted new ways of identifying challenges, brainstorming, and trying different ideas.
- Additional aspects of an HCD mindset emerged from the interview data including comfort with uncertainty, and a bias towards action.

Short-Term Outcomes for End Users

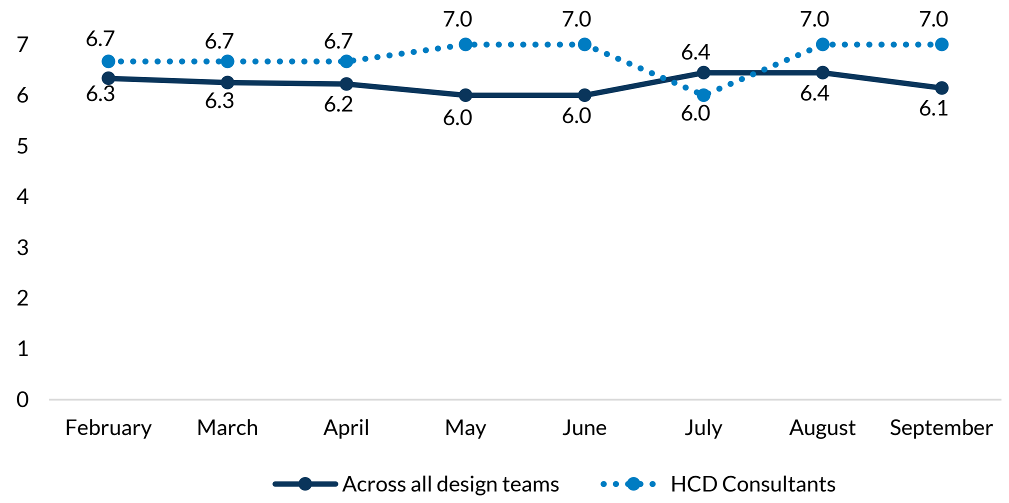
Log ratings and interviews were used to measure the following short-term outcomes for end users: (1) the relevance and usability of the solutions, (2) the likelihood of end users adopting solutions, and (3) whether systems are in place to measure progress toward desired outcomes. At the time of the evaluation, the design teams were in the process of testing the following prototyped solutions:

- **Denver**: Congratulatory email to those exiting TANF accompanied by a phone call from a case worker to discuss supports and resources available based on their specific circumstances, which staff then compile and share with the end user in a customized follow-up email
- **Santa Clara**: A platform and process for staff to propose ideas to leadership and for leadership to respond to the ideas ranked as highest priority by staff
- **Washington**: Video walking end users through paperwork required to initiate a child support order modification

Solution is Considered Relevant and Usable

The HCD Consultant and Monthly Design Team Logs asked respondents to report on their perceptions of how well-suited the HCD approach was to the design team's challenge. Figure 15 reflects high ratings on this item across time from both respondents, with a slight decrease in HCD consultant ratings around the time of the Design Thinking Workshops.

Figure 15. Perceptions of how well-suited the HCD approach was to the design team's challenge, averaged among raters



Source: HCD Consultant Log, Monthly Design Team Log
Note: Scale is 1 (not at all); 4 (somewhat); 7 (a lot). Over time, the range of average HCD consultant ratings was 6.5-6.9 and the range of design team ratings was 6.0-6.5.

One HCD consultant noted that their site started out with a very broad and large challenge that was initially difficult to define more specifically. The HCD consultant suggested that there may have been benefit for design teams to initially use HCD with a smaller challenge. The HCD consultant further explained, "They're using a lot of these tools and techniques for the first time, and it's something so vague for the first time and it takes a lot longer time to do each of the steps. Something more scaled down would have given them a quick success and confidence before tackling a bigger problem… They're where they need to be on their current project, but I wonder if it would have been different or helped to give them a preview of the path ahead." Despite the size and complexity of each agency's challenge, all of the HCD consultants said the process used was a great fit for the challenge their design team targeted.

Design teams were also hopeful about their solutions, though they were still in the process of testing them at the time of data collection. Design team members from the Denver and Santa Clara teams discussed how their solution was guided by end user input, and that leadership is invested in moving the work forward and providing the resources needed to ensure its use with end users. Design team members from Washington noted that relevant stakeholders had given them positive feedback on their proposed solution. One design team member went on to explain how they would continue to engage their end user in the future to keep their product relevant and usable (i.e., translate the video series they developed into other languages their clients speak).

An HCD consultant, however, expressed concerns that their team's proposed solution may not fully address the challenge they set out to tackle, due in part to organizational and feasibility constraints. Another HCD consultant also noted constraints related to the structure of their program and available financial and staffing resources. Nonetheless, HCD consultants described the design teams as being inspired to address the full scope of the challenge and empowered to tackle the next best thing—a more defined, controlled piece of the challenge.

End Users are Likely to Adopt the Solution

Interviews with HCD consultants and design team members suggested that they were hopeful about their solutions working. Design team members at all sites, however, emphasized the need for solutions to be properly advertised and promoted to their intended end user and made easily accessible, or there could be risk that the solutions might not fully reach their intended audiences. One HCD consultant flagged that in order for their team's solution to become a success, all stakeholders would need to be made aware of and support the proposed solution: "A lot depends on how these other key players interact with this process. They need to recommend these resources, otherwise this would become a [solution] that exists but people don't know about."

Systems are in Place to Measure Progress Toward Desired Outcomes

In interviews, HCD consultants and design team members were asked how the success of their solutions will be measured and whether there are any data monitoring systems being used (see Table 8). Although all design teams were considering what would happen after they launch their solutions, no agency had formalized details about how they will track their desired outcomes. This may be due, in part, to design teams not having reached the last phase of HCD implementation.

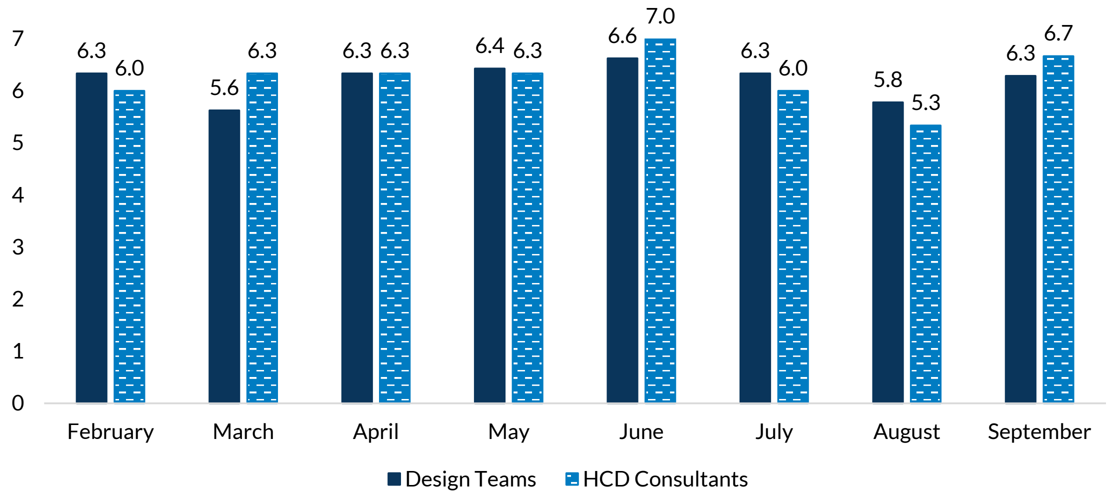
Table 8. Long-term outcomes to be measured, by agency

	Challenge to be addressed	Long term outcomes to be measured
Denver	TANF cliff effect	Decrease in return to TANF after exit
Santa Clara	Employee engagement	Increased staff engagement and well-being
Washington	Completion of child support order modifications	Increase the number of completed order modifications among parents initially requesting a modification

Source: Interviews with HCD consultants and design teams

There is no objective data about agency progress, but design team members and HCD consultants were asked about their perceived progress thus far. The Monthly Design Team and HCD Consultant Logs show that perceived progress increased over the first half of the pilot study and decreased over the summer (after the Design Thinking Workshop), before increasing again in September (see Figure 16, below). During interviews, design team members reported that, after these workshops, the process of synthesizing ideas and coming up with a solution to pursue was hard, so it felt like progress slowed.

Figure 16. Perceptions of progress toward the design team's HCD goals, averaged across sites



Source: Monthly Design Team Log, HCD Consultant Log
Note: Scale is 1 (not at all); 4 (somewhat); 7 (a lot). Over time, the range of average HCD consultant ratings was 6.1-6.3 and the range of design team ratings was 5.9-6.6.

Box 14. Integrated Findings

Short-term outcomes for end users

Design teams believed their chosen solutions were relevant and usable and they were hopeful about end users adopting their solutions as long as the solution reached the end user.

Long-Term Outcomes

To address this construct, interviewers collected data on: (1) indicators of sustainability of the HCD process in the original project and in other projects taken on by design team members in their day-to-day work responsibilities, unrelated to the pilot study work and (2) if desired improvements were obtained in the challenge targeted by the HCD approach. While the original Theory of Change notes that sustainability of the HCD process was not measured in the evaluation, this topic came up during interviews, and thus information regarding project sustainability is discussed below.

Sustainability of the HCD Process in the Original Project and Beyond

At the time of data collection, no design team had reached the phase where they would implement their proposed solution. Therefore, it is not possible to assess if there will be improvements in agencies' outcomes of interests for end users. However, during HCD consultant and design team interviews, indicators of sustainability were identified (for a high-level summary, see Table 9, below).

- **Denver.** Indicators of success include the incorporation of HCD into the agency's strategic plan; use of HCD principles in other areas of work unrelated to the pilot study; and the agency's decision to use HCD to make decisions related to the best use of TANF reserves. One design team member explained, "In an organization, if it doesn't have that fluidity and openness at all levels of leadership, it would just be a nice project that happens for a short period of time. We were committed to not having that happen… We've had a ton of nice projects that become a binder on a shelf—we wanted this to inform change we wanted to see."

- **Santa Clara.** An indicator of sustainability was that design team members used HCD principles in other areas of their work unrelated to the pilot study. One design team member noted, "My definition of success for this agency is to have this continue--to have this live on so we can apply HCD across the agency for different challenges. That will be our measure of success."
- **Washington.** Indicators of sustainability were the incorporation of HCD into the agency's strategic plan; design team members' incorporation of end user feedback into other areas of their work unrelated to the pilot study; and the team's plans to continue to use HCD principles on future challenges. One design team member shared, "A lot of the work has been contained to our team, so it hasn't had time to cause joyful infection in others yet." The interviews also illuminated important political context that also serves as an indicator of sustainability—their governor has demonstrated interest and support for the implementation of HCD, which design team members believe will help propel their current and future HCD related work and keep HCD as a priority in their agency.

Table 9. Observed indicators of sustainability, by agency

	Challenge to be addressed	Observed indicators of sustainability
Denver	TANF cliff effect	Building HCD into strategic plan, using HCD to determine how to best use TANF funding, using HCD principles in other work
Santa Clara	Employee engagement	Using HCD principles in other work
Washington	Completion of child support order modifications	Incorporating HCD into strategic plan, governor supportive of HCD, incorporating end user feedback into other workgroups, using HCD principles in other work

Source: Interviews with design teams

Box 15. Integrated Findings

Long-term outcomes

- All agencies demonstrated indicators of future sustainability specific to agencies and the challenges they were solving.
- All design teams detailed how they had begun implementing HCD principles in other areas of their work unrelated to the pilot study.

Unexpected Outcomes

During the interviews, design team members were asked if they experienced any unexpected outcomes from implementing HCD. One such outcome was that agencies developed or refined their incentive processes so they could show appreciation to stakeholders and end users who supported their work. In addition, one design team identified a preferred platform for virtual engagement with community members (Zoom), and the agency developed a policy based on this finding. Although unexpected, this need for processes to compensate and engage end users is a logical facilitator of HCD implementation. Without such systems, the engagement of end users will likely be more difficult, which jeopardizes a design team's ability to demonstrate key HCD principles.

Key Findings

Given the extensive data collected and described in this report, this section summarizes key findings of the evaluation based on integrating findings across measures. These are related to, but not directly aligned with, our initial research questions, which are answered concisely in Appendix C. The following are the most salient findings from across research questions.

1. **HCD can be evaluated systematically in human services programs with a variety of theoretically-driven data collection tools, although more work is needed in measure development**. This pilot study used a systematic evaluation approach. It began with clear and specific research questions, identified key constructs and how they may be related based upon the extant literature, and operationalized each construct with measurement tools. In the absence of established measures in the field, all our evaluation tools were developed for this pilot study. A mixed methods approach and data triangulation across multiple time points, measures, and reporters promoted understanding of how HCD can be evaluated in human services. This pilot study provides initial evidence of the reliability as well as validity of tools developed in this project, with clear room for future revision and validation. More specifically:

    a) Data collected through multiple methods yielded largely similar findings, providing support for the validity of the tools. For example, it was common to hear of explicit examples of skills or activities in interviews that aligned with the log ratings provided by design team members and HCD consultants.

    b) Reliability was supported by the consistency of log ratings repeated by several respondents every week or month across eight months.

    c) Discrepancies between reporters may reflect important differences in perspectives and inform which measures may be more useful for assessing different types of information (i.e., where the HCD consultant's knowledge is needed for accurately responding to detailed questions about HCD activities).

    d) It was difficult to reliably assess demonstration of the HCD principles and distinguish them from an HCD mindset. Definitions are described below that may be helpful for future evaluations.

    e) Evidence of a surprisingly high level of HCD mindset across design teams at the beginning of the pilot study raised questions about how this construct is measured and to what extent this may pre-exist in human services programs prior to HCD training and coaching.

2. **With expert training and coaching, design teams demonstrated HCD principles and implemented a range of HCD techniques with different challenges, end users, and contexts**. In this project, design teams received approximately 7-9 hours per week of consultation and direct support from an HCD consultant and a content expert, in addition to three full days of initial training. With this capacity-building support, which was rated highly, design teams demonstrated HCD principles and appeared to use HCD techniques effectively, as evidenced by the following:

    a) HCD consultant ratings of design teams' use of techniques consistently met or exceeded 6 on a 1-7 scale for seven of eight months.
    b) Design team logs reflect implementation of a range of activities in 4 of the 5 phases of the HCD process (there was inadequate time for the Implement and Refine phase).
    c) Across the three sites, average design team ratings of use of HCD principles exceeded 6 on a 1-7 scale for three principles (Principle 1: demonstrate empathy for end users; Principle 5: consider end users' needs, preferences, and context; and Principle 6: collaborative team process) and exceeded 5 for the other three principles (Principle 2: engagement of end users and stakeholders in the design process; Principle 3: incorporate end user and stakeholder feedback in testing and revising solutions; and Principle 4: generate, test, and revise potential solutions, going back to earlier steps as needed).
    d) Based on the Implementation Assessment, all three design teams were considered to be successfully implementing three principles (>75% of indicators in place, a threshold shown to predict positive outcomes).[77] One agency was considered to evidence all six principles; one agency evidenced five and one agency evidenced three principles.
    e) Interviews with design team members and HCD consultants provide numerous exemplars of how the principles and strategies were effectively used. These qualitative data also help explain some variability in application of principles across time and raise questions about whether all principles apply equally throughout the HCD process.

Although there was some variability in HCD implementation across sites, there were more similarities as evaluated in this project despite different challenges, end users, contexts, and consultants. Such similarities might be expected given that design teams received very similar training and coaching, with similar timeline constraints. However, these findings suggest that the HCD process can be well-defined and consistently implemented for future evaluations. There was also evidence that suggests that design teams in human services programs that are new to HCD can learn to use it within one project over the course of a year for a reasonably complex challenge. Moreover, multiple sources of data indicate that this implementation was successful, even in the context of ongoing barriers, including an unprecedented pandemic.

3. **From early in the evaluation, design team members demonstrated an HCD mindset, including empathy for end users, openness to different opinions and perspectives, and new ways of identifying challenges and brainstorming.** Based on the operationalization of an HCD mindset in the initial Theory of Change, an HCD mindset was defined as 1) empathy for end users, 2) openness to different opinions and perspectives, and 3) new ways of identifying challenges and brainstorming. These constructs also overlap with some of the HCD principles, specifically Principles 1 (demonstrating empathy for end users) and 4 (using an iterative process), but they are separated for conceptual clarity (see below for further discussion). Evidence of an HCD mindset is as follows:

   a) All design teams demonstrated at least 80 percent of the core mindset elements on the Implementation Assessment, which assessed similar but slightly reworded components to those specified in the Theory of Change (i.e., "truly understands feelings and perspectives of the end user," "openness to trying new ideas," and "comfortable with uncertainty").

   b) Empathy for end users was also demonstrated in the HCD Consultant and Design Team Monthly Log ratings of empathy for end users (all design teams scored greater than or equal to 6 on a 1 to 7 scale). Of note, these ratings were high from the beginning of the project and were generally consistent throughout its duration.

   c) New ways of identifying challenges and brainstorming was rated highly by HCD consultants and design team members (greater than or equal to 6 on a 1 to 7 scale in seven of the eight months).

   d) During interviews, design team members expressed high motivation and interest in engaging end users and stakeholders that was not always fully realized due to various logistical barriers, including pandemic-related barriers. Design team members also described actively seeking diverse end user perspectives, thinking "more creatively" and being more "open to new solutions and the idea of iteration" rather than trying to make their initial ideas work.

   e) An additional aspect of an HCD mindset identified (which was not formally assessed but added to our revised Theory of Change) was a *bias toward action*.

4. **Design teams demonstrated capacity for HCD through using strategies competently, building confidence, developing processes to support sustainability, and addressing challenges that arose.** There was evidence of an increase in design team confidence in and capacity for HCD over the 8 months of the evaluation period. Design teams also developed capacity by creating new processes to support HCD implementation and address challenges. More specifically:

   a) As reported in interviews, one of the most critical facilitators for engaging end users effectively was the ability to provide incentives to them to encourage input and participation. Two of the three design teams created new processes for this purpose by leveraging leadership support and providing non-monetary incentives when gift cards could not be provided.

   b) Design teams reported ongoing challenges to HCD implementation that varied across the period of evaluation and interfered with their work, with an average rating of "somewhat interfered" every month. Staff time was the biggest barrier, as was expected; recruiting end users was also frequently identified. Interestingly, however, the HCD consultants rated interference consistently lower than did the design teams. Interviews reflected that design teams limited the impact of these barriers with creative thinking, support from their agency leadership, and guidance from the HCD consultants and content experts.

c) There was indication that design team members' confidence in implementing HCD techniques increased over time from an average score of 5.3 in the first two months of the project to an average of 6.2 in the last two months. Variability in ratings across time suggest that a dip around the time of the Design Thinking Workshop, after which confidence and perceived progress increased.

5. **HCD was found to be useful and relevant in addressing disparate challenges across three sites, and each site had interest in continuing to use HCD in some way.** Optimism about the solutions that had been identified and were being tested at the time of this evaluation was strong, and HCD was considered to be relevant for each design team's specific challenge. Evidence provided from monthly logs completed by HCD consultants and design team members, as well as in interviews, is as follows:

   a) Both the HCD consultants and design team members reported that the HCD approach was well suited to the challenges they sought to address, with nearly all monthly ratings related to this question at or above 6 on a 1 to 7 scale. Specifically, a design team member and an HCD consultant described HCD's focus on end users as being particularly relevant for solving complicated challenges that have not been solved using more traditional methods in the past.

   b) Interviews with the HCD consultants and design team members suggested that design team members were findings ways to incorporate their HCD mindset and principles into other aspects of their work beyond the pilot study. Design team members shared excitement about using an HCD mindset and strategies, and two of the three agencies had plans to incorporate HCD into their agency's strategic plans. However, concerns were also expressed about feasibility with respect to the time required for implementation of the full HCD process in the future.

   c) After the formal evaluation was completed, all design teams formalized plans and were pursuing funding to continue their HCD work in some way.

Discussion

This project contributes to current understanding of how HCD can be evaluated within a human services context. In particular, it formalized a Theory of Change, developed new evaluation tools and tested methods, and identified key findings regarding the value of building capacity for HCD implementation. The evaluation process was systematic and included preregistration with the Center for Open Science to enhance transparency and objectivity, and consultation with a team of HCD experts to strengthen the validity of our methods and conclusions. Agencies selected challenges to address with HCD that were very difficult, and the design teams were also new to HCD, which is typical for the human services field at this time. Nonetheless, this is considered a descriptive exploratory study[78] and lessons learned must be considered in the context in which it was conducted; they should not be generalized. More specifically:

- We included only three sites that were selected for their readiness and likelihood of successful HCD implementation.
- Training and coaching were designed to reflect a capacity-building approach and were provided fully virtually.[k]
- The project was conducted during the COVID-19 pandemic, which both increased demands on participating agencies and decreased staff capacity.
- Evaluation activities did not begin before the initial HCD Primer Training; thus, findings may not reflect change from a true baseline.
- Given that the primary focus was capacity-building, and that full implementation was not completed by the time data collection for the evaluation concluded, findings do not reflect the impact of the HCD process itself.

Despite these limitations, findings suggest that there is clear influence of HCD training and coaching on design team members' capacity for approaching challenges that may be beneficial in and of itself. However, there was the indication in qualitative data that there may be organizational and feasibility constraints around implementation. This is a challenge that may be exacerbated within human services agencies, or public agencies more broadly, and should be explored in future research.

Theory of Change

As noted, this project included the development of a Theory of Change to describe the process by which HCD may influence expected outcomes, which was based on a review of the literature.[79] This informed the evaluation approach and the assessment tools that were developed, a particular strength of this work. This model can be used by others to drive more theoretically-based research in this area. Based upon this pilot study, several refinements were made to our original Theory of Change (see Figure 17 below).

- **Inputs:**
    - Defined program readiness as leadership support, investment in providing needed resources, and interest in engaging end users, which were embedded in the selection process.
    - Modified subject matter "expert" to "expertise," reflecting that this is important but could be provided in different ways other than by having a specific individual in this role.

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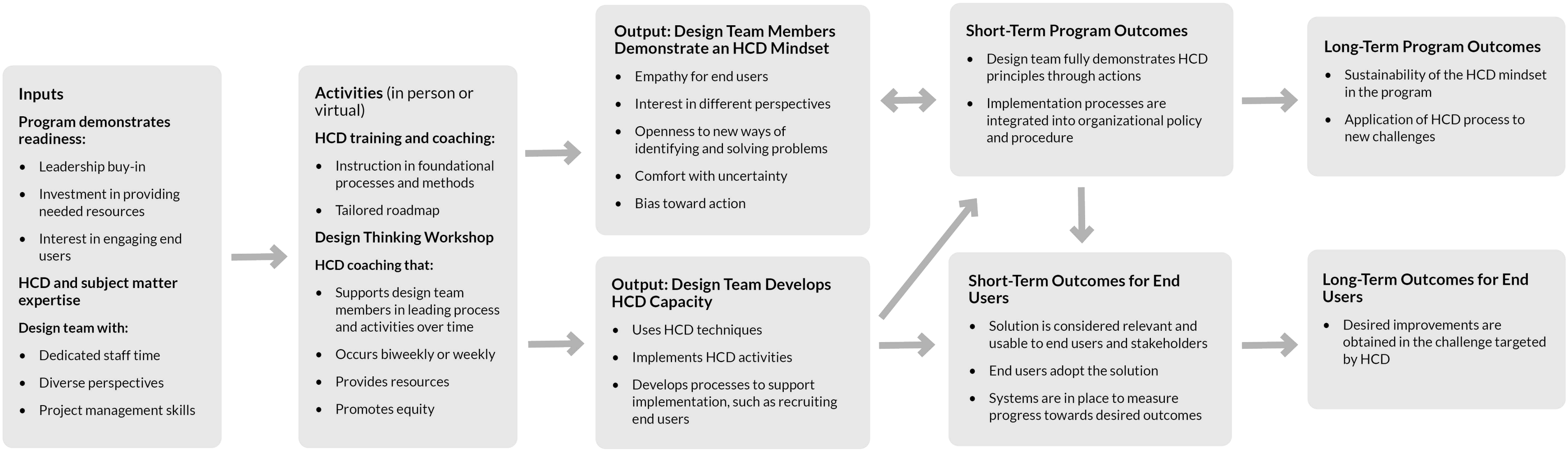
[k] There are other models of training and coaching that may be provided by HCD experts that this project did not assess.

  - Identified key characteristics of a design team needed for HCD implementation, including adequate time, diverse perspectives, and project management skills.

- **Activities:**
  - Specified that training and coaching may be in-person or virtual, and that it should include information about foundational process and activities as well as a program-specific roadmap for the design team's specific challenge.
  - Specified that coaching should include components identified as critical in this project: 1) supporting design team members in developing skills, 2) providing HCD resources (like templates and examples), and 3) promoting equity.
- **Outputs:**
  - Added processes to support implementation as part of a design team's HCD capacity, such as systems for providing incentives to end users.
  - Re-conceptualized an HCD mindset as an output rather than an outcome, given that some human services programs may demonstrate a pre-existing high level of this type of thinking and approach to challenges before training in HCD. Future research might consider assessing the extent to which this pre-exists as an input.
  - Indicated that an HCD mindset and demonstration of HCD principles likely influence each other bidirectionally. That is, a mindset may contribute to use of principles, and experience using the principles may influence one's mindset.
  - Identified one additional aspect of an HCD mindset that emerged from interviews (bias toward action) and explicitly identified comfort with uncertainty in the Theory of Change.
- **Outcomes:**
  - Moved HCD principles from an indicator of HCD capacity and output to a program outcome, and specified full demonstration of the principles requires both an HCD mindset and HCD capacity in the design team.
  - Clarified that HCD principles should be demonstrated through actions, which helps to differentiate the principles from an HCD mindset.
  - Added application of HCD processes into organizational policies and procedures as a new program outcome to achieve long-term outcomes.
  - Clarified that the long-term outcome for the program is sustainability of the HCD mindset in the program and application of the HCD process to new challenges.

Figure 17. Revised Theory of Change



Inputs

Program demonstrates readiness:

- Leadership buy-in
- Investment in providing needed resources
- Interest in engaging end users

HCD and subject matter expertise

Design team with:

- Dedicated staff time
- Diverse perspectives
- Project management skills

Activities (in person or virtual)

HCD training and coaching:

- Instruction in foundational processes and methods
- Tailored roadmap

Design Thinking Workshop

HCD coaching that:

- Supports design team members in leading process and activities over time
- Occurs biweekly or weekly
- Provides resources
- Promotes equity

Output: Design Team Members Demonstrate an HCD Mindset

- Empathy for end users
- Interest in different perspectives
- Openness to new ways of identifying and solving problems
- Comfort with uncertainty
- Bias toward action

Output: Design Team Develops HCD Capacity

- Uses HCD techniques
- Implements HCD activities
- Develops processes to support implementation, such as recruiting end users

Short-Term Program Outcomes

- Design team fully demonstrates HCD principles through actions
- Implementation processes are integrated into organizational policy and procedure

Short-Term Outcomes for End Users

- Solution is considered relevant and usable to end users and stakeholders
- End users adopt the solution
- Systems are in place to measure progress towards desired outcomes

Long-Term Program Outcomes

- Sustainability of the HCD mindset in the program
- Application of HCD process to new challenges

Long-Term Outcomes for End Users

- Desired improvements are obtained in the challenge targeted by HCD

It is also important to note that the duration of this project did not allow for assessment of outcomes for end users or impact of solutions implemented, thus there is no data to evaluate those aspects of the model. Further specification and/or revisions may be indicated based on future application.

Another useful area for future investigation would be to identify mechanisms of change in HCD that can be discriminated from similar components in other problem solving and change management approaches (e.g., Improvement Science, Breakthrough Series Collaborative). Based upon the learning in this project, full demonstration of the HCD principles appears to be a core component of the process. It is also possible that there may be unique aspects of an HCD mindset that provide unique value, such as a bias toward action.

Evaluation Tools and Methods

As previously noted, all of the data collection tools and interviews referenced in this report were created specifically for this project. However, they were grounded in the current literature and a theoretical model, using a systematic evaluation approach. This work may be useful for moving HCD evaluation beyond questions that can be answered by case studies of implementation and toward other research questions that require more rigorous methods. Validation of these and other HCD evaluation tools is not only useful for research, but may help shift organizational priorities, and even metrics, for success.[80] To support this work, the following are specific lessons learned related to the evaluation approach used for this project:

- Use of multiple informants was valuable for particular types of information where perceptions may differ. For example, the use of three reporters on each design team to create an average score was more reliable than a single reporter's perception may have been. In addition, it was important to know when the HCD consultants had different views of the design teams' work than design team members did themselves.
- Some types of information may not require multiple informants. For example, information about HCD activities appeared to be more consistently provided by the HCD consultant than design team members, likely because design team members' understanding of the activities was more variable.
- Interviews could be streamlined to focus on information that may be harder to fully capture in quantitative ratings, such as confidence, plans for the future, and facilitators/barriers.
- Given the relative consistency of ratings related to an HCD mindset over time, monthly reports may not be necessary. The caveat to this is that there were notable changes around the time of the Design Thinking Workshop that others may be interested in exploring in the future.
- HCD principles were not assessed reliably over time in this project due to varying understanding of whether they were applicable at all phases. Conceptually, it may be more meaningful to evaluate the demonstration of principles at the end of a project, when there is adequate information about the solution created and implemented, and principles can be fully assessed.
- Measurement of the HCD principles and mindset should occur prior to any training to obtain a true baseline measure.

Differentiating the HCD Principles from an HCD Mindset

As noted, it was a challenge to differentiate an HCD mindset from HCD principles in this evaluation, which was related to measure limitations as well as a lack of conceptual clarity in the field. Although the HCD principles put forth by ISO (ISO Standard No. 9241-210:2019) are well-established and widely used, they were intended to promote project implementation, not to be used as a measurement tool. In operationalizing the principles for this project, they were not clearly defined in a manner that was distinct from a mindset. This is particularly relevant for Principle 1 (understand end users and stakeholders) and Principle 5 (considers end users' entire experience),[l] where some of the items we measured could be interpreted to reflect an individuals' approach or mindset. Additionally, both a mindset and principles were assessed via self-report on the Monthly Design Team Logs, which may have exacerbated this overlap.

In reviewing the findings and consulting with the team of experts, it was determined that the HCD mindset be defined as the thoughts, perceptions, and beliefs with which a team approaches solving a challenge. Assessment of an HCD mindset should be done prior to any HCD training, as there is indication that aspects such as empathy may pre-exist in human services programs. The HCD principles can then be defined in more objective or observable ways that reflect a design team's *actions*. These definitions would contribute to the refinement of future measures of these important constructs, which are interrelated but distinct.

Specific Measure Considerations

Given the extensive data collected, the potential advantages and disadvantages of the different tools became clear, which may inform future HCD evaluation efforts in the human services context. Different tools and informants might be used for different research questions or objectives (see Table 10).

Table 10. Advantages and disadvantages of HCD4HS evaluation tools

Method or tool	Advantages	Disadvantages
Activity logs	• Provide rich data on how the HCD process is being implemented • Useful for assessing experiences that may change across time	• High time burden for participants • Potential for misunderstanding of items contributing to inconsistencies across participants
Interviews	• Provide context to ratings, help identify barriers and unexpected themes, and explain discrepancies	• Individual interview format and thematic analysis are resource intensive
Implementation Assessment	• Quantifies key elements of the HCD process, mindset, and principles in a comprehensive manner • Allows for comparison across programs • Could be used to show change across time	• Group interview format is resource intensive and may encourage participants to respond in a desirable manner • May have ceiling effects as currently worded (i.e., may not accurately measure high levels of implementation)

There may be particular value to assessing HCD principles through: (1) a facilitated interview with key design team members, with multiple questions for each principle (similar to the Implementation Assessment), and (2) observations from a neutral party to assess the degree to which principles are demonstrated via the actions of design team members. There are existing measures of design thinking for

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[l] Note that these definitions are from Rosinsky et al. (2022) and differ in subtle but important ways from the ISO 9241 principles, which appear to emphasize the nature of the design in these two principles.

individuals, such as the Design Thinking Questionnaire.[81] However, within the context of human services, there is a need for a design thinking measure to assess teams, not just individuals, which appears to be the primary focus of work to date. Measures of related constructs like creativity in the business context (e.g., Competency Based Creative Agency Scale[82]) and innovation self-efficacy in engineering[83] could also be adapted for application within human services programs.

In considering the utility of the tools used in this project, some limitations must be acknowledged. Beyond the small sample size (three sites) in which the tools were piloted, our timeline did not allow for the evaluation of how well these tools may predict successful implementation of a solution and whether the original challenge of interest was solved. Moreover, it was not possible to fully assess the later stages of the HCD process (Test and Iterate; Implement and Refine). It is also important to note that there are other approaches to evaluation that were not included in the current project that could be useful to consider in future work. In particular, more objective measures (e.g., interactions with end users, review of implementation products and notes, observation of design team activities) might have added additional insight or even modified the conclusions.

Box 16. Recommendations to Advance HCD Evaluation in Human Services

- Use theoretical models to design and test HCD initiatives.
- Test applicability of related measures from other fields.
- Standardize measures of key constructs, like an HCD mindset, organizational capacity for HCD, and quality of implementation.
- Evaluate the extent to which more easily measured outputs, like an HCD mindset or demonstration of principles, may predict end user outcomes.
- Allow adequate time for the HCD solutions to be fully implemented and follow up to assess sustainability and any unanticipated outcomes.

Implications of Findings for HCD Implementation in Human Services

Beyond the evaluability of HCD within human services, this project generated information that may be useful for informing learning agendas for others interested in implementing HCD in this context.

- Program readiness, including leadership support and adequate staff capacity and resources, was a critical component for successful implementation of HCD in this project, similar to the broader literature on implementation of other programs and change initiatives.
- Fully virtual training and coaching were viable and effective based on feedback from design team members and HCD consultants. This approach gives more people access to national experts and resources.
- HCD implementation takes extensive time for new learners and involves regular challenges, albeit ones that can generally be overcome with persistence, skill, and adequate support. This may be important to communicate to interested programs to help set realistic expectations and ensure readiness for full engagement.

- The capacity-building approach used in this project where staff received training and coaching to implement HCD with the ongoing support of a dedicated HCD consultant appeared to have clear strengths and was well-received by the design team participants (although the approach was not compared to other ways of implementing HCD). Although the investment with this approach may initially be higher, it is expected to enhance sustainability and generalizability of the HCD process within an organization. Given this cost, it may be helpful to train design teams by working on a smaller, more manageable challenge before using HCD for complex challenges.
- Content expertise in the programmatic or policy area challenge being addressed by design teams from outside of the human services program appears to have value, although it is not clear that having a specific individual in a content expert role is critical or how best to match the expert's skills to the needs of the agency.
- There was indication of a decrease in design teams' use of techniques and demonstration of an HCD mindset immediately following the Design Thinking Workshop, which is understandable given that stage of the HCD process is particularly challenging. However, it may be useful for design teams to anticipate and engage additional supports or coaching as needed during this phase of the HCD process.
- Equity was intentionally integrated into the HCD training and coaching through a variety of approaches, and design team members reported that this was well-aligned with their way of working. However, design team members also experienced many challenges fully engaging end users and obtaining input from a diverse group of stakeholders throughout the project. This is an important area for future initiatives to prioritize, which should theoretically optimize HCD outcomes.

Conclusion

The HCD4HS project developed an approach for evaluating capacity-building to support HCD implementation within three agencies addressing different challenges related to human services delivery. Acknowledging the specific context of this work related to agencies' high level of initial readiness and the unique demands of the pandemic, there are important lessons learned that may inform future HCD evaluation. An HCD capacity-building approach was quite feasible for the selected agencies, which were highly satisfied with the training and coaching they received. Evaluation data provide evidence that design teams members can learn HCD and effectively implement HCD strategies, develop processes to support sustainability, and address challenges that arise. Human services program staff may demonstrate some preexisting aspects of an HCD mindset, like empathy, although a bias toward action may need more development. What is unclear is the extent to which HCD capacity will result in full implementation of the solutions design teams developed through the HCD process and translate into positive impact for end users. Additionally, although HCD as implemented within this pilot study appeared generally useful for three very different challenges in different organizations, it is certainly possible that it may be better suited for some challenges and contexts than others.

This project also demonstrates the evaluability of HCD within human services with operationalization of key constructs in a theoretical model to inform multi-method measures. The HCD4HS project highlights the value of different assessment approaches and identifies specific areas for future research, including work to further operationalize the HCD principles and mindset and validate research tools. This report, along with the associated literature review developed as part of this project,[84] is intended to help advance the use and evaluation of HCD within the human services context.

Appendix A. Glossary of Terms

Accessibility	Accessibility is the concept of whether a product or service can be used by everyone—however they encounter it. Accessibility focuses on people with disabilities (vision, movement, thinking, remembering, learning, communicating, hearing, mental health, social relationships, and more).
Analytics	Analytics refers to the statistical analysis of data or information. A common example of analytics is to measure human behavior on a website by analyzing data points like how long they are on the site, where they click, where they came from, and what search terms they use, etc. Analytics from other sources like organizational program data can also be used to help identify patterns. They help us better understand and interpret patterns of behavior with the products and services we use.
Assumption	An assumption is a thing that is accepted as true or certain, without proof.
Bias	A bias is a tendency, inclination, or prejudice toward or against something or someone. An interviewer might inadvertently bias an interviewee's answers by asking a "loaded" question, in which the desired answer is presupposed in the question.
Brainstorming	Brainstorming is defined as an idea creation method for generating a large number of creative ideas in a short period of time.
Co-creation	Co-creation is the active involvement of end users in the design and decision-making process. It includes specific activities like reviewing needs or user stories, iterating on prototypes, etc. See also: *Concept posters, Storyboards, Service blueprints, Rapid prototyping*
Cognitive walkthrough	A cognitive walkthrough is a usability method that steps through the many actions people need to take to achieve a goal. Use cognitive walkthroughs when - you want to test how intuitive the steps of a process are, - you don't have an interactive prototype yet, - you want to assess whether you've captured every piece of the experience your users would expect to be a part of your design.

Concept	A concept is an idea with a rationale that supports how the solution you are designing will overcome a problem or challenge. A concept is more polished and has more details than an idea. It's a thought-out idea that designers want to test with the people they are designing for to gain feedback and challenge their assumptions. The concept is what they begin to build prototypes around.
Concept poster	A concept poster is a worksheet used to solidify an idea and prepare to share that idea. It includes space to define who the concept is for, what the challenge solves, how it works, known issues, and planning tools. See also: *Storyboards, Service blueprints, Rapid prototyping, Co-creation sessions*
Conceptualize & Prototype	Conceptualize and Prototype is a phase in the HCD process. This is a "focus" phase where you develop a limited set of ideas and do more evaluative processes to make sure things work. This is creative and converging at the same time. See also: *Human-centered design*
Context	The circumstances that form the setting for an event, statement, or idea, and in terms of which it can be fully understood. Context describes external elements that surround and influence design. These items can be physical and non-physical, as well as cultural.
Continual user feedback	Continual user feedback is a built-in system or plan for continuous product or service improvement based on collecting and acting on feedback from the people using the product or service.
Design	Design consists of the processes we use to create things, as well as the form of those things themselves.
Design principles	Design principles are the key characteristics your "solution" must address or incorporate to be successful (based on what you've learned). Use design principles when you need reminders of constraints and goals that influence design decisions.

Design Thinking Workshop	A Design Thinking Workshop is a hands-on, activity-based session that has a defined problem area, is focused on doing over discussing, and generates solutions in the form of prototypes. See also: *Prototype*
Designer	Anyone participating in creating or altering a process, product, service, or experience. See also: *Stakeholder, User*
Diary study	Diary study is a research method that asks users to record daily events, tasks, and perceptions around a given subject in order to gain insight into their habits, behavior, and needs over time.
Empathy	Empathy is the ability to recognize, understand, and share the thoughts and feelings of another person. Empathy enables us to understand not only our users' immediate frustrations but also their hopes, fears, abilities, limitations, reasoning, and goals.
Equity	Equity refers to proportional representation (by background, skills, expertise, perspective, etc.) in access to the same opportunities. Equity involves distributing resources based on the needs of the recipients.
Equity pause	An "equity pause" is a pause in the design or planning process to reflect, remind ourselves of our goals, and name what we might do better in support of equity and inclusion.
Ethnography	Ethnography is a qualitative research method of observing users in their natural habitat rather than in a lab to understand their behavior. Use ethnography when you need an in-depth understanding of the people you are designing for and how their context affects their experience.
Experience maps	An experience map is a visualization of all the experiences that a "generic" person goes through in order to accomplish a goal. This experience is agnostic of a specific business or product. It's used for understanding general human behavior.

Facilitation	Facilitation is the art of moving a group of people through meetings, planning sessions, or training and successfully achieving a specific goal.
Facilitator	A facilitator is a researcher who works with a person or group to moderate a discussion or activity in order to collect feedback and information.
Focus group	A focus group is a moderated group discussion that typically involves between 5-10 participants. Use focus groups to learn about users' attitudes, beliefs, desires, and reactions to concepts.
Governance	Governance is the system or a set of guidelines that guide the maintenance of a technology or a service. See also: *Governance framework, Governance plan*
Governance framework	A governance framework is the structure of governance and reflects the interrelated relationships, factors, and other influences on the technology or service being governed. See also: *Governance, Governance plan*
Governance plan	A governance plan is a set of rules, responsibilities, and processes put into place to guide the maintenance of a technology or a service. See also: *Governance, Governance framework*
High-fidelity (hi-fi) prototype	High-fidelity (hi-fi) prototypes are highly functional and interactive concepts. They are very close to the final product, with most of the necessary design elements and components developed and integrated. Hi-fi prototypes are often used in the later stages to test usability and identify issues in the workflow and visual experience. See also: *Low fidelity (lo-fi) prototype*
How Might We (HMW)	"How might we" (HMW) questions are short questions that launch brainstorms. "How Might We?" is a positive, actionable question that frames the challenge but does not point to any one solution. HMWs create a seed that is broad enough that there is a wide range of solutions but narrow enough that the team has some helpful boundaries.

Human-centered design (HCD)	Human-centered design is a process and a mindset to iteratively addressing complex challenges by facilitating the design of solutions with those who will ultimately use the solution.
Ideation	Ideation is a creative process where designers generate ideas in sessions. Participants gather with open minds to produce as many ideas as they can to address a problem statement in a facilitated, judgment-free environment.
Implement & Refine	Implement and Refine is a phase in the HCD process. To implement and refine is to bring the solutions to life and plan for ways to continue to get user feedback post-launch with the intention of continuing to improve and adapt the solution over time. See also: *Human-centered design*
Insights	Insights are ideas or anecdotes expressed as succinct statements that serve to interpret patterns in research findings. Insights offer a new perspective, even if they are not new discoveries.
Interviews	Interviews are in-depth sessions with users, customers, and people who know what is going on in the community first-hand. Use interviews to gather information on users' feelings, goals, motivations, and daily routines or understand how people use a product, program, or service.
Iterate	Iteration is the steady refinement of a design based on user testing and other evaluation methods.
Landscape analysis	A landscape analysis, or comparative analysis, is a process of identifying peers or related efforts and reviewing their approaches to identify trends, strengths, and weaknesses. Use landscape analysis to understand what approaches are already being used by others and any strengths, weaknesses, or lessons learned.
Launch roadmap	A launch roadmap is a visual tool communicating a rollout that includes all teams involved and outlines pre-launch, launch, and post-launch tasks.
Longitudinal	"Longitudinal" describes something that happens over a period of time.

Longitudinal study	A longitudinal study is a study that captures data over a period of time (days, week, months, or years) to understand the long-term effects of changes in products, processes, or environment. See also: *Diary study*
Low fidelity (lo-fi) prototypes	Low-fidelity (lo-fi) prototyping is a quick and easy way to translate high-level design concepts into tangible and testable experiences. The first and most important role of lo-fi prototypes is to check and test functionality rather than the visual appearance of the product. See also: *High-fidelity (hi-fi) prototypes*
Message testing	Message testing is a research method to assess how clear and impactful communication will be. Use message testing when you want to evaluate written, audio, or visual content or when you have multiple message prototypes and need to understand which messaging achieves your goals better.
Metrics	Metrics are the data that we collect during a usability study. Metrics help answer the research questions you have posed. The most basic measures are based on the definition of usability as a quality metric: - success rate (whether users can perform the task at all), - the time a task requires, - the error rate, and - users' subjective satisfaction. See also: *Usability testing*
Participatory design	Participatory design is an approach that brings customers into the heart of the design process. In participatory design, the end users of a product, service, or experience take an active role in co-designing solutions for themselves. See also *Co-creation sessions*
Persona	A persona is a generalized representation of the people you are designing to summarize characteristics, behaviors, needs, expectations, and more. They aren't necessarily a real individual but are constructed using real information and data based on real users.

Pilot study	To pilot a study is to launch a high-fidelity prototype with a small sample to evaluate the design. Use pilot studies when you've iterated enough to have a fully fleshed out design with all its features, and you want to test your prototype for any remaining issues to address before launching the solution more broadly.
Problem statement	Problem statements explain the user's need and goal and contribute to a "How Might We" question. Use problem statements to explain what we're trying to solve.
Prototype	A prototype is a model or artifact built to test a concept with users in order to learn from them. A prototype helps designers understand, explore, and communicate what it feels like to engage with a solution in real working conditions rather than theoretical conditions.
Qualitative research	Qualitative research focuses on research methods that help to uncover an in-depth understanding of something. It often includes methods like interviews, focus groups, observation, and open-ended questions. Qualitative research helps us understand the what, why, and how.
Quantitative research	Quantitative research emphasizes the statistical, mathematical, or numerical analysis of data. Quantitative research helps us measure trends.
Rapid prototyping	Rapid prototyping is an iterative process of mocking up the future state of a system, like a website or application. Rapid prototyping consists of cycles of prototyping and review or testing. The rule of thumb is to prototype 20 percent of the interface used 80 percent of the time. This allows you to focus on the crucial interactions and features. See also: *Concept posters, Storyboards, Service blueprints, Co-creation sessions, Prototype*
Research question	A research question is any question that a research project sets out to answer. Choosing a research question is an essential element of both quantitative and qualitative research.
Roadmap	A roadmap is a strategic plan that defines a goal or desired outcome and includes the major steps or milestones needed to reach it. It serves as a communication tool, a high-level document that helps articulate strategic thinking—the why—behind both the goal and the plan for getting there.

Scenario	Scenarios are stories that designers create to show how users might act to achieve a goal in a system or environment. Designers make scenarios to understand users' motivations, needs, barriers, and more in the context of how they would use a design and to help ideate, iterate, and test optimal solutions. See also: *Designer*
Service blueprint	A service blueprint is a diagram that visualizes the relationships between different service components—people, props (physical or digital evidence), and processes—that are directly tied to touchpoints in a specific customer journey. See also: *Concept posters, Storyboards, Rapid prototyping, Co-creation sessions*
Stakeholder mapping	Stakeholder mapping is a way of diagramming the network of people who have a stake in a system or process. Use stakeholder mapping to document the relationships, needs, and interactions of people impacted by the design or determine who to involve in the design process.
Stakeholders	People who have the power to affect or are affected by the design. See also: *Designer, User, Stakeholder mapping*
Storyboard	Storyboards are a visual representation of a user's experience with a product or problem space. They document the important acts of the experience as if telling them like a story.
Study	A study is a detailed investigation and analysis of a subject or situation.
Survey	A survey is a research method used for collecting data from users by asking them to respond to a questionnaire (online, paper, or phone). Use surveys when you need a snapshot of a user population at a relatively low cost or need many responses quickly from a geographically dispersed population or to quantify insights from qualitative research.
Synthesis	Synthesis a collaborative process of sensemaking, which leads to creating a coherent summary of all the data gathered during research. Synthesis involves bringing together, sharing, and organizing what you've learned. Synthesis is best done collaboratively, with multiple disciplines and stakeholders representing different perspectives and areas of expertise.

Synthesize and Generate Solutions	During this phase of HCD, the team synthesizes the research findings to fully understand the challenge from the perspective of the end user and generates insights that can lead to new or creative solutions or opportunities for change. See also: *Human-centered design*
Task	The procedures that include goals, steps, skills, start state, inputs, end state, and outputs required to accomplish an activity. They can be organized into larger tasks, such as driving to work, and sub-tasks such as opening the car door.
Test & Iterate	The Test & Iterate phase of HCD is all about trying out your designs in progress with the people you are designing for and then immediately applying what you learn to make changes to your design. As soon as you start building drafts or prototypes of your design, you can start testing and iterating. See also: *Human-centered design*
Usability	Usability is a measurement of how easy or difficult it is for people to use something they want or need to interact with.
Usability testing	Usability testing is a task-based method where you observe participants as they try to use your product or service to complete tasks. Participants think out loud, and you often interview them afterward about their experience. See also: *Metrics*
User	Those who will, directly and indirectly, interact with the thing you're building, those who are experiencing the challenge you are working to solve. See also: *Designer, Stakeholder*
User experience (UX)	User experience is every aspect of the user's interaction with a product, service, or company that makes up the user's perceptions of the whole. User experience design is concerned with all the elements that make up the experience of interacting with a product or service.
User scenarios	See also: *Scenarios*

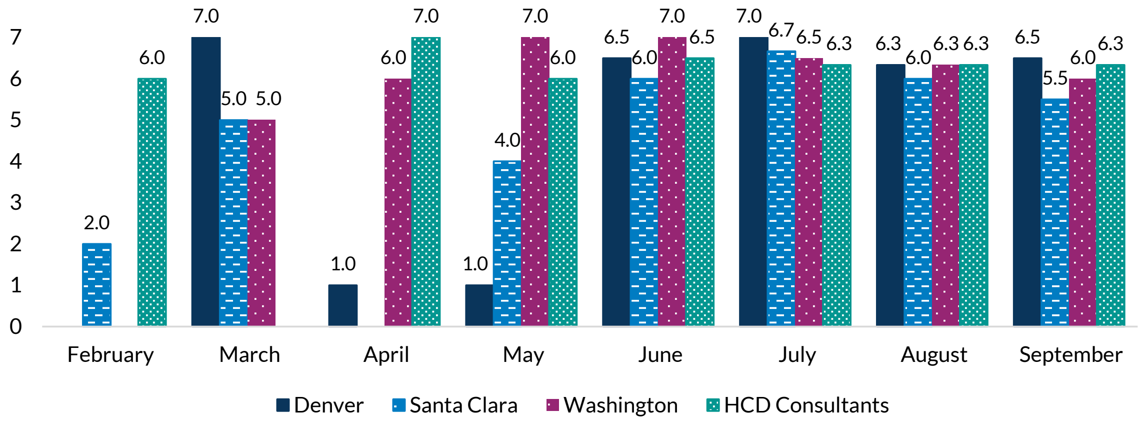
Appendix B: Supplemental Figures and Tables

Table B-1. Number of design team members reporting "Our team engages end users and other stakeholders in the design process" was not applicable each month

Month	Number of design team members reporting "not applicable" (out of 9)
February	5
March	3
April	1
May	1
June	0
July	0
August	1
September	0

Source: Monthly Design Team Log

Figure B-1. Perceptions of the extent to which design teams incorporated feedback from end users and stakeholders in testing and revising solutions, averaged among raters



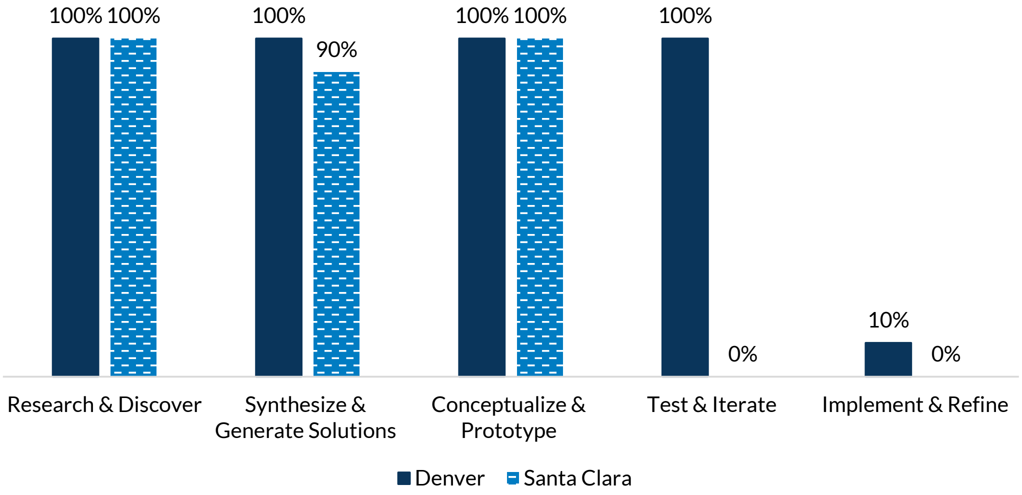
Source: HCD Consultant Log, Monthly Design Team Log
Note: Scale is 1 (not at all); 4 (somewhat); 7 (a lot).

Table B-2. Number of design team members reporting "Our team incorporates feedback from end users and stakeholders in testing and revising solutions" was not applicable each month

Month	Number of design team members reporting "not applicable" (out of 9)
February	8
March	5
April	7
May	4
June	1
July	1
August	2
September	1

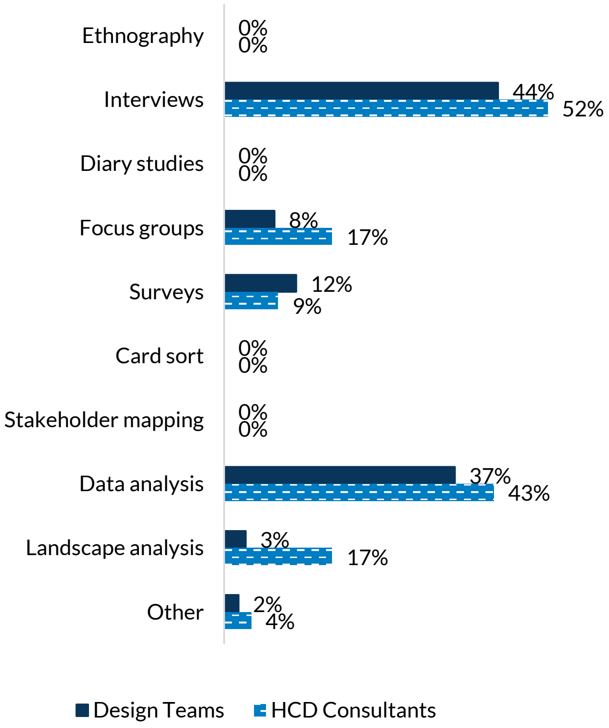
Source: Monthly Design Team Log

Figure B-2. Extent of implementation of HCD phases



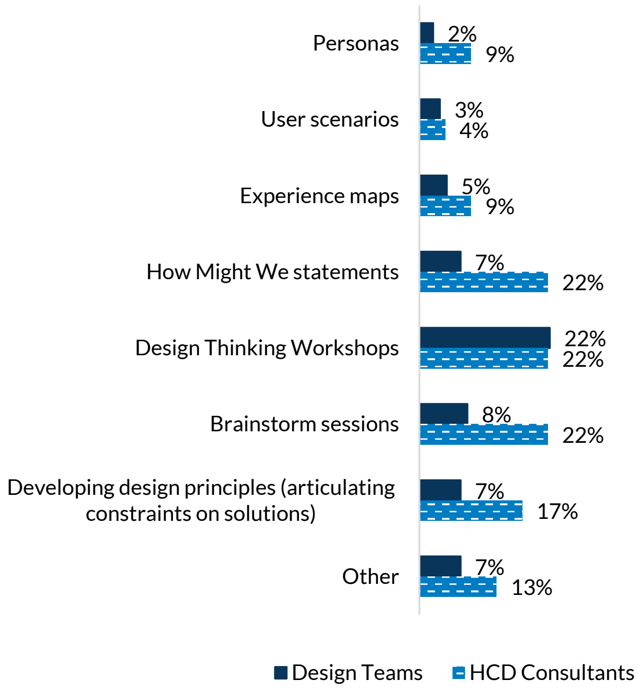
Source: Implementation Assessment

Figure B-3. Research & Discover: Percentage of time activities occurred, averaged across sites



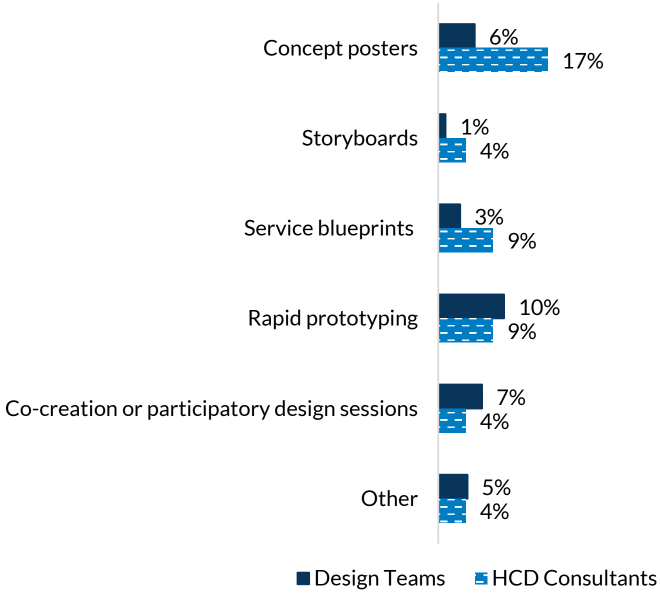
Source: Weekly Design Team Log, HCD Consultant Log

Figure B-4. Synthesize & Generate Solutions: Percentage of time activities occurred, averaged across sites



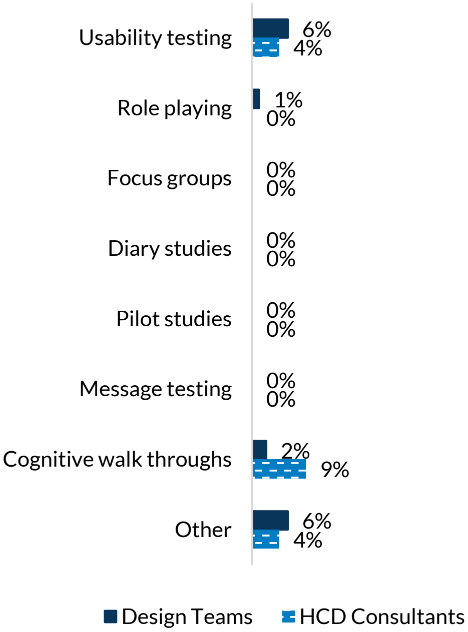
Source: Weekly Design Team Log, HCD Consultant Log

Figure B-5. Conceptualize & Prototype: Percentage of time activities occurred, averaged across sites



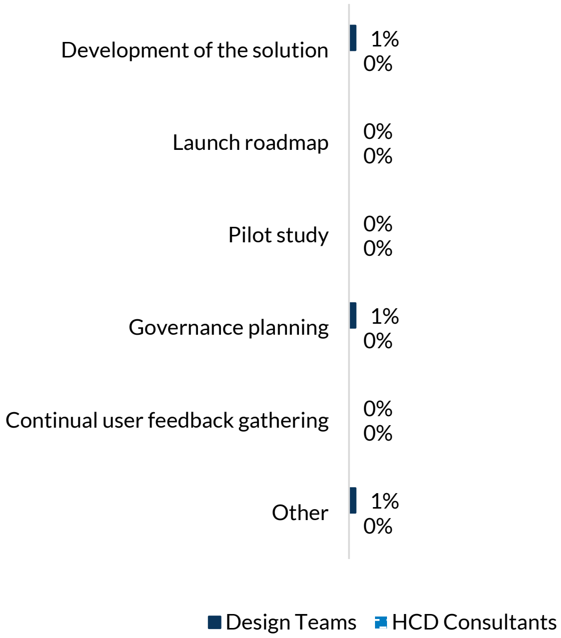
Source: Weekly Design Team Log, HCD Consultant Log

Figure B-6. Test & Iterate: Percentage of time activities occurred, averaged across sites



Source: Weekly Design Team Log, HCD Consultant Log

Figure B-7. Implement & Refine: Percentage of time activities occurred, averaged across sites



Source: Weekly Design Team Log, HCD Consultant Log

Appendix C. Summary of Findings by Research Question

Table C-1. Summary of findings by research question

Research question	Finding
1: What types of challenges within ACF programs are best suited for an HCD approach?	
What types of challenges did programs want to address with an HCD approach? How were these similar/different across programs?	The three sites addressed very disparate challenges: TANF cliff effect, staff engagement, and completion of child support order modifications. However, given that there were only three sites, we cannot fully address which types of challenges within the broad range of ACF programs may be best suited for HCD.
What progress did programs show in addressing challenges they identified?	Design teams progressed through the Research & Discover, Synthesize & Generate Solutions, and Conceptualize & Prototype phases. At the time of the evaluation, all design teams were testing/preparing to test their prototype and had not yet implemented a solution to their challenge, although were hopeful about doing so.
2: What resources are required to implement HCD approaches in ACF programs?	
What resources did programs use to implement HCD? Which specific resources were perceived as necessary for facilitating HCD implementation? Which were helpful (but not necessarily critical)? Which were not helpful?	Design teams identified project management, leadership support, and incentives as critical resources. Other resources design teams identified as helpful included having diverse perspectives on the team, technology resources, access to HCD expertise and tools, strategic engagement of stakeholders, and alignment with organizational culture/priorities. The content expert role received mixed feedback, with some design team members not finding the role helpful.
To what extent did HCD design team members experience support from executive leadership and buy in from other relevant staff?	All design teams experienced strong leadership support, which they described as critical to the pilot study's success. Teams were also able to generate buy in from other relevant staff.
How were resources similar or different across programs?	All design teams used similar resources, notably staff time, leadership support, and strong design teams.

3: What systemic or cultural barriers may make implementation a challenge, and can those be mitigated?	
What barriers made HCD implementation a challenge and how did programs address those barriers?	Design teams reported time and capacity, recruitment of end users, incentives, organizational structures and processes, end user confidentiality, and the COVID-19 pandemic as primary barriers. Design teams addressed most barriers with strategies such as bringing in more team members, setting up new incentive processes, changing recruitment practices, and communicating with leadership. However, time constraints remained a significant challenge.
How did barriers to implementation differ across the participating programs?	All design teams faced common barriers, albeit to differing degrees.
4: What does HCD implementation look like?	
What HCD activities did the design teams complete during implementation?	All design teams participated in an HCD Primer (24 hours) followed by 11 months of training and coaching from an HCD consultant (average of 5 hours/week) and content expert (average of 2-4 hours/week). All training and coaching were provided virtually. Design teams spent the most time on earlier HCD phases. Within each phase, some activities were more frequently used than others.
How did implementation of the HCD process differ across the participating programs?	Implementation of HCD was similar across design teams as expected, given the structure of this pilot study.
How did the HCD training and coaching inform HCD design team's HCD mindset?	Design teams demonstrated an HCD mindset. Design team members found the "coaching, not doing" model of consultation important for helping them remain focused on HCD principles and implement the HCD mindset.
How helpful was the HCD training and coaching?	Design teams were highly satisfied with the HCD training and coaching, although the value of the content expert was less clear.
To what extent did design teams effectively use HCD techniques?	Design teams appeared to effectively use HCD techniques and design teams generally became more confident in implementing HCD over time.

To what extent did each design team demonstrate the HCD principles? Which principles were more and less difficult to demonstrate?	Design teams clearly demonstrated the following principles: understanding end users and stakeholders, considering entire end user experience, and collaborating across disciplines. Design teams did not demonstrate the following principles as fully as other principles in part because later phases of HCD implementation had not been completed: end user/stakeholder engagement throughout, testing and revising solutions based on end user and stakeholder feedback, and iterative and nonlinear processes.
5: How can the HCD approach be evaluated in order to better understand outcomes of interest to ACF? Can HCD be evaluated to determine whether or not this approach is more or less successful than traditional approaches?	
What tools did our project team use to evaluate the HCD process? Which ones seemed most valuable for future evaluations?	This project used weekly and monthly logs, interviews, and an Implementation Assessment. All data collection tools used for this pilot study are a step forward in evaluating HCD, but should continue to be refined. Evaluations of HCD implementation for large complex challenges like the ones in this study should be conducted over a longer time period (more than 1 year) to capture implementation of the solution and outcomes for end users. In order to compare HCD to similar approaches in a meaningful way, measures need to be validated and unique components of HCD identified through more theoretically-driven research.
6: What criteria are defined as successful outcomes when evaluating this process?	
What objective measure of success did design teams identify for their challenge?	Criteria that could be used to define successful implementation based on the Theory of Change developed for this study include: demonstration of an HCD mindset, development of HCD capacity, demonstration of HCD principles in action, integration of HCD implementation into organizational policies and procedures, and development of relevant and usable solutions that end users adopt and for which progress is monitored on an ongoing basis. Design teams defined successful outcomes for their challenges based on the challenge being addressed.
How did they track these outcomes? By the end of the study, were systems in place to measure progress toward desired outcomes?	No agency had a system in place for tracking outcomes at the time this evaluation ended.
Is the solution considered relevant and usable?	HCD consultants and design team members considered proposed solutions to be generally relevant and usable, with some concerns expressed about addressing the full challenge and organizational/feasibility constraints.

Are end users likely to adopt the solution? Why or why not?	Design teams were hopeful about end users adopting the solution given the process used, as long as the solution reached the end user.
7: Were improvements observed on outcomes of interest for end users?	
Were improvements observed on the outcomes of interest? If so, what factors seemed to be associated with this improvement?	As design teams did not get to the "Implement and Refine" phase, no outcome improvements for end users occurred.
Did improvements on outcomes of interest vary by program? If so, how? What contributed to any variation?	As design teams did not get to the "Implement and Refine" phase, no outcome improvements for ends users occurred.
8: Were improvements observed within the organization?	
To what extent did design team members adopt an HCD mindset?	All design teams demonstrated an HCD mindset by demonstrating empathy; openness to the opinions and perspectives of end users and others; and adopting new ways of identifying challenges, brainstorming, and trying different ideas. They also demonstrated a bias toward action.
Did programs notice unexpected improvements in outcomes?	An unexpected positive outcome was the development of a new incentive process at one agency, and a gained understanding at another agency that Zoom is the preferred platform for virtual engagement with community members (ex. more accessible), which led to the organization developing a policy based on this finding.

Appendix D. Data Collection Measures and Recommended Changes to Project-Specific Measures

Table D-1. Data collection measures and corresponding suggested modifications

Data source	Content	Frequency	Reporter	Suggested modifications
Logs and repeated ratings	Activities completed	Weekly	HCD consultant	Provide definitions to promote more accurate and consistent responses; ask the design team lead to confirm the HCD consultant's responses
	Ratings of HCD principles	Monthly	HCD consultant and 3 people from each design team	Clarify questions and directions to promote more accurate and consistent responses
	Barriers	Monthly	3 people from each design team	Provide more varied list of barriers to reflect learnings from this pilot study
	What is working well/not working well	Monthly	HCD consultant and 3 people from each design team	N/A
Interviews (end of pilot)	Goals for the work, details about the HCD process and activities, resources required, facilitators, barriers, perceived outcomes of the process, plans for the future	At end of implementation	HCD consultant and 3 people from each design team	N/A
Implementation assessment (end of pilot)	Demonstration of principles, extent of implementation of each phase, demonstration of mindset	At end of implementation	3 people from each design team	Clarify language so questions are more consistently interpreted

HCD Consultant Log

Month ______ Site ___________ Name_______

This monthly log will help us learn about your experience providing support to your assigned site and your site's experience with the HCD process. Your participation in this survey is voluntary and you may stop participating at any time. If there is a question you do not want to or do not feel comfortable answering, you can skip to the next question. Any personally identifiable information will be kept confidential among our project team. Your responses will be combined with responses from others and may be shared in published documents. What we learn about each site's experiences may be attributed to the site. We will not identify who said what. However, because of the relatively small number of sites and staff who are participating, there is a possibility a response could be attributed correctly to you. By continuing, you agree to participate in this survey.

1. How much time did you spend working directly with this team on average, per week, during the past month (this is time spent working with the sites directly, such as time spent on coaching calls, observing/participating in design team meetings, and attending design team activities/events)?:
   [Drop down menu]
   ○ <1 hour
   ○ 1 - <2 hours
   ○ 2 - <3 hours
   ○ 3 - <4 hours
   ○ 4 - <5 hours
   ○ 5 - <6 hours
   ○ 6 - <7 hours
   ○ 7 - <8 hours
   ○ 8 - <9 hours
   ○ 9 - <10 hours
   ○ 10 hours or more

2. How much additional indirect time did you spend supporting this team, on average per week, during the past month (this is all other time you spent on this project that does not involve interacting with sites directly, such as preparing for meetings with sites, reviewing deliverables or design solutions, corresponding with teams over email, and analyzing insights)?
   [Drop down menu]
   ○ <1 hour
   ○ 1 - <2 hours
   ○ 2 - <3 hours
   ○ 3 - <4 hours
   ○ 4 - <5 hours

- ○ 5 - <6 hours
- ○ 6 - <7 hours
- ○ 7 - <8 hours
- ○ 8 - <9 hours
- ○ 9 - <10 hours
- ○ 10 hours or more

3. In what ways did you support the team during the past month? (Please select all that apply)
   - ☐ HCD primer
   - ☐ Virtual technical assistance meeting
   - ☐ Design thinking workshop
   - ☐ Design team activity
   - ☐ Ad-hoc or unscheduled support
     - ☐ Support over email
     - ☐ Support over phone or video conference

   Please briefly describe the topic(s) of support provided. [Textbox]

   - ☐ Other (please specify) ______________________________

The next set of questions will ask you to specify the activities the design team engaged in during the past month.

4. For the activities that the design team engaged in, please select the design phases that they fall under. (Please select all that apply).
   - ☐ Research and Discover
     - What activities from the Research and Discovery phase are you aware of that the design team engaged in during the past month?
       - ☐ Ethnography
       - ☐ Interviews
       - ☐ Diary studies
       - ☐ Focus groups
       - ☐ Surveys
       - ☐ Card sort
       - ☐ Stakeholder mapping
       - ☐ Data analysis
       - ☐ Landscape analysis
       - ☐ Other

☐ Synthesize and Generate Solutions
- What activities from the Synthesize and Generate Solutions phase are you aware of that the design team engaged in during the past month?
    - ☐ Personas
    - ☐ User scenarios
    - ☐ Experience maps
    - ☐ How Might We statements
    - ☐ Design thinking workshops
    - ☐ Brainstorm sessions
    - ☐ Developing design principles (articulating constraints on solutions)
    - ☐ Other

☐ Conceptualize and Prototype
- What activities from the Conceptualize and Prototype phase are you aware of that the design team engaged in during the past month?
    - ☐ Concept posters
    - ☐ Storyboards
    - ☐ Service blueprints
    - ☐ Rapid prototyping
    - ☐ Co-creation or participatory design sessions
    - ☐ Other

☐ Test and iterate
- What activities from the Test and Iterate phase are you aware of that the design team engaged in during the past month?
    - ☐ Usability testing
    - ☐ Role playing
    - ☐ Focus groups
    - ☐ Diary studies
    - ☐ Pilot studies
    - ☐ Message testing
    - ☐ Cognitive walk throughs
    - ☐ Other

☐ Implement and Refine

- What activities from the Implement and Refine phase are you aware of that the design team engaged in during the past month?
  - ☐ Development of the solution
  - ☐ Launch roadmap
  - ☐ Pilot study
  - ☐ Governance planning
  - ☐ Continual user feedback gathering
  - ☐ Other

Please rate on a scale of 1-7 the extent to which you agree with the following statements for the past month.

	Not at all 1	2	3	Somewhat 4	5	6	A lot 7	Not applicable
5. The design team has made progress on their HCD goals.								
6. The design team effectively uses HCD techniques.								
7. The design team works collaboratively with each other.								
8. The design team engages their end users and stakeholders (e.g. other staff, and executive leadership) in the design process.								
9. The design team incorporates feedback from end users and other stakeholders in testing and revising solutions.								
10. The design team generates, tests and revises potential solutions, going back to earlier steps as often as needed (i.e., uses an iterative process).								
11. The design team tries new ideas and new ways of identifying challenges and brainstorming.								

	Not at all 1	2	3	Somewhat 4	5	6	A lot 7	Not applicable
12. The design team demonstrates empathy for end users.								
13. The team considers end users' needs, preferences, and context.								
14. Barriers have interfered with the design team's work.								
15. The HCD approach to problem-solving is well suited to this team's challenge.								

16. Please specify any barriers the team is encountering (Please select all that apply):
    - ☐ Lack of time
    - ☐ Lack of institutional or leadership support
    - ☐ Lack of other resources
    - ☐ Other [text box]
    - ☐ None

17. What is working well for this design team? [Text box]

18. What is not working well for this design team? [Text box]

Content Expert Log

Month ______ Site ______________ Name__________

This monthly log will help us learn about your experience providing support to a site engaged in Human Centered Design (HCD) and about your role in the HCD design process.

Your participation in this survey is voluntary and you may stop participating at any time. If there is a question you do not want to or do not feel comfortable answering, you can skip to the next question. Any personally identifiable information will be kept confidential among our project team. Your responses will be combined with responses from others and may be shared in published documents. What we learn about each site's experiences may be attributed to the site. We will not identify who said what. However, because of the relatively small number of sites and staff who are participating, there is a possibility a response could be attributed correctly to you. By continuing, you agree to participate in this survey.

1. How much time on average did you spend working directly with the design team per week, during the past month (this is time spent working with the design team in absence of the HCD consultant, observing/participating in design team meetings, and attending design team activities/events or providing consultation):
   [Drop down menu in half hour intervals]
   - No time
   - Less than 30 minutes
   - 30 minutes – <1 hour
   - 1 hour – <1.5 hour
   - 1.5 hour – <2 hours
   - 2 hours – <2.5 hours
   - 2.5 hours – <3 hours
   - 3 hours – <3.5 hours
   - 3.5 hours – <4 hours
   - 4 hours or more

2. How much time on average did you spend working directly with the HCD consultant per week, during the past month (this is time spent working with the HCD consultant directly in absence of the design team):
   [Drop down menu in half hour intervals]
   - No time
   - Less than 30 minutes
   - 30 minutes – <1 hour
   - 1 hour – <1.5 hour
   - 1.5 hour – <2 hours
   - 2 hours – <2.5 hours
   - 2.5 hours – <3 hours

○ 3 hours – <3.5 hours
○ 3.5 hours – <4 hours
○ 4 hours or more

3. How much time on average did you spend working directly with the HCD consultant and design team (together) per week, during the past month (such as time spent on coaching calls or design thinking primer/workshop):
   [Drop down menu in half hour intervals]
   ○ No time
   ○ Less than 30 minutes
   ○ 30 minutes – <1 hour
   ○ 1 hour – <1.5 hour
   ○ 1.5 hour – <2 hours
   ○ 2 hours – <2.5 hours
   ○ 2.5 hours – <3 hours
   ○ 3 hours – <3.5 hours
   ○ 3.5 hours – <4 hours
   ○ 4 hours or more

4. How much additional indirect time did you spend supporting this team, on average per week, during the past month (this is all other time you spend on this project that does not involve interacting with the design team or HCD consultant directly, such as preparing for meetings with the design team or HCD consultant, reviewing deliverables or design solutions, corresponding with the team or HCD consultant over email, and analyzing insights)?
   [Drop down menu in half hour intervals]
   ○ No time
   ○ Less than 30 minutes
   ○ 30 minutes – <1 hour
   ○ 1 hour – <1.5 hour
   ○ 1.5 hour – <2 hours
   ○ 2 hours – <2.5 hours
   ○ 2.5 hours – <3 hours
   ○ 3 hours – <3.5 hours
   ○ 3.5 hours – <4 hours
   ○ 4 hours or more

5. In what ways did you support the team during the past month? (Please select all that apply)
   ☐ Virtual technical assistance meetings
   ☐ Participated in design team activities
   ☐ Support provided to the design team outside of regular meetings

    - Who initiated support?
        - ☐ Design team reached out to me
        - ☐ I reached out to the design team
    - Please briefly describe the topic(s) of support provided. [Textbox]
- ☐ Support provided to the HCD consultant outside of regular meetings
    - ☐ Who initiated support?
        - ☐ HCD consultant reached out to me
        - ☐ I reached out to the HCD consultant
    - ☐ Please briefly describe the topic(s) of support provided. [Textbox]
- ☐ Other (please specify) ______________________________

6. How was your expertise most helpful to the design team this month? [Text box]

7. What challenges have you faced in your role this month? [Text box]

Monthly Design Team Log

Date__________ Team Member completing log ________________________

This monthly log is used for us to learn about your own and your team's experience using human-centered design (HCD) in a little more depth. This log should be completed separately by three design team members, including the individual who completes the weekly log and ideally someone on the team in a leadership position in the agency.

1. What have you learned about HCD in the past month? [Text box]

Please rate on a scale of 1-7 the extent to which you agree with the following statements for the past month.

	Not at all 1	2	3	Somewhat 4	5	6	A lot 7	Not applicable
2. Our team has made progress towards our goals.								
3. Our team feels confident about using HCD techniques.								
4. Our team works collaboratively with each other.								
5. Our team engages end users and other stakeholders (e.g. other staff, and executive leadership) in the design process.								
6. Our team incorporates feedback from end users and stakeholders in testing and revising solutions.								
7. Our team generates, tests, and revises potential solutions, going back to earlier steps as often as needed (i.e., uses an iterative process).								
8. Our team tries new ideas and new ways of identifying challenges and brainstorming.								

	Not at all 1	2	3	Somewhat 4	5	6	A lot 7	Not applicable
9. Our team demonstrates empathy for end users.								
10. Our team considers end users’ needs, preferences, and context.								
11. Barriers have interfered with our work.								
12. The HCD approach to problem-solving is well suited to our challenge.								

13. Please specify any barriers your team is encountering (select all that apply):
    - ☐ Lack of time
    - ☐ Lack of institutional or leadership support
    - ☐ Lack of other resources
    - ☐ Other [Text box]
    - ☐ None

14. What is working well for your team? [Text box]

15. What is not working well for your team? [Text box]

16. What have you learned so far from your HCD experience about approaching and solving difficult challenges in your work? [Text box]

Weekly Design Team Log

Date______ Team Member completing log ______________________

This weekly log is used for us to learn about your team's experiences using human-centered design (HCD). Please select one person from your team to fill out the log on behalf of your team. We encourage the team member who is filling out the log to consider the input of other team members, to make sure all voices are incorporated in this log.

Your participation in this survey is voluntary and you may stop participating at any time. If there is a question you do not want to or do not feel comfortable answering, you can skip to the next question. Any personally identifiable information will be kept confidential among our project team. Your responses will be combined with responses from others and may be shared in published documents. What we learn about each site's experiences may be attributed to the site. We will not identify who said what. However, because of the relatively small number of sites and staff who are participating, there is a possibility a response could be attributed correctly to you. By continuing, you agree to participate in this survey.

In this section, you will be asked to describe the activities/tools your team engaged in during the past week. First you will be asked to specify the activities/tools you engaged in. You will then be asked to describe your experience using each of the activities/tools you selected.

1. Please select the design phases that the activities/tools your team conducted this week were conducted in.
    - Research and Discover
        - Please select the names of the activities/tools your team engaged in from the Research and Discovery phase.
            - ☐ Ethnography
            - ☐ Interviews
            - ☐ Diary studies
            - ☐ Focus groups
            - ☐ Surveys
            - ☐ Card sort
            - ☐ Stakeholder mapping
            - ☐ Data analysis
            - ☐ Landscape analysis
            - ☐ Other
    - Synthesize and Generate Solutions
        - Please select the names of the activities/tools your team engaged in from the Synthesize and Generate Solutions phase.
            - ☐ Personas
            - ☐ User scenarios

    - ☐ Experience maps
    - ☐ How Might We statements
    - ☐ Design thinking workshops
    - ☐ Brainstorm sessions
    - ☐ Developing design principles (articulating constraints on solutions)
    - ☐ Other
- Conceptualize and Prototype
  - Please select the names of the activities/tools your team engaged in from the Conceptualize and Prototype phase.
    - ☐ Concept posters
    - ☐ Storyboards
    - ☐ Service blueprints
    - ☐ Rapid prototyping
    - ☐ Co-creation or participatory design sessions
    - ☐ Other
- Test and iterate
  - Please select the name of the activities/tools your team engaged in from the Test and Iterate phase.
    - ☐ Usability testing
    - ☐ Role playing
    - ☐ Focus groups
    - ☐ Diary studies
    - ☐ Pilot studies
    - ☐ Message testing
    - ☐ Cognitive walk throughs
    - ☐ Other
- Implement and Refine
  - Please select the name of the activities/tools your team engaged in from the Implement and Refine phase.
    - ☐ Development of the solution
    - ☐ Launch roadmap
    - ☐ Pilot study
    - ☐ Governance planning
    - ☐ Continual user feedback gathering

☐ Other

[PROGRAMMING NOTE: FOR EACH ACTIVITY/TOOL SELECTED, QUESTIONS 2 AND 3 BELOW WILL APPEAR]

2. Were end users included in this activity/tool?
    - Yes
    - No
3. Please enter the number of team members who were involved in this activity/tool: [Text box]
4. What worked well this week? [Text box]
5. What was challenging this week? [Text box]
6. Do you have anything else to say about this week? [Text box]

HCD Consultant Interview Protocol

Introduction

Thank you for taking the time to talk with us. My name is **[NAME],** and this is **[NAME]**. We work for Child Trends. We are interested in speaking with the Human Centered Design (HCD) consultants who participated in the study of the application of HCD, to learn more about your experiences consulting on and supporting the design process.

We are speaking with key staff in each of the three sites participating in this study. This includes agency leadership, key members of the design team, and other consultants who worked to support the design process. Overall, our hope is that the information you, your colleagues, and other sites provide will give us insight into the broader applicability of HCD for other programs.

Your participation in this interview is voluntary and you may stop participating at any time. If there is a question you do not want to or do not feel comfortable answering, please let us know and we will skip to the next question. Any personally identifiable information will be kept confidential among the HCD4HS project team. Your responses will be combined with responses from others who are participating in these interviews and may be shared in published documents. What we learn about each site's experiences may be attributed to the site. We will not identify who said what. However, because of the relatively small number of sites and staff who are participating in this project, there is a possibility a response could be attributed correctly to you.

As we're talking today, please keep in mind there are no right or wrong answers to the questions we're going to ask. You're the expert, and we want to hear your honest answers—positive or negative. Honest feedback will help us the most and will help other sites in the future consider HCD in their work.

We will take notes and record the interview, so we can make sure that we don't miss important details. If you would like us to turn off the recorder at any point, please ask and we will do so. Only the project team will have access to the recordings. Once we capture all the information on paper, we will delete the recordings. Our discussion will take roughly an hour.

Do you have any questions before we get started?

Do you agree to participate in this interview, and do you agree to be recorded?

Background

1. Let's start by talking briefly about your role at Anthro-Tech and work you've done that you think is most relevant to this project.

Goals for HCD Pilot

2. Please describe your understanding of the challenge the agency you worked with was facing that they sought to address through this pilot.

HCD Process and Intervention

3. During this project, you filled out a log every month, and we have noted that you supported the team in the following ways: [Interviewer, please list out activities noted in Q3 the HCD Consultant log.] How would you describe your role in these activities/processes?

   a. How did this vary, if at all, at different points in the process? Can you provide examples of key points in the design process where you feel your support of the site was especially important in informing their design work?
   b. Thinking about the technical assistance you provided to the site, what worked well, and why?
   c. Thinking about the technical assistance you provided to the site, what didn't work so well, and why?
   d. What challenges, if any, were there in working with the site?
4. We know that participating in this process requires that design team members work collaboratively as a team. Please describe how the design team you were supporting worked together.
   a. What do you think worked well in this team?
      i. What do you think contributed to that?
   b. What didn't work so well in this team?
      i. What do you think contributed to that?
5. Using HCD to design and implement new solutions can be complicated. We are curious to hear what resources were required to make this process work.
   a. When you think about the resources you just mentioned, which ones were especially helpful for the site?
   b. Which ones were helpful but less critical? Which ones were not helpful?
6. Thinking about this project as a whole, what worked well?
   a. [For additional probes, please reference HCD consultant monthly logs of what worked well for design teams (Q16), particularly if there are notes that need further elaboration]
   b. To what extent did the design team shift their mindset in using HCD principles in their work?
7. Thinking about this process as a whole, what were the barriers that interfered with the design team's work? What barriers did the site encounter in participating in this process?
   a. How did they address or overcome these barriers?
   b. [For additional probes, please reference HCD consultant monthly logs of what is not working well for design teams (Q17), particularly if there are notes that need further elaboration.]
8. [Note to interviewer: Please review monthly logs prior to interview and note any ratings that you would like to explore more in depth and that seem particularly interesting and need more context.]
   You also rated several statements on a monthly basis, from a scale of 1-7, and we'd like to ask follow-up questions on some of the ratings you provided related to how the team worked, as well as end user involvement.

Design of Solution to Problem

9. Please briefly describe the solution that was designed.

10. What are the strengths and weaknesses, from your perspective, of the solution that was designed?
    a. Was the team able to use user feedback to iterate and refine the solution? Tell me how that process went.

Working with the Content Expert Consultant

11. Describe your work with the content expert consultant.
    a. What role did they play in the HCD process as a whole, from your perspective? Tell me more.

Effectiveness of HCD

12. In measuring progress towards the team's outcome of interest, how did the team use data to determine if there was progress?

13. To what extent do you think that the HCD design team made progress on their outcomes of interest? Tell me more.

Final Reflections

14. As you reflect on your work with the site, how good a fit was this challenge for the HCD process, in your opinion?

15. What, if anything, would you suggest to improve or enhance the role that design consultants could play in future engagements like this?

16. Is there anything else you'd like to share with us today?

Thank you for your time and for your honest feedback today. This will be of great use for the HCD field and others interested in participating and implementing a design approach to challenges.

Executive Leadership and Design Team Interview Protocol

Introduction

Thank you for taking the time to talk with us. My name is **[NAME],** and this is **[NAME]**. We work for Child Trends, a nonprofit research center in Washington, D.C. We are interested in speaking with design team members who participated in the study of the application of Human Centered Design (HCD), to learn more about your experiences with the design process.

We are speaking with key staff in each of the three sites participating in this study. This includes agency leadership, key members of the design team, and the consultants who worked with your agency to support the design process. Overall, our hope is that the information you, your colleagues, and the other sites provide will give us insight into the broader applicability of HCD for other programs.

Your participation in this interview is voluntary and you may stop participating at any time. If there is a question you do not want to or do not feel comfortable answering, please let us know and we will skip to the next question. Any personally identifiable information will be kept confidential among our project team. Your responses will be combined with responses from others who are participating in these interviews and may be shared in published documents. What we learn about each site's experiences may be attributed to the site. We will not identify who said what. However, because of the relatively small number of sites and staff who are participating, there is a possibility a response could be attributed correctly to you.

As we're talking today, please keep in mind there are no right or wrong answers to the questions we're going to ask. You're the expert, and we want to hear your honest answers—positive or negative. Honest feedback will help us the most and will help other sites in the future consider HCD in their work.

We will take notes and record the interview, so we can make sure that we don't miss important details. If you would like us to turn off the recorder at any point, please ask and we will do so. Only the project team will have access to the recordings. Once we capture all the information on paper, we will delete the recordings. Our discussion will take about an hour.

Do you have any questions before we get started?

Do you agree to participate in this interview, and do you agree to be recorded?

Background

1. Let's start by talking about your role or job at [Agency]. I would love to know more about your job at [Agency] and how long you have held this position.

Goals for HCD Pilot

2. Next, we'd like to discuss how [Agency]'s involvement in the HCD pilot began. Let's start with the process of submitting a nomination for the HCD pilot. Can you tell me more about what your involvement was in the decision to submit a nomination for the HCD pilot or in the preparation of the nomination?
    a. [If involved]: What do you remember about why you/your team was interested in participating in the pilot?
    b. [If not involved]: Do you know who was involved in the decision? Tell me more. [Skip to Question 4]

3. [If involved] Can you tell me about the challenge your agency was facing at the time that you wanted to address through this pilot. [Use the following probes as needed to prepare the respondent for the HCD process as some of this information may already be available.]
    a. What made [insert answer from Question 3] a challenge?
    b. What prior attempts had your organization made to address this challenge, and to what extent were those attempts effective?
    c. Why did you think that HCD would be an appropriate fit for this challenge?
    d. How did your understanding and articulation of the challenge change or evolve during the course of the HCD project?

HCD Process and Intervention

Role and Experiences Participating in the Pilot **(non-executive leaders only)**

4. There were several steps you participated in as part of the HCD design process. Your team filled out a log every week, and we have noted that you participated in the following HCD activities: [Interviewer, please list out activities noted in the design team log]. How would you describe your role and involvement in these activities/processes?
5. Which activities did you find most useful? Why?
6. Thinking about your team's work over the five-month period, how would you describe that process?
    a. Can you tell me more about what worked well? [For additional probes, please reference answers provided in weekly logs of "what worked well" and ask probes for further clarification and deeper perspective]
    b. Can you tell me more about any challenges you or your team experienced? [For probes, please reference weekly logs of "what was challenging," and ask probes for further clarification and deeper perspective] * Note to interviewer: distinguish between COVID related challenges and non-COVID related challenges.
    c. [For challenges noted] What do you think could be done to address [list barriers participant mentions]? Was your team able to overcome this barrier?
7. Using HCD to design and implement new solutions can be complicated. We are curious to hear what resources were required to make this process work.
    a. When you think about the resources you just mentioned, which ones were especially helpful for the site?
    b. Which ones were helpful but less critical? Which ones were not helpful?
8. We'd like to know more about how your team worked together. As a reminder, your name will not be tied to any of your answers, and we're looking for honest feedback.
    a. What do you think went well with the way your team worked together?
        i. What do you think contributed to that?
    b. What didn't go so well in your team?
        i. What do you think contributed to that?

   c. Would you say that the team changed in any way over the course of the project?

9. We are also interested in how your team involved and interacted with end users of the solution you've being designing. Can you describe some of the key ways you did that? [Interviewer, reference activities noted in the weekly logs involving end users].
   a. Was this different from how your agency has worked with end users before? If so, how?
   b. What was most useful or valuable about engaging end users?
   c. What was most challenging about involving and interacting with end users? Do you have thoughts about what might have helped with this?
10. We know that executive leadership influences how new initiatives or approaches to problem solving are implemented and sustained in organizations. Describe what the support/involvement from executive leadership looked for your agency during the pilot process.
    a. [For each support noted] How helpful was it and did it make a difference in the HCD team's work?
    b. For other organizations in the future doing this kind of work, what kind of support do you think a team needs from executive leadership to be most effective?

Role and Experiences Participating in the Pilot **(executive leaders only)**

11. Tell me about your role or involvement in the HCD pilot process.
    a. What kind of support, if any, did you provide to the team?
    b. What kind of support do you think an HCD Design Team needs to be most effective when engaging in this type of work?
    c. Did supporting the team require you to make any changes to administrative practices, procedures, or accountability? If so, tell me more.
12. Using HCD to design and implement new solutions can be complicated. We are curious to hear what resources were required to make this process work.
    a. When you think about the resources you just mentioned, which ones were especially helpful for the site?
    b. Which ones were helpful but less critical? Which ones were not helpful?
13. Thinking about [Agency]'s participation over the five-month period, what are some factors that made it easier for your site to participate in the HCD pilot process? Are there other factors that you think would help sites participate in the HCD process?
14. What do you think the barriers are in participating in the HCD process? *Note to interviewer: distinguish between COVID barriers and non-COVID barriers
    a. What do you think could be done to help with [list barriers participant mentions]? Tell me more.

Design and Implementation of the Intervention **(non-executive leaders only)**

15. Please describe the HCD solution you designed:
    a. How did your team decide on this solution in particular?
    b. In what ways do you feel like your solution is relevant for end users?

    c. How likely do you think it will be that your end users will adopt your solution?

HCD Design Consultants and Content Expert Consultants

16. We'd now like to shift gears and talk about your work with consultants, [HCD consultant name] and [Content Expert consultant name] over the past five months. We'll start with [HCD consultant name], your HCD consultant. Tell me about what it was like to work with [HCD consultant name]?
    a. How would you describe the level of support provided by your HCD consultant? (too little, just right, not enough). Tell me more.
    b. What was helpful about your work with them?
17. Now, let's talk about your work with your content expert consultant, [list Content Expert consultant name]. What was it like to work with [Content Expert consultant name]?
    a. How would you describe the level of support they provided (too little, just right, not enough)? Tell me more.
    b. What was helpful about your work with them?
    c. What recommendations do you have for other sites working with content expert consultants in similar roles?
18. Now, let's think back to some of the initial trainings you had in the first month of this process. You had two trainings, one primer workshop and one design thinking workshop. How helpful were the primer and design thinking workshops? What specifically was helpful?
    a. Now that you have some experience with the HCD process, is there anything you think could have been done differently in those trainings that would be more helpful? Tell me more.

Implementation Process Outcomes (non-executive leaders)

Note to interviewer: Please review monthly logs prior to interview and note any ratings that you would like to explore more in depth and that seem particularly interesting and need more context.

19. [If filled out monthly logs] You also completed monthly logs, and we'd like to ask follow-up questions on some of the ratings you provided. [Interviewer will ask questions they have from reviewing monthly logs here].

Effectiveness of HCD on Key Outcomes

20. What did your team identify as a key outcome of interest? In other words, what were you trying to change in developing a solution?
    a. What did your team use to measure change or movement? How did you track this data?
        i. Was this new data collection, use of existing measures, or some combination?
        ii. [if new or combination] What was this process of collecting/tracking data like?
    b. Did your team make movement on your key outcome of interest?
        i. Why or why not? [Probe: What data supports this?]
    c. What do you think about the progress your team made towards the outcome of interest you identified?
21. Were there any unexpected positive or negative outcomes that resulted from the HCD design process? If so, please explain.

22. Are there any plans to continue to implement the design you developed, even though the pilot study has ended? Tell me more.

Broader Applicability of HCD

23. Do you think the HCD approach to problem-solving was well suited to addressing the challenge you wanted to solve? Why/why not?
24. What broader changes, if any, do you think have occurred in your team or organization that you think are a result of participation in the pilot?
25. Do you have any plans to address other problems in your agency with HCD? Why or why not?

Final Reflections

26. Having gone through this process, how would you describe HCD to a colleague who didn't know anything about it?
27. Are there lessons learned or advice you would like to share with others interested in designing or implementing an HCD solution?
28. Anything else you'd like to share with us today?

Thank you for your time and for your honest feedback today. This will be of great use for the HCD field and others interested in participating and implementing a design approach to challenges.

Implementation Assessment

HCD Implementation Assessment

Developed by Murray, Boyd, and Rosinsky
with input from consultants Corcoran, de Castillo, Johnson, and Sandfort

Site Name: ____________________ Date: ____________________ Interviewer: ____________________

Instructions to HCD design team members (to be sent out via email with the measure itself, not administration instructions): *In preparation for our upcoming meeting, when we'll formally complete the HCD Implementation Assessment as a group, please feel free to review the questions and consider your individual responses (although there is no need to write down your responses).* ***However, please don't discuss your individual responses with others on the HCD design team until we meet.*** *This will ensure we make the most meaningful and efficient use of time when we complete this as a team. We will use the following scale when completing all items:*

> ***No or Not in Place (0):*** *No activities or elements are in place and/or this has not yet been started.*
> ***Sometimes or Partially In Place (1):*** *Some activities or elements are in place and/or initiated.*
> ***Yes or Fully In Place (2):*** *All dimensions of the activity or element are in place and there is clear evidence to support this.*

Administration Protocol

The facilitator reads each question aloud and asks all participants to vote whether the item is "Yes or Fully In Place" (2), "Sometimes or Partially In Place" (1), or "No or Not In Place" (0). Individuals will first be given a moment to consider their individual vote. The facilitator will then ask individuals to simultaneously indicate their vote using their fingers (i.e., 0 fingers, 1 finger, 2 fingers). The facilitator will prompt simultaneous public polling by stating, "*ready, set, vote.*" If voting is unanimous, the facilitator will immediately move on to the next question. If voting is not unanimous, then the facilitator will facilitate a brief discussion to see if modified consensus can be reached, using strategies to ensure that all voices at the table are heard. "Modified consensus" means that all individuals in the group agree to move forward with a single group vote (0, 1, or 2) and can support that vote outside the context of the original group, even if individual members have or had a dissenting vote. The facilitator will ask for examples of "evidence to support" for each indicator to help the group come to an agreement. The facilitator will clarify the meaning of each question as needed to assist in the determination of a response. Consistent with the NIRN Capacity Assessment after which this is modeled, data should thereby be comparable across teams and sites.

Consent Language

Your participation in this focus group is voluntary and you may stop participating at any time. If there is a question you do not want to or do not feel comfortable answering, please let us know and we will skip to the next question. Any personally identifiable information will be kept confidential among our project team. Your responses will be combined with responses from others and may be shared in published documents. What we learn about each site's experiences may be attributed to the site. However, we will not identify who said what. However, because of the relatively small number of sites and staff who are participating, there is a possibility a response could be attributed correctly to you.

Do you agree to participate in this focus group, and do you agree to be recorded?

HCD Design Team Members Participating in Interview (Name and Role; note specifically if end user):

Who are the identified end users?

Who are the other stakeholders?

The HCD design team in its full composition will be referenced in this assessment as the "team," which does not need to include end users.

Principles

Principle 1: Understanding End Users and Stakeholders			
To what extent are the following indicators present?	***Not In Place (0)***	***Partially In Place (1)***	***Fully In Place (2)***
1. The team actively works to understand the needs, feelings, and experiences of the people for whom the solution is being designed (i.e., "end users").			
2. The team regularly expresses genuine care and concern for the identified end users.			
3. The team considers the perspective of others who "have a stake in" the solution but may not be directly affected by it (i.e., stakeholders such as program managers, funders, service providers).			
4. The team considers broader systems contexts including racial/ethnic injustice in identifying the problem and understanding the context in which end users live.			

Principle 2: End User and Stakeholder Engagement throughout the Process			
To what extent are the following indicators present?	***Not In Place (0)***	***Partially In Place (1)***	***Fully In Place (2)***
5. End users are directly involved in the entire design process from start to finish.			
6. End users help define the problem to be addressed.			
7. End user needs are prioritized in the initial design of the solution.			
8. End users help brainstorm solutions.			
9. End user feedback and testing (beyond simply asking them what they think) helps refine the design solution.			
10. Stakeholder feedback is considered in the design process.			
11. End users' feedback is given more weight than stakeholder feedback.			

Principle 3: Testing and Revising Solutions			
To what extent are the following indicators present?	***Not In Place (0)***	***Partially In Place (1)***	***Fully In Place (2)***
12. Information is collected from end users on how the potential solution addresses the problem they identified.			
13. Stakeholders (other than end users) give feedback on how the potential solution could work (i.e., “feasibility”) from their perspective.			
14. Multiple methods are used to collect end user feedback, including observing their use of the potential solution. *			
15. Data are gathered on end users’ satisfaction with the potential solution.			

*A score of ‘2’ requires observational or behavioral methods; a score of ‘1’ is used for other methods.

Principle 4: Iterative and Nonlinear Process			
To what extent are the following indicators present?	***Not In Place (0)***	***Partially In Place (1)***	***Fully In Place (2)***
16. As the team engages in the design process, they are open to gathering more research and doing more brainstorming and testing when needed.			
17. The team considered the need to redefine the problem as additional information was gathered and learned.			
18. The team designs, tests, and revises potential solutions as many times as needed to effectively address the problem or challenge for end users.			

Principle 5: Design Solution Considers the Entire User Experience

To what extent are the following indicators present?	*Not In Place (0)*	*Partially In Place (1)*	*Fully In Place (2)*
19. The solution considers end users' feelings, motivation, and preferences.			
20. The solution takes into consideration important aspects of the end users' context (culture, resources, and organizations) where it will be used.			
21. The solution considers different places in the process where the solution could be implemented and its potential effects.			
22. The solution considers barriers that may interfere with how end users may be able to use it.			

Principle 6: Collaborative Multi Disciplinary Team

To what extent are the following indicators present?	*Not In Place (0)*	*Partially In Place (1)*	*Fully In Place (2)*
23. The team includes individuals with different professional roles (i.e., a designer, researcher, program manager).			
24. The team includes individuals with different perspectives on the challenge being addressed (e.g., community members, other social sectors, etc.).			
25. Team members are encouraged to share different views and perspectives in meetings.			
26. All perspectives are fully considered, regardless of the person who holds that perspective (or their "power" on the team).			
27. The team listens and shares ideas respectfully when perspectives differ.			
28. When perspectives on the team differ, decisions are made based on feedback gathered from end users.			
29. Team members are motivated to work toward team goals rather than individual goals.			

HCD Activities

Research and Discovery Activities *Note that "research" is defined as intentionally gathering input and information.*			
To what extent are the following indicators present?	***Not In Place (0)***	***Partially In Place (1)***	***Fully In Place (2)***
30. The team conducts research (e.g., interviews, focus groups, observations, surveys) to understand the end user, their goals, and contexts.			
31. The team gathers information to better understand past efforts to solve the problem.			
32. The team develops initial solutions based on this research (instead of their initial assumptions).			
33. The team conducts discovery activities to better understand the context and constraints of stakeholders beyond the end users.			

Synthesize and Generate Solutions			
To what extent were the following indicators present?	***Not In Place (0)***	***Partially In Place (1)***	***Fully In Place (2)***
34. Research is analyzed and summarized in a way that helps the team understand the problem from the end user's perspective (e.g., could be interview clips; does not have to be fancy graphs and charts).			
35. The team considers how possible solutions align with the organizational and broader environmental context (such as existing structures, processes, and values).			
36. When brainstorming solutions, the team focuses first and foremost on how desirable they may be to end users.			
37. The team prioritizes ideas based on feasibility and sustainability.			
38. The team develops "design parameters," or rules for the solution, based on what was learned through research (e.g., if end users are staff who are already overburdened, any solution must not result in a net workload increase).			

Conceptualize and Prototype			
To what extent are the following indicators present?	***Not In Place (0)***	***Partially In Place (1)***	***Fully In Place (2)***
39. A rough draft of the solution (or "prototype") is created before the final solution is developed.			
40. Prototypes are shared with end users to collect feedback.			
41. End user feedback is incorporated.			
42. Prototypes are shared with stakeholders to collect feedback.			
43. Stakeholder feedback is incorporated, although not at the expense of end user preferences and needs.			
44. Very rough prototypes are tested before more polished prototypes are tested.			

Test and Iterate			
To what extent are the following practices in place?	***Not In Place (0)***	***Partially In Place (1)***	***Fully In Place (2)***
45. Possible solutions are evaluated by end users to determine what is working well, what needs improvement, and why.			
46. Solutions are tested with end users using methods such as usability tests, interviews, focus groups, diary studies, or role playing.			
47. Data are gathered regarding end users' ability to understand and use the solution, their satisfaction with the solution, and likelihood of adopting it.			

Implement and Refine			
To what extent are the following practices in place?	***Not In Place (0)***	***Partially In Place (1)***	***Fully In Place (2)***
48. The design team develops a plan for implementing the chosen solution. *			
49. There is a process for end users to provide continuous feedback on the solution.			
50. The solution is tried out on a small scale first, before being implemented more widely.			
51. Plans for introducing the solution are developed, including any marketing, communication, and needed training methods.			
52. A framework is developed to make sure the solution will be sustained.			

*Score of 2 requires this in writing.

HCD Mindset

To what extent were the following indicators present?	***Not In Place (0)***	***Partially In Place (1)***	***Fully In Place (2)***
53. The team is interested in and open to trying new and creative ideas.			
54. The team truly understands the feelings and perspectives of the end users.			
55. The team is comfortable with uncertainty about the problem and solutions and avoids “jumping to conclusions.”			

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October 3, 2022

Denice Ross
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Washington, DC 20504

Dear Ms. Ross:

The Infectious Diseases Society of America (IDSA) appreciates the opportunity to provide comments to the White House Office of Science and Technology Policy in response to its Request for Information regarding equitable data engagement and accountability. IDSA represents a community of more than 12,000 physicians, scientists, public health experts and other health professionals who specialize in infectious diseases and HIV medicine. Our members work across a variety of health care settings and are on the front lines in responding to COVID-19, monkeypox virus (MPV), antimicrobial resistance and other infectious diseases challenges. Comments and recommendations on selected questions from the RFI are found below.

Among examples of existing Federal collaborations with (a) Tribal, territorial, local, and State governments or (b) local communities involving equitable data, *what lessons or best practices have been learned from such collaborations*?

In the interest of protecting the public's health, standardized definitions are needed, especially for demographic data. Health care institutions need to collect the same information in the same categories. We also need expanded definitions, e.g., "Asian" and "Latino/a/x" are extraordinarily broad and mask inequities between and among different groups. Gender identity also needs to be collected for comparison purposes. Reporting these elements should be required so that data are complete nationally and can be used for health care and public health decision making.

COVID-19 and Monkeypox Virus

Both the COVID-19 pandemic and the current MPV outbreak demonstrate the need for equitable data and utility of collaborations across levels of government. Inequitable impacts of disease, and in the case of COVID, hospitalizations and deaths, have been documented through access to equitable data. During the COVID pandemic, access to health care data by local, state and federal governments increased due to required reporting of COVID cases. Timely access to data provides health care facilities, local communities and governments with the ability to plan and respond to public health emergencies with greater effectiveness and speed. Hospitals need data to conduct surge planning and adjust staffing and other resources based on expected patient volume. Local and state public health departments need access to timely data to identify outbreak trends and determine appropriate prevention and mitigation measures to keep communities safe. More granular data is important to illustrate how an outbreak impacts subgroups, including disproportionate impacts based upon race, ethnicity, age, geography, gender, sexual orientation and socioeconomic status. It is crucial to uncover disparities early and track them closely in order to inform equitable responses and target resources (such as limited quantities of therapeutics) to communities with the greatest need and highest risk. Access to equitable health data is facilitated by the continuation of the requirement for hospitals to maintain COVID-19 and seasonal influenza reporting and electronic reporting of information on acute respiratory illness in any future public health emergency by reporting to the Centers for Disease Control and Prevention (CDC) National Health Safety Network (NHSN), or other appropriate CDC-supported surveillance system, as determined by the Health and Human Services Secretary.

Antibiotic Resistance

IDSA has long been a leader in combating the worldwide spread of antibiotic resistance (AR) and supports clinicians treating patients with resistant infections, leading antibiotic stewardship and infection prevention and control programs and conducting research into new treatments and methods of preventing AR. Each year, more than 35,000 people die because of antibiotic-resistant infections, with more than 2.8 million infections occurring in the United States, according to CDC's Antibiotic Resistance Threats Report. Last year, CDC and experts at the University of Utah School of Medicine released estimates that treating six of the top AR threats identified by CDC contribute to more than $4.6 billion in health care costs annually. Initial data indicate the existence of health disparities related to AR. For example, community-associated ESBL-Enterobacterales have higher incidence rates in certain geographic areas with lower median incomes and limited English proficiency; community-associated MRSA rates are higher among Black communities; and candidemia rates are nearly twice as high among Black individuals. AR complicates care and worsens outcomes for a wide range of health care conditions in which disparities exist, further exacerbating health inequities.

CDC is addressing AR health equity through the following goals:

- More systematically expanding the collection of disparities- and equity-focused data across multiple surveillance and data collection efforts to improve antibiotic use (AU) and reduce AR in disproportionately affected populations.
- Continuing to characterize health inequities related to key bacterial pathogens across incidence, infection outcome and antibiotic resistance at a geospatial level, linking inequities to social determinants of health indicators.
- Supporting infection control and patient safety efforts, including support to states to address health disparities related to AR pathogens and antibiotic use.
- Addressing educational needs that impact diverse frontline health care workers' ability to protect themselves and their patients from infections.
- Focusing on strategies to address disparities in quality of care in long-term care.

IDSA applauds these goals and calls on the federal government to continue pursuing additional research and data on AR in order to understand differences in risk and strategies to combat AR in different communities. It is critical to provide CDC with additional funding to support this work and to build the infrastructure in health care facilities necessary to support the collection and reporting of data.

What resources, programs, training, or other tools *can facilitate increased data sharing between different levels of government (Tribal, territorial, local, State, or Federal) related to equitable data*?

Public health emergencies such as COVID-19 and MPV have shone a spotlight on the lack of equitable health data. The *New York Times* recently published an article that addressed the lack of transparency of health data and lack of information on COVID-19 broken down by demographic groups. The article reported that race/ethnicity data were missing in about a third of COVID case reports collected by the federal government because of a lack of infrastructure and workforce in health departments to collect demographic data and fill in gaps after surges of COVID cases. Additionally, public health departments still have very little data on inequities surrounding uptake of therapeutics, particularly oral antivirals, despite the fact that the federal government has been directly managing their allocation and distribution. Sustainable public health infrastructure would allow the collection and interoperable exchange of equitable data by public health professionals and health care providers. This would help inform decisions about where to focus scarce resources and how to implement community outreach and health care services to slow the spread of disease and associated human and economic impacts. This has real world consequences as the United States still experiences 400-500 deaths a day from COVID-19, and more than 24,000 people have been infected in the current MPV outbreak in the U.S., with MPV disproportionately impacting minorities, notably African American and Hispanic/Latino communities.

An influx of funding is needed to sustain the public health infrastructure needed to seamlessly share equitable health data in the 21st century. Congress has already provided nearly $1 billion to date for the CDC's Data Modernization Initiative (DMI). The DMI – which began before the COVID-19 pandemic – is a commitment to build the world-class data infrastructure and workforce that are ready for the next public health emergency. Robust, sustained, annual funding would ensure we can build and maintain modern public health systems and infrastructure, including at state, territorial, local and tribal health departments. The need for investment in modern public health data systems that keep pace with evolving technology is far greater than existing resources will support and will require a sustained federal investment, including more than $7.84 billion over the next five years. The DMI is creating a standards-based interoperable public health infrastructure, ensuring all systems can communicate and share data seamlessly with one another; advancing standards so that information can be stored and shared across systems; and facilitating complete and timely reporting so that our public health system has essential data on race, ethnicity, treatments and comorbidities that are critical for achieving equity in public health response.

Similarly, funding is needed to support the health care infrastructure and workforce necessary to collect and report data and to partner with public health. The CDC NHSN supports health care facilities (including hospitals and long-term care facilities) in the collection and reporting of data on health care associated infections, antibiotic resistance and antibiotic use. During the COVID-19 pandemic, NHSN has expanded to more than 37,000 health care facilities providing data and strengthening surveillance efforts. Additional resources are needed for NHSN to sustain these efforts and expand to additional facilities.

What resources, programs, training, or other tools *can expand opportunities for historically underrepresented scholars and research institutions to access and use equitable data across levels of government*?

In order to expand opportunities to access and use equitable data, research institutions need to hold diversity, equity, inclusion and access (DEIA) as central tenets, especially when working with underrepresented populations and communities. Mistrust of research in underrepresented populations stems from failures in transparent communication by researchers and investigators as well as historical examples of experimentation on marginalized groups. When communities engaged in research such as clinical trials are not engaged as partners, it creates mistrust and limits the impact of these studies. Mistrust can also dissuade students in underrepresented communities from pursuing careers in research. In order to develop a base of trust, non-interrupted education and partnership with communities is needed to be built over time, not only when they are engaged in research activities.

The federal government should fund research that fills patient- and stakeholder-prioritized evidence gaps and is representative of diverse patient populations and settings. Additional recommendations for research are found below.

- In funding clinical trials, incentivize research that prioritizes including diverse participants from a variety of ethnic, racial, gender identity and age backgrounds to improve representation in clinical research. African American/Black, Latinx and Indigenous populations and adults aged 75 and older often have incredibly low participation in clinical trials, which contributes to health inequities. Additionally, increase inclusion of vulnerable groups, such as pregnant and immunocompromised patients, in clinical research trials when possible.
- Study the effectiveness of recruitment strategies for clinical trial volunteers, and factors that may prevent these strategies from reaching underrepresented populations.
- Support clinical trial research that actively fosters community engagement in underrepresented populations in clinical research trials. Further support should be directed to studies evaluating the impact of community-based and nontraditional clinical trial sites compared to traditional urban academic health centers on community and participant engagement.
- Evaluate the impact of engaging community clinicians and frontline physicians in clinical trial research and development, particularly clinicians and researchers who are a part of the community being studied or who have lived experience of the health issue. Frontline physicians and other community clinicians can offer insight to trial planning and should be reimbursed for their time and expertise. As active members and trusted figures in trial site communities, these individuals help build transparency and public trust. Additionally, they help expand potential trial participant pools, which can improve trial diversity. Further, studies have shown that involving clinical researchers can ease the translation of research results into clinical care.
- Include international sites where feasible in funded research trials to increase generalizability of findings globally.
- Proactively fund and develop infrastructure that supports research on emerging infectious disease threats.

What resources, programs, training, or tools *can make equitable data more accessible and useable* for members of the public?

Agencies within the Department of Health and Human Services conduct a tremendous amount of research. Communications tailored toward the public to explain this research and equitable data generated by research are essential to help people without a health care or public health background understand how equitable data can inform decisions about their health and health care. Communication strategies should study different communication methods and modalities and consider approaches that have been shown to be best suited to different population groups, especially groups that have historically experienced discrimination and stigma and who have been heavily impacted by health inequities, including people of color, sexual and gender minorities and people with HIV.

The federal government should research the effectiveness of novel strategies to engage the public and target audiences beyond academia in the dissemination of scientific findings and public health recommendations, including digital and social media strategies, live participatory "short talk" events and community outreach initiatives. Research is also needed to study the impact of misinformation on trust in scientific research, specifically focusing on key populations most likely to fall prey to misinformation, the effect of misinformation on willingness to cooperate with scientists and clinicians and the effect of novel strategies in combating misinformation surrounding scientific research.

Thank you for the opportunity to provide comments on equitable data engagement and accountability. If you have questions about these comments, please contact Amanda Jezek, IDSA senior vice president, public policy and government relations, at [redacted]

Sincerely,

[redacted]

Daniel P. McQuillen, MD, FIDSA
President

WHAT IS INTERSECTIONALITY?

"Intersectionality is a way of understanding and analyzing complexity in the world, in people, and in human experiences. The events and conditions of social and political life and the self can seldom be understood as shaped by one factor. They are shaped by many factors in diverse and mutually influencing ways. When it comes to social inequality, people's lives and the organization of power in a given society are better understood as being shaped not by a single axis of social division, be it race or gender or class, but by many axes that work together and influence each other.…People use intersectionality as an analytic tool to solve problems that they or others around them face (Collins and Bilge 2016:2)."

Collins, P. H., and S. Bilge. 2016. *Intersectionality.* Malden, MA: Polity Press.

INVITAE

October 03, 2022

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Re: Engagement and Accountability RFI

Dear Ms. Ross,

Thank you for the opportunity to provide feedback on equitable data production and use. Invitae is a leading medical genetics company, delivering genetic information services that support a lifetime of patient care — from inherited disease diagnoses and family planning to proactive health screening and personalized diagnosis, treatment and monitoring of cancer — combining genetic and clinical information to improve health decision-making. Our pursuit is to improve healthcare for everyone, including by making genetic testing more accessible and more affordable to all who may benefit. Throughout the company's lifetime, we have served over 3 million patients, providing them information relevant to their care for decades to come. Our core philosophies surrounding patient data are as follows:

1. Patients own their data and have the right to do what they wish with their data; and
2. Data is more valuable when shared.

With these values in mind, we offer responses to questions 4 and 6 below.

4. What resources, programs, training, or other tools can expand opportunities for historically underrepresented scholars and research institutions to access and use equitable data across levels of government?

Before scholars and researchers can access equitable data, equitable data needs to exist. There is no question that there is a lack of diversity within clinical trials and databases leading to limited data sets and research that is not generalizable to the entire US population. The most striking examples of lack of diverse genomic data input resulting in patient harm can be seen within the field of pharmacogenomics.[1] Approximately 20% of the drugs approved from

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[1] https://link.springer.com/article/10.1007/s40615-015-0101-3

2009-2015 produced responses that differed across racial and ethnic groups.[2] Asian and Pacific Islanders have a higher rate of a gene mutation that impacts the way they process clopidogrel,[3] and warfarin is shown to have poorer outcomes for Black people.[4] This calls for improved collection of diverse data in databases and diversity requirements in clinical trials for medication development and approvals.

Active collection of data from diverse populations and incentives to submit data into publicly available databases is one way to enable access by historically underrepresented scholars and research institutions. Invitae is the largest contributor of genomic data to a public database called ClinVar. Funded by the National Institutes of Health, ClinVar is a freely accessible, public archive of reports of the relationships among human variations and phenotypes, with supporting evidence. Our company is able to make significant contributions to this public database by de-identifying patient data using HIPAA-compliant methods. This is an essential resource allowing researchers to perform secondary research, and we hope that discoveries made using this data will help to resolve variants of uncertain significance (VUS) that disproportionately affect people of color. This requires that contributors commit to collecting and submitting diverse data and often, the only incentive is to contribute to the common good. Policymakers should explore ways to further encourage sharing of this critical genomic information to these public databases.

Due to historical and contemporary harms committed by researchers and scientists against people of color, there continues to be justified hesitancy — and lack of trust in some cases — when it comes to engaging in healthcare and research which further limits the availability of diverse data. We are pleased that OTSP has opened this comment period as it fosters discussion on how to address institutional barriers to enhance the diversity of the data available.

Invitae has invested greatly in establishing patient trust and providing a pathway to contribute data to research. In 2021, Invitae acquired the patient-mediated health data platform Ciitizen, which leverages patients' rights under HIPAA to access and control their electronic health record data. Patients consent to Ciitizen reaching out to their providers and request, on the patient's behalf, their medical records. Upon receipt of those records, Ciitizen aggregates them and makes them accessible to the patient through their portal. With this data, patients are empowered to do what they want with it, including using it in their personal medical journeys, contributing to research, or enabling Ciitizen to link them with relevant clinical trials based on the content of their records. The contributions to research and linking to clinical trials occur only if patients consent.

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[2] https://pubmed.ncbi.nlm.nih.gov/25669658/

[3] https://www.ncbi.nlm.nih.gov/pmc/articles/PMC5061802/

[4] https://www.ncbi.nlm.nih.gov/pmc/articles/PMC4280295/

Ciitizen's impact is enabled by its innovative technology, but made possible because of its patient-community first approach to research and patient engagement, resulting in genuine and lasting relationships with patients. This ties into the next question we address regarding access and utility of equitable data by the public.

6. What resources, programs, training, or tools can make equitable data more accessible and usable for members of the public?

Enabling access to data contribution by diverse populations early in the process is important in defining the ultimate utility of the data collected. Please find below a few examples in which Ciitizen partners closely with members of the public to facilitate and empower equitable data collection and sharing.

Advocacy research collaborations:

Ciitizen has been successful at partnering closely with patient advocacy groups and patient foundations to first study barriers and then develop both the educational tools and resources necessary to appropriately mitigate the true barriers to research and clinical trial participation.

In early 2021, Ciitizen partnered with TOUCH, The Black Breast Cancer Alliance, Breastcancer.org, Morehouse School of Medicine, Susan G. Komen, and the Center for Healthcare Innovation to design our own research that would investigate the emotional barriers to clinical trial participation for Black Breasties under the umbrella of #BlackDataMatters.

Starting with Black Breast Cancer, the mission of Black Data Matters is to put patients in a position of power to directly change a research and medical system that often fails Black patients. In this Black Breast Cancer and Barriers to Clinical Trial Research study, we aimed to: uncover and seek to understand awareness, perceptions, and beliefs that drive the genuine emotional barriers to clinical trial participation, assess the unmet needs that must be addressed in order to drive participation in clinical trials, and understand the disconnect from current recruiting tactics, information, and messaging. A full special report can be found here.[5]

Health system collaborations:

Morehouse School of Medicine is a leading historically Black medical school that provides medical services for a safety net hospital in the greater Atlanta region. Ciitizen and Morehouse

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[5] https://blackdoctor.org/when-we-trial-special-report/

School of Medicine have partnered for several years now to bring the Ciitizen technology into their clinics, enabling community health workers to first educate patients on the importance of research and then make it easy for them to consent and participate in clinical trials and getting their medical records under their control. Coming out of the early recruitment success of the American Association for Cancer Research-supported Total Cancer Care study (link),

Morehouse School of Medicine has now signed a letter of intent to partner with Invitae to power a national precision medicine & prevention initiative (*Comprehensive Approaches to Reimagine Health Equity Solutions*™). Spanning clinical decision support tools, equitable access to genetic and genomic testing and the Ciitizen and Medeon research platforms, the Morehouse CARhES™ precision medicine and prevention initiative aims to improve health outcomes in the Black Belt. Together, Morehouse School of Medicine and Invitae will drive greater access to precision medicine and participation in research and clinical trials to advance health equity. Collaborations such as these are scaling community based, high trust efforts to increase research participation and equitable access to precision medicine.

Conclusion

When patients and communities are engaged from the beginning and data collection are done respectfully with appropriate consent, equitable data generation is achievable. These data can further be used to contribute to our scientific understanding of human health and disease through the secondary use of these data. Invitae hopes that by illustrating one technology solution and two partnership-driven solutions, we have demonstrated that equitable data can be collected and shared for the benefit of everyone.

If you have any questions, please contact me at [redacted]

[redacted]

Chantelle Schenning, Ph.D., MHA
VP, Head of Healthcare Transformation
Invitae Corporation

knowledge alliance

American Institutes for Research

Basis Policy Research

Cognia

Community Training and Assistance Center

Curriculum Associates

Education Analytics

Education Development Center

Education Northwest

Education Testing Service

FHI360

Learning Forward

Marzano Research

Policy Studies Associates

Results for America

RMC Research Corporation

SRI International

University of OK, College of Continuing Education – Outreach

Westat

WestEd

October 3, 2022

Denice Ross
U.S. Chief Data Scientist
Office of Science and Technology Policy
[redacted]
Washington, DC 20502

Re: Engagement and Accountability Notice of Request for Information, Office of Science and Technology Policy (OSTP) – Document Number 2022 - 19007

Dear Ms. Ross,

I am writing on behalf of Knowledge Alliance (KA) with comments and recommendations in response to the Office of Science and Technology Policy (OSTP) request for information (RFI) on identifying equitable data engagement and accountability practices between Federal agencies and other levels of government. Knowledge Alliance, a non-profit, non-partisan organization, is comprised of leading education organizations committed since 1971 to the greater use of high-quality and relevant data, research, evaluation, and innovation in education policy and practice at all levels. Collectively, we promote the use of rigorous research to figure out "what works," and why, to improve student outcomes and then share those findings with policymakers, practitioners, and the general public.

Knowledge Alliance believes the collection and dissemination of high-quality research and evidence is integral to innovating and improving learning outcomes for all students, especially those who have been historically marginalized. Our members strive to support the collection and analysis of equitable data that is disaggregated by demographic information to enable insights on disparities in student academic outcomes from the U.S. Department of Education (ED), State educational agencies (SEAs), and local educational agencies (LEAs). KA has been actively engaging around these issues, particularly following the release of the National Academies of Sciences, Engineering, and Medicine (NASEM) report titled "Toward a Vision for a New Data Infrastructure for Federal Statistics and Social and Economic Research in the 21st Century." We applaud the Administration for investing in the creation of a "durable, equitable data infrastructure" across all levels of government and in tandem with external organizations, like ours. While our response focuses on the collection and transmission of equitable data in education, we believe our members' experiences and recommendations can be extrapolated to other sectors. We appreciate the opportunity to respond to this RFI and have provided the responses below to select questions, numbered in order of how they appear in the Federal Register notice.

Responses to Questions

1. What are examples of successful collaborations involving equitable data between the Federal government and (a) Tribal, territorial, local, and State governments, or (b) local communities?

- ***State Tribal Education Partnerships Program:*** The State Tribal Education Partnerships (STEP) Program was created to promote increased collaboration between tribal education agencies (TEAs) and the SEAs and LEAs that serve students. In 2021, the STEP program generated four webinars providing technical assistance to grantees on logic models and data-driven decision making. Knowledge Alliance members have found that providing technical assistance directly to State and local contexts streamlines the collection of high-quality data.
- ***Native Education Collaborative:*** The National Comprehensive Center (NCC), led by Westat and funded by ED, established the Native Education Collaborative (NEC) to provide additional support to Indian/Alaska Native students. The NEC develops and disseminates resources, including a facilitated framework called Circles of Reflection, to help build SEAs capacity to more comprehensively support Native education through collaboration with districts and tribes. Circles of Reflection also involves rich, collaborative conversations between SEAs, tribes and districts, on topics such as what the SEAs are doing or not doing to support data sharing, to jointly determine priorities; and then collectively develop and implement plans to improve Native education. The NCC has facilitated Circles of Reflection in five States
- ***National Center on Program Management and Fiscal Operations:*** The National Center on Program Management and Fiscal Operations (NCPMFO) works with the Office of Head Start to strengthen program management, disseminate evidence-based management strategies, and inform fiscal policies. NCPMFO creates materials, webinars, webcasts, and training modules to support Head Start grantee data collection and analysis.

2. Among examples of existing Federal collaborations with (a) Tribal, territorial, local, and State governments or (b) local communities involving equitable data, what lessons or best practices have been learned from such collaborations?

- ***Incorporate Field Perspectives:*** In any technical assistance efforts with TEAs, SEAs, or LEAs, KA members emphasize the importance of building strong relationships and providing culturally responsive services that directly meet the field's needs. To create an equitable data infrastructure, those at the local level need a voice in shaping what data is collected and how it is analyzed.

3. What resources, programs, training, or other tools can facilitate increased data sharing between different levels of government (Tribal, territorial, local, State, or Federal) related to equitable data?

- ***State Longitudinal Data Systems:*** Knowledge Alliance has been actively advocating for improvements to the Statewide Longitudinal Data Systems (SLDS) over the past year. The initial investment in SLDS provided States with the resources needed to design, develop, implement, and expand K-12 and P-20W (Pre-K to workforce) longitudinal data systems. These initial investments have been extremely helpful to States; however, KA strongly believes that the Federal government should invest additional resources to improve the utility of these systems to maximize their potential to increase data sharing. Moreover, our members believe that the Federal government should accompany these investments with a nationwide SLDS strategy, rather than support State by State implementation, to create efficiencies and scalability across States. To that end, KA supports IES Director Mark Schneider's call for a SLDS 2.0 which would make SLDS data more accessible by:

  - "Using a modern, often cloud-based, architecture
  - Emphasizing interoperability
  - Aligning coding schema and data definitions across States
  - Making data more widely available while remaining consistent with existing and future privacy laws at the State and Federal level
  - Integrating data from early childhood through labor market outcomes and for other services States identify"

  Additionally, KA member Education Analytics has advocated for SLDS 2.0 to invest in a reference software build (e.g., a template) that would create a common schema that States could customize to their needs and build off of, instead of each State building their own interoperable system from the ground up. A standardized SLDS software template would enable interoperability between State datasets (e.g., facilitate data sharing and merging, streamline Federal reporting efforts). Overall, KA is a strong supporter of SLDS' efforts and believes there is progress to be made in increasing States' data interoperability and accessibility. We know that SLDS funded projects are collecting swaths of data that can be used to address inequities from pre-K to workforce. We encourage OSTP to track SLDS' programs and its successes and push to expand and enhance these systems.

- ***State Report Cards:*** Under the Elementary and Secondary Education Act (ESEA), SEAs and LEAs that receive Title I, Part A funds must create an annual report card that includes a variety of data about public schools, such as measures on student performance, accountability, per-pupil expenditures and educator qualifications. The comprehensive data provided by State report cards has potential to offer administrators, educators, parents, and communities critical information on academic and non-academic performance in an easy-to-read manner. It is difficult, however, to study trends across States, districts, and schools since there is no standardized methodology between State report cards. This means that States are using different metrics to collect and analyze their data. Knowledge Alliance members believe that standardizing State report card metrics could strengthen the tool and provide a more uniform set of data to school leaders, educators, families, and students. We encourage OSTP to investigate the work of the Common Education Data Standards (CEDS) which has been providing common element names and definitions across the entire P-20W system, standardizing the current vocabulary of data elements while also making them more accessible and user-friendly. By leveraging a tool like CEDS, we believe standardized State report card data could be further used to provide insight on the challenges students from historically marginalized populations face and to inform solutions.

6. What resources, programs, training, or tools can make equitable data more accessible and useable for members of the public?

- ***Regional Educational Laboratories (RELs)***: KA encourages OSTP to leverage 10 Regional Educational Laboratories (RELs), which work in partnership with SEAs, LEAs, and other education stakeholders, to support the collection of equitable data for education research and to inform policymaking. RELs partner with districts, States, and other education stakeholders to identify high priority needs and conduct applied research to address such needs, helping stakeholders understand problems and learn what is working in their schools. RELs produce clear, objective, and peer-reviewed research products designed to be actionable for partners and national audiences alike. RELs also develop toolkits that support the scaling up of best practices, such as those identified through the What Works Clearinghouse's Practice Guides on topics like "Using Student Achievement Data to Support Instructional Decision Making." REL's are strategically placed to disseminate high-quality information to their partners and could be leveraged to share information about data usage best practices to the public. REL dissemination activities, products, and strategies are co-developed in partnership with policymakers and educators to help ensure that they can leverage and apply research evidence in their local context. We believe RELs could be meaningfully used in the education space to provide direct technical support to the public regarding the use of equitable data.

- **Comprehensive Centers (CCs)**: The Comprehensive Center (CC) program supports the establishment of 20 CCs that provide capacity-building services to SEAs, LEAs, and schools to improve educational outcomes for all students, close achievement gaps, and improve the quality of instruction. The National Comprehensive Center (NCC) is already making headway on improving the data SEAs and LEAs can use to answer questions relating to diversity, equity, and inclusion. In February 2021, the NCC began a community of practice with teams from seven States utilizing the following recommendations from the 2019 NASEM report, "Monitoring Educational Equity," to identify key indicators for measuring and monitoring the extent of equitable opportunities and outcomes in low-performing schools. The Committee identified a core group of equity indicators with the expectation that different educational agencies could select constructs or add indicators tailored to each local system's needs. These indicators can guide the collection and use of educational data through an equity framework. As the NCC's work shows, CCs are well positioned to provide the SEAs and LEAs with technical assistance on the collection and analysis of equitable data.
- **IES' "Ask An Expert" Service:** The new "Ask an Expert" service provides rapid-turnaround methodological expertise, and evidence-based thought partnering to SEAs and LEAs. IES' "Ask an Expert" services help SEAs and LEAs succinctly answer research-related questions based on the evidence-based subject matter. SEAs and LEAs can also use the "Ask an Expert" service to build their own capacity to design research to answer pressing questions of policy or practice. "Ask an Expert" services are designed to provide answers to requestors in a matter of weeks, not months or years. The RELs stand ready to provide more intensive training, coaching, and technical supports in cases where an "Ask an Expert" request may not be feasible to complete within 4-5 weeks.

Please reach out to Rachel Dinkes at [redacted] with any questions.

Best,

[redacted]

Rachel Dinkes, President

RACE.
UNM.
EDU

Making the Invisible Visible: Advancing Quantitative Methods in Higher Education Using Critical Race Theory and Intersectionality

Nancy Lopez[a], Chistopher Erwin[b], Melissa Binder[b], Mario Javier Chavez[a]
[a]Department of Sociology, University of New Mexico, [b]Department of Economics, University of New Mexico

UNM
Mentoring Institute

ABSTRACT

We appeal to critical race theory and intersectionality to examine achievement gaps at a large public university in the American southwest from 2000 to 2015. Using white, high-income women as our reference group, we report linear combinations of marginal effects for six-year graduation rates and developmental course taking across 20 distinct social locations varying according to race-ethnicity, gender, and class. We find substantial achievement gaps that remain unseen in conventional models treating such characteristics as independent. Nearly every group has a significantly lower likelihood of graduation compared to the reference group, and there is substantial variation in estimated achievement gaps. Low-income, American Indian men are approximately 45 percent less likely to graduate within six years relative to the reference group. For high income, black men this gap is approximately 30 percent. Our paper proposes a method and praxis for exploring the complex, interdependent relationship between race-ethnicity, gender, and class.

PURPOSE / METHODS

To examine disparities in completion rates and developmental course-taking in college, we use an administrative data-set from SPU, a large Hispanic-serving research university in the southwestern United States. Data capture the population of first-time, full-time students matriculating in the fall from 2000 to 2015. We estimate saturated logistic models for three outcomes: the six-year completion rate, developmental English course-taking, and developmental mathematics course-taking. Models are saturated in that they include a full set of gender, race, and class dummy variables, as well as all possible interactions.

Table 1. Descriptive Statistics, Graduation and Remediation Models

Variable	2000 - 2008	2000 - 2015
Graduated within 6 Years	0.406	-
Developmental English	0.294	0.268
Developmental Mathematics	0.326	0.301
Any Developmental	0.431	0.397
Female	0.582	0.577
White	0.406	0.371
Black	0.03	0.024
Hispanic	0.444	0.499
American Indian	0.069	0.058
Asian	0.05	0.047
Low-Income	0.539	0.498
Observations	6,427	13,953

RESULTS / PROGRESS / OUTCOMES

- Table 1 reveals that over the period 2000–2008, 41 percent of students completed within six years. Developmental course-taking is common over both the sample periods: approximately 40 percent of students were required to take at least one developmental mathematics or English course over these cohort years.

- As shown in Table 3 below, nearly every group (not high-income Hispanic and Asian women) has a significantly lower likelihood of graduation compared to high-income white women. We estimate especially large achievement gaps for students in American Indian and black social locations. For example, American Indian low-income men are approximately 45 percent less likely to graduate within six years relative to the base group (white high-income women). For black high-income men this gap is approximately 30 percent (although cell sizes are unreasonably small), which is surprisingly similar to the estimated achievement gap for low-income white men.

- Every social location, with the exception of high-income white and Asian men, has a higher probability of developmental English placement at SPU than high-income white women. Social locations that have large estimated achievement gaps are low-income Asian men and women (34–35 percent), low-income American Indian men (34 percent), and low-income Hispanic men (31 percent).

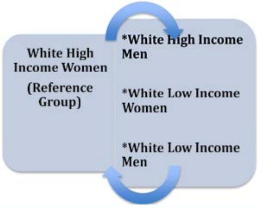
- Black students experience the largest achievement gap in mathematics, with low-income black women being 36 percent more likely to be placed in a developmental course relative to high-income white women. It is clear however, that low-income women of color are much more likely to be placed in such a course when compared to high-income white women.

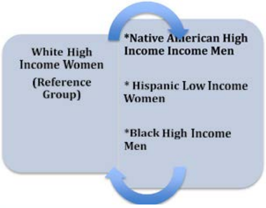
Table 3: Multilevel Logistic Estimates of Probability of 6-Year Graduation by Race, Ethnicity, Gender, and Class, 2000-2008

Variable	Marginal Effect	Sig.	Standard Error	Cell Size
White, High-Income Women (Base)	-	-	-	869
White, Low-Income Women	-0.142	***	0.026	594
White, High-Income Men	-0.137	***	0.025	705
White, Low-Income Men	-0.288	***	0.031	440
Black, High-Income Women	-0.226	***	0.069	57
Black, Low-Income Women	-0.185	***	0.059	76
Black, High-Income Men	-0.305	**	0.126	18
Black, Low-Income Men	-0.223	***	0.077	45
Hispanic, High-Income Women	-0.033		0.026	599
Hispanic, Low-Income Women	-0.225	***	0.024	1,094
Hispanic, High-Income Men	-0.172	***	0.029	462
Hispanic, Low-Income Men	-0.24	***	0.027	699
American Indian, High-Income Women	-0.093	*	0.055	85
American Indian, Low-Income Women	-0.396	***	0.05	186
American Indian, High-Income Men	-0.371	***	0.072	66
American Indian, Low-Income Men	-0.453	***	0.066	108
Asian, High-Income Women	0.0009		0.071	50
Asian, Low-Income Women	-0.137	***	0.046	128
Asian, High-Income Men	-0.211	***	0.069	54
Asian, Low-Income Men	-0.217	***	0.055	92
Likelihood Ratio Statistic				48.23
Residual Intraclass Correlation				0.025
Observations				6,427

DISCUSSION

The achievement gap in higher education is often the topic of conversation in NM. Although well intentioned, the idea of using income as a proxy for the racial/ethnic (or gender gap) is not born out by any empirical analysis that considers the simultaneity of race, gender, and class. A rigorous equity-impact analysis of proposals to limit the NM lottery scholarship or any other type of financial aid / higher education resource is needed before policy decisions are made. We recommend a moratorium on policy changes that only look at household income for awarding universal lottery scholarships. We find that one unintended consequence could be that vulnerable racial and ethnic minorities communities may be disproportionately affected even if they are in the high income bracket. A policy change limiting access to the lottery by income could further exacerbate the "achievement gap" for racial and ethnic minorities. Going forward, policy changes should examine race, gender, and class together for advancing equity-based policies.


White High Income Women (Reference Group)
*White High Income Men
*White Low Income Women
*White Low Income Men


White High Income Women (Reference Group)
*Native American High Income Income Men
* Hispanic Low Income Women
*Black High Income Men

CONCLUSIONS

The sedimentation of intergenerational intersecting structural configurations of inequality vis-à-vis race–gender–class in education, employment, wages, wealth, health, and criminal justice for entire categories of people in our state took a long time. Consequently, social justice liberatory movements will also require continued strategic dedicated and sustained social justice efforts over a long period of time; however, as long as historic and ongoing intersecting race–gender–class gaps are not interrogated, they remain invisible and inactionable.

REFERENCES (APA STYLE)

For a full list of references please see:
López, N., Erwin, C., Binder, M., & Chavez, M. J. (2017). Making the invisible visible: advancing quantitative methods in higher education using critical race theory and intersectionality. Race Ethnicity and Education, 0(0), 1–28. https:// doi.org/10.1080/13613324.2017.1375185

Visit us at RACE.UNM.EDU

Thank you for the opportunity to provide feedback on improvements that are needed for equitable data for impact. I'd like to share my peer-reviewed articles (Sociology of Race and Ethnicity Journal; Critical Public Health Journal-PDFs attached) that employ intersectionality and my street race measure as a value-added measure for detecting discrimination. I've also included related commentary, essays, summaries of research grants, etc.. I hope you can consider employing intersectionality as inquiry and praxis as well as a adding a street race measure in as well as self-identified race in your work as key for detecting discrimination and advancing equity. To be clear this would be a both/and approach. We would still keep self-identified race as a separate measure from street race or perceived race. Multi-dimensional measures of race are extremely important for Latinx communities as we are often racialized very differently based on our street race/perceived race and research shows that this matters for our experiences with discrimination. Imagine high school that is predominantly Hispanic over 60% but all the light-skinned/white Hispanics are in the school council, high-status extracurriculum, model UN, honors classes and Brown, Indigenous, Black and other racially stigmatized Hispanics are in the vocational/non-college tracks and they are over represented in school discipline and school departures before graduation. If we assume that there is no problem in this high school then we are missing an opportunity to advance racial equity. Below I include my Tedex talk (in my native language Spanish/subtitles and close captions in English are available, along with other presentations that employ intersectionality as inquiry and praxis and showcase the value added by intersectionality departing from the premise that race, ethnicity, gender, nativity, ancestry, gender, class origin, sexuality and other axes of inequality can be understood as ***analytically distinct and simultaneous*** for interrogating inequities. I've also attached additional comments.

With appreciation, Nancy

****

Nancy López, Ph.D., Professor, Sociology (she, her, ella) **I'm first-gen college!**
Director & Co-founder, Institute for the Study of "Race" & Social Justice, http://race.unm.edu/
Co-Chair, Education Subcommittee, NM Governor's Advisory Council for Racial Justice
Affiliated Faculty: Africana Studies; Chicana and Chicano Studies; Native American Studies; Women, Gender & Sexuality Studies
Secondary Appointment: College of Education & Human Sciences, College of Population Health
[redacted]
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VIDEOS AND PUBLICATIONS

2018 Dr. Nancy López, "Que vas a macar para el Censo 2020? What Race will you select on the 2020 Census?" (10 min) Tedex en Español.
https://www.youtube.com/watch?v=CGsNwqgcHPo&t=56s

Que vas a macar para el Censo 2020
What Race will you select on the 202
Census?

¿Y tú, que vas a macar para el Censo 2020: Origen Hisp
Que es tu Raza o color en la calle?" Para avanzar la jus
social tenemos que entender que la r...
www.youtube.com

STREET RACE EXPLAINED (2 min):
https://www.youtube.com/watch?v=4QMuZmwTp1o

Video: 2020 Data Working Group Proposal, NM Gov Advisory Racial Justice Council Recommendations (8 minutes) Dr. Nancy López presenting: https://www.youtube.com/watch?v=lsGNEGkvJcA

Presentation (40 min) I gave on the urgency of intersectionality for equity-based policy making where I share some of that preliminary data at the 2021 National Association for Diversity Officer in Higher Education.

https://www.youtube.com/embed/caRvrK5uMZI

Interview in June 2022 (25 min) regarding my role as core faculty for the Intersectional Qualitative Research Methods for Advanced doctoral students at UT-Austin. https://www.youtube.com/embed/DuALmtrtVYI

[Interview - YouTube](http://www.youtube.com)

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PUBLICATIONS

Vargas, E. D., Juarez, M., Stone, L. C., & Lopez, N. (2019). Critical ‘street race’praxis: advancing the measurement of racial discrimination among diverse Latinx communities in the US. *Critical Public Health*, 1-11.

López, Nancy, Edward Vargas, Melina Juarez, Lisa Cacari-Stone and Sonia Bettez. 2017. “What’s Your “Street Race”? Leveraging Multidimensional Measures of Race and Intersectionality for Examining Physical and Mental Health Status among Latinxs.” Sociology of Race and Ethnicity. doi:10.1177/2332649217708798.

Innovative Multidimensional Measure of Race/Racialization as Analytically Distinct from Ethnicity or National Origin: “Street race” has been measured empirically in the following surveys: 2015 Latino National Health and Immigration Survey (N=1,473) RWJF Center for Health Policy; 2016 Collaborative Multiracial Post-Election Survey (N=10,145); 2016 The New Landscapes of a Majority-Minority State: Politics, Economy, Health, and Well-Being in New Mexico (NLMMS) RWJF Center for Health Policy (N= 1,505); 2017-2018 Visibilizing AfroLatin@s: Measuring Race Among Latin@s, AfroLatino Forum Survey, New York (in progress). See also, Reyna, Chandra. 2018. “‘Street Race’ and Health,” In Brief, Contexts 17(2): 4-7. [*http://journals.sagepub.com/doi/10.1177/1536504218785907*](http://journals.sagepub.com/doi/10.1177/1536504218785907)

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Making the Invisible Visible: Advancing Quantitative Methods in Higher Education Using Critical Race Theory and Intersectionality

Nancy Lopez[a], Chistopher Erwin[b], Melissa Binder[b], Mario Javier Chavez[a]

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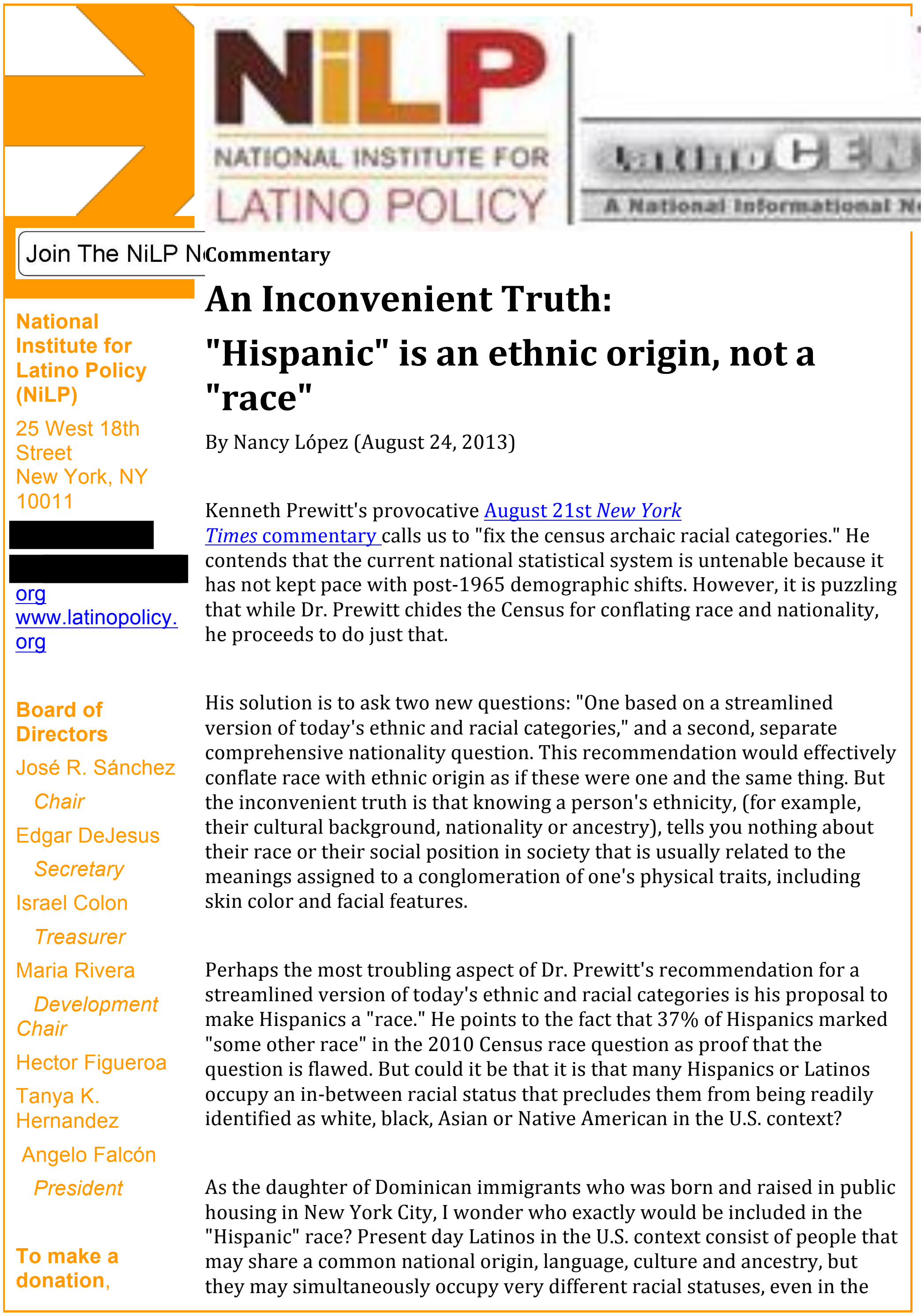

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Commentary

An Inconvenient Truth:

"Hispanic" is an ethnic origin, not a "race"

By Nancy López (August 24, 2013)

Kenneth Prewitt's provocative August 21st *New York Times* commentary calls us to "fix the census archaic racial categories." He contends that the current national statistical system is untenable because it has not kept pace with post-1965 demographic shifts. However, it is puzzling that while Dr. Prewitt chides the Census for conflating race and nationality, he proceeds to do just that.

His solution is to ask two new questions: "One based on a streamlined version of today's ethnic and racial categories," and a second, separate comprehensive nationality question. This recommendation would effectively conflate race with ethnic origin as if these were one and the same thing. But the inconvenient truth is that knowing a person's ethnicity, (for example, their cultural background, nationality or ancestry), tells you nothing about their race or their social position in society that is usually related to the meanings assigned to a conglomeration of one's physical traits, including skin color and facial features.

Perhaps the most troubling aspect of Dr. Prewitt's recommendation for a streamlined version of today's ethnic and racial categories is his proposal to make Hispanics a "race." He points to the fact that 37% of Hispanics marked "some other race" in the 2010 Census race question as proof that the question is flawed. But could it be that it is that many Hispanics or Latinos occupy an in-between racial status that precludes them from being readily identified as white, black, Asian or Native American in the U.S. context?

As the daughter of Dominican immigrants who was born and raised in public housing in New York City, I wonder who exactly would be included in the "Hispanic" race? Present day Latinos in the U.S. context consist of people that may share a common national origin, language, culture and ancestry, but they may simultaneously occupy very different racial statuses, even in the

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same biological families. If Hispanics were designated as a "race" instead of an ethnic origin, would this mean that, by fiat, Sonia Sotomayor, Thomas Perez, Dolores Huerta, Sammy Sosa, Ricky Martin, George Lopez, Jennifer Lopez, Cristina Aguilar, Zoe Saldana, Eva Langoria, would suddenly become members of the same "race"?

I agree that we need to do a better job of collecting race and ethnicity data in the Census and beyond. For example, Dr. Prewitt's suggestion that we bring back the parental place of birth question is an important suggestion that will allow us to examine the experiences of the children of immigrants. However, the conflation of race and ethnic origin has many unintended consequences that will impede our ability to monitor whether there are different experiences among Hispanics as well as many other groups that are analytically distinct from ethnicity.

For example, an innovative 2013 study by the U.S. Department of Housing based on 8,000 participants in 28 metropolitan areas, used multiple measures of race to test for the presence of housing discrimination. They found while there was discrimination related to ethnic markers, such as name and sound of voice, the most prevalent form of discrimination was based on the meanings assigned to physical appearance or race. This meant that potential apartment renters with the same social class credentials received different treatment based on their racial status. There is also a plethora of social scientific research that finds similar value in keeping two separate questions on race and ethnic origin for understanding inequality in labor market outcomes, schooling, earnings, health status, and criminal justice.

Dr. Prewitt very clearly affirms the need to continue to collect race data; however he falls short of recommending that continued testing of Census questionnaire formats be assessed in terms of their ability to interrogate inequalities in social outcomes. For example, the U.S. Census can test whether the inclusion of "Hispanic" as a race would mask the levels of racial segregation that exist among Latinos who identify as white vs. some other race, etc.

We cannot kill two birds with one stone. Two separate questions on race and ethnicity are necessary on the Census, not only for monitoring and eliminating inequalities among Latinos but also for assessing social outcomes among our growing mixed race population and other communities vis-a-vis residential segregation, labor market discrimination, unequal schooling, race-gender profiling, voting rights violations and other social inequalities. How else would we know whether we have made progress in creating a more perfect union for all?

***Nancy López** is Director of the Institute for the Study of "Race" & Social Justice at the RWJF Center for Health Policy, and associate professor of sociology at the University of New Mexico. She is co-editor of "Mapping 'Race': Critical Approaches to Health Disparities Research" (New Brunswick, NJ: Rutgers University Press, 2013). Dr. Lopez can be reached* [redacted]

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Guest Commentary

Some Critical Thoughts on the Census Bureau's Proposals to Change the Race and Hispanic Questions

By Nancy Lopez (January 10, 2013)

As a sociologist of racial, ethnic and gender stratification, I applaud the Census Bureau's ongoing efforts to examine how we can collect race and ethnicity data that address our increasingly complex and changing demographics for generations to come. Among the key recommendations of their 2010 Alternative Questionnaire Experiment (AQE) Report is a call for further testing of the combined race and Hispanic origin question format.

Accordingly, the Census will continue testing questionnaire formats that include Hispanic as a racial category (the first and only time that a specific Hispanic origin group was included in the U.S. Census was in 1930 when "Mexican" was included as a racial group). Including Hispanic as a racial category is a significant departure from current Office of Management and Budget (OMB) guidelines that require that Hispanic Origin (ethnicity) is asked as a separate question from Race (racial status). It is important to note that since 2000, individuals may mark one or more race (but only one Hispanic ethnicity).

While the Census engages in further testing and refinement of questionnaire formats for race and ethnicity data collection, it is important that we consider why we collect and analyze race and ethnicity data in the first place: the focus is to assess our progress in Civil Rights enforcement. Data collection on race and ethnicity is used by federal, state and local agencies to monitor discrimination and segregation in housing (Fair Housing Act), labor market participation (Equal Employment Opportunity Commission), political participation (Voting Rights Act, Redistricting), educational attainment (Department of Education), health (Centers for Disease Control and Prevention), and criminal Justice (Department of Justice), among other policy areas.

If we agree that the key purpose of data collection on race and ethnicity is for monitoring our progress in creating a more perfect union for all, then we should consider several questions:

- To what extent is one's ethnicity, cultural background, national origin, generational status, and ancestry conceptually interchangeable with one's race or racial status as a social position in society?
- What is the value-added of a given questionnaire format?
- What is lost or improved by keeping or changing the current two-question format?

- Do these data allow us to monitor patterns of inequality among entire categories of people by race and ethnicity?

The "gold standard" for all racial and ethnic data collection should be meaningful use for interrogating inequalities across a variety of social outcomes.
As a native Spanish-speaker who was born and raised in New York City's public housing projects, I am viscerally aware of the distinction between race and ethnicity. Although I share the same ethnic background of my immigrants from the Dominican Republic, my father, who is light skinned and not of discernible African phenotype, occupies a different racial status than my mother and I who share a common racial status as Black women.

The distinction between race and ethnicity is not trivial. A growing number of scholars have found that distinguishing race from ethnicity is extremely important for monitoring and ameliorating inequalities in housing segregation (Massey and Denton; Logan); health (LaVeist-Ramos *et al.*); education (Murguia and Telles); criminal justice (Steffensmeier and Demuth); and employment (Rodriquez *et al.*), etc.. If we collapse race and ethnicity as interchangeable concepts, we may miss the opportunity to examine whether there are unique experiences among co-ethnics that may occupy very different racial statuses.

While it is true that the combined questionnaire formats being tested by the Census instruct individuals to mark one or more race and write in an ethnic designation if they desire, it will be challenging to capture the two concepts with one question. Indeed, the AQE report found that while the total number of Hispanics was not reduced by the combined questionnaire formats, the detailed information on national origin groups did decrease. In other words, one of the potential shortcomings of the combined format is that, although it will not necessarily reduce the number of Hispanics that are counted, we will have less information about their racial status and national origin.

In the end, if we depart from the premise that race and ethnicity are two analytically distinct concepts then we will require two different questions. Currently, only the American Community Survey (ACS) includes a question about ancestry. The value added by the extra "real estate" of a having two separate questions on race and ethnicity, not only for Hispanics but also for other demographic groups, surely outweighs the costs of having poor data that will hinder our ability to assess distinct pathways of inequality.

Another value-added question that the Census could pilot is bringing back the parental place of birth question. Given our changing demographics and diverse immigration streams, the collection of these data would allow us to examine patterns of inequality related to national origin and immigrant status (e.g., first generation-immigrants who came as a adults vs. second generation-U.S.-born children of immigrants). The last time that this value-added question was included in the Census was in 1980. These data would allow us to map whether there are unique inequalities faced by foreign-born individuals and their children by national origin.

Again, I applaud the Census for proceeding with caution before recommending any major changes in national data collection systems that will shape how we assess Civil Rights enforcement for generations to come. While I have focused on the experiences of Latinos, the analytical distinction between race and ethnicity is also important for other groups that have experienced historic and ongoing discrimination, including Native Americans, Blacks, Asians and Middle Eastern communities, etc..

It is my hope that the Census also pursues further testing of what is lost and/or gained in terms of interrogating inequalities by keeping Hispanic ethnicity and race or racial status as separate questions. In particular, I am optimistic about the strategic partnerships between the Census, OMB and diverse Civil Rights organizations, scholars, researchers and communities working towards creating a more perfect union for all.

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Forward email

Nancy López PhD Want Disaggregated & Granular Race & Ethnicity Data? An Invitation to Intersectionality as Inquiry and Praxis for Interrogating Inequality, Adva [redacted] ributing Resources
Email [redacted] October 1, 2022

Cutting edge, rigorous, interdisciplinary scholarship, research and public engagement for creating a state of the art federal race and ethnicity data infrastructure is paramount for the future of our nation. Below are some of my reflections on the challenges and opportunities:

1. How do you define race and ethnicity? What is your theory of reality about the conceptual basis of race and ethnicity? Are race and ethnicity interchangeable concepts? Are they dependent on familial of distant genetic ancestry, geographical origin, cultural background, a relational social standing in a given place or sociohistorical context, or something else, etc.?
2. Consider the ontological and epistemological difference between disaggregated or granular data and intersectional inquiry and practice that considers the simultaneity of race and ethnicity. For example, one can disaggregate health status, COVID-mortality, housing segregation, employment status, educational attainment or any other social outcome for various groups, including Hispanic origin groups, Asian origin groups, American Indian origin groups, Middle Eastern origin groups, African origin groups, but if we stop there—we may miss an opportunity to investigate if there are different outcomes for people from the same racial, ethnic or nation origin group that may have radically different experiences with the visual and ocular dimension of racialization (Omi and Winant 1995) based on their street race/perceived race--from the emergency room to the voting booth (Jones et al, 2008; Saenz and Morales 2015; López et al., 2017). I ask: Is creating disaggregated and granular data is the same thing as engaging in intersectional knowledge production that considers the simultaneity of self-identified race and street race/perceived race for equity-based policy and distribution of resources? What are the unintended consequences of employing one question to measure self-identified race, ethnicity, origin and street race/perceived race for interrogating experiences of discrimination? What if we took a both/and approach, rather than and either/or approach to data on race and ethnicity, whereby one can self-identify with one or more races but when asked about street race/perceived race, one is asked to mark only one box that best captures how one is racialized in most social circumstances?
3. Consider how skin color is not a proxy for street race/perceived race. For example, President Barack Obama is probably lighter skinned than many East Indians; however, if President Obama were out in public, he would be racialized as street race Black, not street race East Indian. Many Asian Americans who have been targeted for hate crimes, are often light skinned but they are still racialized as street race Asian as skin color is not the only physical characteristic that is ascribed social meanings for racialization (Bonilla-Silva and Glover 2005).
4. Consider your answer to the following question about your own street race: If you were out in public on the street, what race do you think others who do not know you would automatically assume you are based on what you look like? Consider how lived experience and shape your reality of identity. If you believe your street race is racially ambiguous, consider your relational street race as a social standing that in comparison to others that may be subjected to racial stigma

(e.g., racially ambiguous people may be seen as relational closer to people racialized as white, Black, Brown, Asian, etc.) (López et al., 2017; Zuberi 2001).

5. Consider reflecting on the explicit and implicit ontologies/theories of reality about race in your primary/secondary data sets. Are self-identified race, geographic origin, ethnicity, ancestry and nationality assumed to be analytically equivalent to street race/perceived race? What are the unintended consequences of conflating self-identified race with perceived race for equity use? (Zuberi 2001; OMB Guidelines)
6. Invite your team members, communities of practice to engage in intersectionality or the importance of considering the simultaneity of systems of inequality/resistance as inquiry and praxis (reflection and action). Consider discussing the following questions: What are the ways in which existing data sets can be leveraged for intersectional inquiry (e.g., if a given institution/federal agency collects educational attainment, race and gender, could reporting outcomes by intersectional social location yield a more accurate picture of inequities? For example, if we are interested uncovering differences in teacher perceptions within a given group such as Latinx or Asian groups, how could we use intersectionality to assess inequities in teacher perceptions (Irizarry 2015); poverty rates (Hogan 2017) or college graduation (López et al., 2018).

RECOMMENDATIONS

When possible, consider using more than one measure of race as a new gold standard for equity research. Include at least one question on self-identified race where one can mark one or more boxes and later include another question on street race/perceived race where one marks only one box that most closely approximates your relational racial status (See Gravlee and Dressler 2005; Jones et al., 2008). While some may argue that adding an additional question on street race/perceived race is not practical, too expensive or asking about race is racist at worst or may make some people uncomfortable at best, I think about the importance and urgency of creating a more perfect union for all. Measuring and analyzing data that helps us shed light on unequal treatment may help us address and rectify historic and contemporary inequities that undermine the principles of our nation. It is my hope that through rigorous, state of the art race and ethnicity data collection we can build a state of the art data infrastructure for equity use for posterity.

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We are responding to the OSTP RFI as we believe that opening data related to organ procurement organizations offers a powerful use case for OSTP's question on the need to open data. We believe the responses below are relevant to questions 4 - 7.

We write as graduate researchers in the Healthy ML Lab and Wilson Lab at MIT who have been working with Drs. Marzyeh Ghassemi, Ashia Wilson, and Tom Pollard to open data from organ procurement organizations (OPO) and understand how open data and the research it enables can help understand health inequities in the organ procurement process.

We support the response of our colleagues to the February RFI from the Centers for Medicare and Medicaid Services (CMS) on Health and Safety Requirements for Transplant Programs, Organ Procurement Organizations, and End-Stage Renal Disease Facilities.

Through our collaboration with pro-transparency OPOs from around the country and the Federation of American Scientists, we see that opening OPO data is crucial to answering questions about health equity in the organ procurement process.

Publicly available OPO data is critical to understanding how current processes are impacting health equity, and should be required from all OPOs as federal contractors providing a life-and-death service. Open data is critical for the federal government - and the public - to have evidence of effective and equitable service regardless of race/ethnicity or urban/rural status.

Information from open data can help guide next steps that will give communities across the country equal opportunities to be organ donors, and therefore to save lives through organ donation.

Yours sincerely,

Vinith M. Suriyakumar
MIT EECS, CSAIL, LIDS, IMES

Hammaad Adam
MIT IDSS

MIGRATION POLICY INSTITUTE

NATIONAL CENTER ON IMMIGRANT INTEGRATION POLICY

COVER PAGE

Response to Request for Information, Document ID OMB-2022-19007
Equitable Data Engagement and Accountability

Submitted: October 3, 2022

The Migration Policy Institute's National Center on Immigrant Integration Policy is pleased to provide information to the Office of Management and Budget (OMB) in response to its Request for Information (RFI) regarding Equitable Data Engagement and Accountability (87 FR 54269). Our comments include information and recommendations specific to Questions 5 and 7 of the RFI.

The Migration Policy Institute (MPI) is an independent, nonpartisan think tank that seeks to improve immigration and integration policies through authoritative research and analysis, opportunities for learning and dialogue, and the development of new ideas to address complex policy questions. MPI's National Center on Immigrant Integration Policy (NCIIP) seeks to educate the public on the complexity and urgency of issues of immigrant integration and through its research, policy and data analysis efforts promote policies and practices that support the linguistic, economic, and civic integration of immigrants and their children.

Immigrants and their children number 85.7 million persons, or 26 percent of the overall U.S. population. Since 2000, the number of immigrants has grown by over 16.5 million, while the number of children of immigrants has grown by over 13.4 million. Many immigrants face multiple and often compounding barriers to their integration into American society such as limited proficiency in English, low levels of formal education, poverty, and a lack of access to services and information, all of which can also have two-generational effects on the economic mobility of their families. Limited proficient English individuals have the right to meaningful access to all federally funded programs, yet the right to language access remains largely unrealized due to a number of factors including relatively weak enforcement mechanisms and a lack of awareness of the right across LEP communities, government, and the general public. With the U.S. government lacking coordinated research, data collection, consultation, and policy analysis capacities related to integration needs and opportunities, OMB's interest in using equitable data to illuminate opportunities for targeted actions that will result in improved outcomes for underserved communities represents an important opportunity to better serve immigrant communities in public programs, particularly around the issue of language access.

Information provided in response to this RFI draws from NCIIP's research and policy expertise in the areas of early childhood education and care (ECEC), elementary and secondary education, adult education, workforce training, language access, and the governance of integration policy.

For more information, please contact Margie McHugh, NCIIP Director, [redacted] or Jake Hofstetter, Associate Policy Analyst, [redacted]

Question 5: What resources, programs, training, or tools can increase opportunities for community-based organizations to use equitable data to hold government accountable to the American public?

There is a clear need for federal programs to center immigrant and refugee communities in planning for the equitable delivery of government services, particularly in states, regions, and cities with large foreign-born populations. Most federal anti-poverty and education programs aimed at adults were conceived to foster self-sufficiency among the individuals and communities they serve; however, many of the original assumptions and designs of these programs either no longer apply or were not considered in light of the demographic characteristics of the country's growing immigrant population. The multitude of federal programs intended to support or directly lead to full engagement in the workforce overlook the modern reality that a large portion of those in poverty are immigrants and that the vast majority of low-income immigrants are employed. In the case of the country's immigrant population, poverty is likely tied to barriers that individuals face to higher wages and economic mobility such as limited proficiency in English, low levels of formal education, and a lack of legal status.

Despite this persistent challenge for many immigrant communities, government programs are often not recognizing or addressing this issue due to not possessing or not leveraging equitable data. Many government programs fail to use data disaggregated by race, ethnicity, nativity, education level, or English proficiency when assessing service needs, designing their programs, and evaluating their effectiveness. Without collection or consideration of these key data points during policymaking processes, federal programs are not able to adjust their approaches to address the changing nature of those in need of their services and risk perpetuating the use of inappropriate program designs and performance measures that create inequitable access to services.

While many individual program design elements should be considered as part of the government's data equity strategy, addressing language access across all federal programs represents a particularly powerful lever due to its importance in supporting equitable access to government services for immigrant communities as well as the fact that language access represents an established civil rights requirement for federally funded programs. Creating new tools, resources, or programs to develop more specific data around both the languages spoken by communities across the U.S. and their levels of English proficiency could increase opportunities for community-based organizations (CBOs) as well as the public to hold government accountable for their federally-mandated responsibility to provide equitable and meaningful access to public services for individuals who are Limited English Proficient (LEP).

Over 25 million people in the U.S., including 20.9 million immigrants and 4.5 million U.S.-born residents, speak English less than "very well" and are thus considered LEP by the federal government. Although a majority (63 percent) of the LEP population speaks Spanish as their primary language, the remaining 37 percent (or 9.4 million individuals) speak a variety of other languages from around the world, some of which may be relatively rare in the areas they live. Many immigrants also face compounding barriers to their limited proficiency in English which may limit their economic mobility, their level of access to critical social services such as healthcare, the academic success of their children, and their broader integration into American society. For example, roughly one in four or 8.7 million immigrant adults are both LEP and have less than a high school diploma or equivalent, and one in four immigrant adults are low-income and LEP.

Both the Civil Rights Act of 1964 along with subsequent court decisions prohibit discrimination in any federally funded program based an individual's ability to speak English. This requirement means that all federally conducted or funded programs must provide meaningful access to their services for LEP individuals. Not providing equitable delivery of public services to all individuals regardless of their level of proficiency in English can create serious disparities for many communities, particularly immigrants and refugees but also Native Americans and other groups. These disparities become even more stark when considering the range of essential government services such as education, healthcare, and emergency services that entire populations could potentially be denied equitable access to solely on account of not speaking English proficiently. Serious violations of due process and civil rights can also occur if adequate language access is not provided to LEP individuals involved in the criminal justice system or immigration enforcement proceedings.

Despite these civil rights requirements and the risk of serious inequities, federal programs as well as federally supported services managed by state and local governments often fall short of providing meaningful language access to LEP communities. Although some structures exist to monitor language access at the federal level, community-based organizations (CBOs), local advocates, and LEP communities themselves play an important role in holding federal, state, and local governments and agencies accountable in ensuring equitable access to their programs for those who are LEP. Holding these government actors accountable and determining if LEP communities have sufficient access to public programs, however, requires quality data on the languages spoken in specific areas and the level of English proficiency of those speaking languages other than English.

Currently, the public and CBOs can access American Community Survey (ACS) data on both languages spoken in their specific geographic areas as well as the level of English proficiency of the speakers of those languages. This existing data is essential in efforts to evaluate and advocate for language access, but it contains limitations. Most notably ACS data does not provide as granular of data as needed on some language spoken, instead offering overly broad categories such as "Indo-European languages" which is of little use to CBOs and governments working on expanding equitable access to government services for LEP communities. In addition, proposed changes to how ACS data is provided to the public may also eliminate the ability of the public to access any quality data on LEP populations in their areas.[1]

Besides some of the challenges related to the use of ACS data, CBOs and other advocates also lack access to any significant sources of data detailing to what extent federal agencies along with state and local governments are using language services such as interpreting and translation. Without this data, which is generally not collected by any level of government and even if so not published, CBOs and the public lack the ability to compare the need for linguistically accessible based on population data with the rates at which governments, systems, and programs are delivering those services to LEP individuals as they are required to under federal civil rights regulations.

Potential resources, programs, training, or tools to increase opportunities for community-based organizations and the public to use equitable data to hold government accountable around the issue of language access include:

- OMB could further leverage the American Community Survey as a key source of equity-relevant data to aid CBOs in holding government accountable for serving LEP communities. For example,

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[1] IPUMS, "Changes to Census Bureau Data Products," accessed September 30, 2022.

by working with the Census Bureau and publishing the richest data possible for state and local geographies with the languages LEP households speak (data which is already collected in annual ACS surveys), OMB can empower CBOs and the public to monitor efforts by federal agencies as well as state and local government to proactively prepare to serve all LEP communities in their jurisdictions. Access to this data will also enable CBOs and the public to detect significant language groups that are not being equitably served by federally funded programs. This approach will also have to be balanced with ensuring privacy for smaller LEP communities in less densely populated areas, potentially by setting a threshold of number of individuals under which data would not be published.

- Federal agencies could provide additional trainings and tools to empower CBOs and other stakeholders at the state and local level to utilize local sources of data such as public data from their K-12 districts to better estimate the size of their LEP populations and the languages they speak. For example, Washington State was able to use an analysis of K-12 and ACS data to provide more precise estimates on the size and makeup of their LEP communities which in turn was published for review and use.[2] These tools, however, often require additional financial resources as well as statistical expertise that many CBOs may not possess. With more direct step-by-step guidance on how to use local and state sources of data to estimate LEP populations, CBOs could potentially gain access to new troves of data to hold government accountable on equitable access for LEP communities.
- The Digital Equity Working Group should continue to make itself available to hear the perspectives of community groups and other stakeholders, particularly those who can speak to the experiences of LEP individuals in attempting to access government services. Across the country, many legal aid groups and organizations representing or serving ethnic communities such as the AAPI community have spent decades pushing to hold government accountable around the issue of language access and can provide invaluable perspectives on how governments, systems, and programs at the federal, state, and local levels can improve their collection and consideration of data to better address access to their services for LEP individuals. Similarly, state refugee coordinators are aware of problems that language minority groups and speakers of low incidence language face in accessing federally funded services and should be consulted regarding potential data collection and sharing efforts that could improve equity in federal programming.

Question 7: In which agencies, programs, regions, or communities *are there unmet needs, broken processes, or problems related to participation and accountability* that could be remedied through stronger collaborations and transparency around equitable data?

As detailed in the opening of the response to Question 5, there are several larger areas in which the federal government could use data to better promote equitable access to government services for immigrant communities. As also described in the response to Question 5, the federal government requires its own departments as well as state and local agency partners to ensure that meaningful and equitable access to federally funded programs and activities is not limited due to language barriers. This requirement not only addresses a critical equity issue but also upholds central tenets of the Civil Rights Act of 1964. Under the current monitoring structure concerning language access, the Federal

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[2] Christy Hoff and Erica Gardner, "An Innovative Model for Generating Limited English Proficient Population Estimates," *Migration Policy Institute*, January 25, 2022.

Coordination and Compliance Section within the Civil Rights Division of the Department of Justice provides guidance and informational resources for agencies related to their obligation ensure language access while agencies monitor language access within in their own programs. Under this structure, agencies have a great deal of latitude in determining the extent of their efforts on language access. Consequently, planning and implementation efforts are often weak or under resourced while federal monitoring and enforcement of requirements are limited. This particularly true in the collection and use of data related to language access.

Federal programs generally do not require recipients of their funding to collect data on the languages spoken and English proficiency levels of those they serve. Although DOJ guidance suggests recipients and federal programs use population-level data to estimate what LEP populations they should expect to serve, using this data for planning the equitable delivery of services is not a requirement. Similarly, recipients and federal programs are generally not required to collect data on their usage of language services such as interpreting or translations of written materials, and if this data is collected administratively, it is generally not published publicly.

This ongoing gap in data collection means that there are limited ways for any entity outside of government to hold federally funded programs accountable for failing to provide equitable access to LEP communities. Outside of launching formal civil rights investigations, advocates, researchers, and other stakeholders interested in ensuring language access cannot easily determine if government agencies have even considered how to best serve LEP individuals in their service areas let alone planned for it. Without transparency in terms of data on the usage of language services, external stakeholders also cannot know if federally funded programs are using methods, such as the deployment of interpreters and bilingual staff as well as translations of written materials, that would provide evidence of government, systems, and programs providing at least some level of access to LEP communities. In addition to external stakeholders, government actors working to advance language access in their own departments or programs also lack the tools to evaluate and push forward their own efforts.

Addressing these intertwined issues related to transparency and accountability around language access could be addressed by the federal government and agencies through a range of strategies:

- On a broad level, federal agencies in partnership with OMB must consider how equity and data are embedded throughout the cycles of programs. Such efforts will include incorporating equity and the use of meaningfully disaggregated data in efforts to ensure that needs assessments, program designs, grantmaking processes, and the monitoring of services delivered by agencies and recipients are based upon and informed by equity-relevant data. Implemented holistically, data such as this would create a feedback loop whereby federal programs could use population data as well as data on the demographic characteristics of those using federal services to refresh needs assessments or adjust program designs and data collection practices on a regular basis, to ensure that the equitable delivery of government services remains a feature of all federal programs.
- OMB along with federal agencies should consider how to include data related to language access more directly and prominently in both federal grant making processes as well as the distribution of formal funding to states and local recipients. For example, OMB and federal agencies could require states and recipients as well as applicants for federal funding to include data on LEP populations in the areas they are serving and evidence of budgeting for necessary

language services. In addition, OMB should also consider how to create cross-agency guidance on how federal programs can infuse data around language access into funding announcements and the awarding of funding.

- OMB and the Census Bureau, federal agencies, or a cross-agency entity could develop estimates of the size of the LEP population as well as the top languages spoken for recipients of federal funding and federally conducted programs. For example, these actors could publish data for all 50 states, every county in the United States, and a certain number of the largest cities within the country. This data could be relatively easily developed from ACS data and then with the assistance of OMB distributed to federal programs to distribute to their recipients via the grantmaking process or through the distribution of formula funding to state governments. This data would save recipients and states from expending resources to develop their own estimates.
- OMB or a federal agency could pilot better tracking methods related to the usage of language services across a particular federal program or activity. Even beginning at a municipal or state level, a particular federal program could develop a pilot to collect, analyze, and publish data on the use of interpreters and bilingual staff along with the translations of written materials compared against the number of encounters with LEP individuals as well as the size of the catchment area's LEP populations eligible or likely to be served. Such a pilot would provide a model for transparency and accountability around the use of data in ensuring equitable access to government services for LEP communities and could provide a more realistic idea of the level of resources as well as infrastructure needed to scale such an approach to other activities, programs, or agencies.

September 20, 2022

NSTC Subcommittee on Equitable Data
Office of Science and Technology Policy
Eisenhower Executive Office Building
[redacted]
Washington, DC 20504

RE: Comments in Response to FR Document 2022-19007, Request for Information on Equitable Data Engagement and Accountability

Thank you for the opportunity to submit comments regarding the Office of Science and Technology Policy request for information on Equitable Data Engagement and Accountability, published in the Federal Register on September 2, 2022. These comments are jointly submitted by the National Council of Asian Pacific Americans (NCAPA) and AAPI Data.

The National Council of Asian Pacific Americans (NCAPA) is a coalition of 38 national Asian American (AA) and Native Hawaiian and Pacific Islander (NHPI) organizations around the country. Based in Washington D.C., NCAPA serves to represent the interests of the greater AA and NHPI communities, the fastest growing racial group in the nation, and to provide a national voice for Asian American and Native Hawaiian and Pacific Islander issues.

AAPI Data is a nationally recognized publisher of demographic data and policy research on Asian Americans and Pacific Islanders, with hundreds of news mentions in national and local outlets. Based at the University of California, Riverside, our reputation is built on data and research that is accurate, compelling, and timely. In addition to our news impact, community organizations, government agencies, and decisionmakers regularly reach out to us, to better understand key aspects of AAPI communities.

Data equity is a top priority for Asian American, Native Hawaiian, and Pacific Islander (AA and NHPI) communities across nearly every issue area. We are a highly diverse group of communities with over 50 ethnic groups, speaking over 100 languages.[1] However, this diversity is rarely represented in federal data collection, which collects data on our communities in the aggregate, creating severe challenges for racial and ethnic groups within our communities whose urgent needs are obscured in this process. Therefore, increasing the availability of disaggregated data for AA and NHPI communities remains at the core of our data equity advocacy efforts.

As our communities continue to press for disaggregated data, it is increasingly important to engage in other important aspects of data equity such as timeliness, accessibility, human-centered design, community inclusion, and integration of subject-matter expertise and population expertise among community organizations and researchers alike. As NCAPA and AAPI Data outlined in our recent report, *2022 Asian American, Native Hawaiian, and Pacific Islander (AA and NHPI) Roadmap for Data Equity in Federal Agencies*, these recommendations that stem from this "data disaggregation plus" approach will be outlined in this public comment.[2] The report is enclosed with this public comment.

Our recommendations are to:

1) Update the federal minimum standard for data collection across all relevant agencies that expand upon the categories used in the 2020 Census and American Community Survey, to include smaller AA and NHPI populations. This process must include as wide a range of voices from these communities as possible and comprehensive engagement including guidance on how to provide comments and sufficient time to help under-resourced community organizations to properly prepare their input.
2) Ensure the inclusion of community and scientific expert voices in all stages of federal statistical data collection, including its design and development, collection, compilation, processing, analysis, dissemination, and preservation.
3) Include community members and researchers in evaluating and changing data criteria and data systems, particularly for data dissemination and outreach. Data equity can only truly be achieved when all members of the public are able to access and understand the data available from the federal government.
4) Work closely with community groups and researchers to identify case studies and pilot programs specific to AA and NHPI communities that will build on the knowledge base and methodologies to increase data equity and data collection and disaggregation.

Increase Availability of Disaggregated Data By Updating Federal Minimum Standards for Data Collection

In 1997, recognizing the inadequacies of the then-current single aggregate race and ethnicity category of "Asian and Pacific Islander," the OMB separated it into "Asian" and "Native Hawaiian and Other Pacific Islander." The 2020 Census, on the other hand, utilized the evidence-based format of a "Combined Question for Race and Ethnicity with Detailed Checkboxes and Write-in Areas" because Census Bureau's

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[1] https://www.ncapaonline.org/wp-content/uploads/2020/05/NCAPA_PolicyPlatform_2020.pdf

[2] https://aapidata.com/wp-content/uploads/2022/05/AANHPI-DataEquityReport-May-2022.pdf

research demonstrated that this format yielded the most accurate responses. For Asian Americans, the format lists 7 checkboxes (Chinese, Filipino, Asian Indian, Vietnamese, Korean, Japanese, and Other Asian), followed by a write-in section for respondents to enter other Asian identities (e.g. Pakistani, Cambodian, Laotian, and Hmong). For Native Hawaiians and Other Pacific Islanders, the format lists 4 checkboxes (Native Hawaiian, Samoan, Chamorro, and Other Pacific Islander), followed by a write-in section for respondents to enter other NHPI identities (e.g. Tongan, Fijian, and Marshallese).[3]

There are some efforts by specific federal agencies that serve as examples of data disaggregation collection efforts that are already underway: The Health Center Program Uniform Data System (UDS) and Federally Qualified Health Centers may serve as appropriate candidates to house a data disaggregation pilot program as they already collect AA and NHPI subpopulation data on the ground but aggregate data when reporting publicly. UDS currently only reports data for topline Asian, Native Hawaiian, and Other Pacific Islander categories, and does not allow for health centers to report more granular subpopulation data. The Consumer Financial Protection Bureau (CFPB)'s collection of Home Mortgage Disclosure Act (HMDA) data may also serve as an excellent model for federal agencies in implementing disaggregated data practices. HMDA data have included detailed race and ethnicity categories starting with the 2018 data.

Certain other federal agencies, such as the Department of Health and Human Services (HHS), have also gone beyond the minimum standards provided by the OMB and offer an example for what improved data disaggregation and data equity standards currently look like in practice. The HHS's preferred means of collecting race and ethnicity data is self-identification and asking separate questions for ethnicity first and then race. For Asian Americans, the HHS uses 7 categories (Asian Indian, Chinese, Filipino, Japanese, Korean, Vietnamese, and Other Asian). For Native Hawaiians and Other Pacific Islanders, the HHS uses 4 categories (Native Hawaiian, Guamanian or Chamorro, Samoan, and Other Pacific Islander).[4]

However, most agencies and offices, with the exception of the few listed above, do not disaggregate AANHPI data. The current aggregate options are particularly inadequate to capture our communities' needs – disaggregated data across datasets and programs of the various federal agencies is long overdue, and sorely needed in order to to meet the needs of AANHPI communities.

Health

The global COVID-19 pandemic has exposed disparities and unaddressed systematic inequities throughout the country and within our communities, with communities of color frequently bearing the brunt of the virus's health toll. For AA and NHPI communities, COVID-19 is yet another stark reminder that data disaggregation can be a matter of life or death. Aggregate health data does not paint an accurate or complete picture of COVID-19 impacts on AA and NHPI communities. The Centers for Disease Control (CDC), has reported that as of June 17, 2021, Asian Americans had 0.7 times as many COVID-19

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[3] https://www2.census.gov/about/training-workshops/2020/2020-02-19-pop-presentation.pdf

[4] https://aspe.hhs.gov/basic-report/hhs-implementation-guidance-data-collection-standards-race-ethnicity-sex-primary-language-and-disability-status

cases as white Americans and were on par with white Americans in terms of hospitalization and death rates.[5] However, the CDC's public-facing information does not disaggregate Asian American data and does not include data on Native Hawaiians and Pacific Islanders. The COVID-19-Associated Hospitalization Surveillance Network, from where the CDC draws its data on hospitalization rates, furthermore, *aggregates* AA and NHPI data into a single category.[6]

The passage of the Affordable Care Act enabled noticeable gains among Asian Americans in terms of obtaining health insurance. However, while aggregated data suggest that Asian Americans have the lowest uninsured rate of any racial or ethnic group, these numbers do not tell the full picture without disaggregated data.[7] In 2015, of the top 10 highest uninsured groups in the US, 5 are Asian Americans (Pakistanis at 20.9%, Koreans at 20.5%, Cambodians at 18.9%, Vietnamese at 18.5%, Bangladeshis at 18.2%) and 2 are Native Hawaiian and Pacific Islanders (Micronesians at 18.3% and Samoans at 16.7%).[8]

There is urgent need for the CDC and those offices within Health and Human Services (HHS) that have yet to disaggregate AANHPI data to do so.

Education

While aggregate data report that Asian Americans surpass all other racial groups in educational attainment, disaggregated data reveals a much more nuanced picture. Although 50% of Asian Americans in general hold a bachelor's degree, disaggregated data demonstrate that less than 20% of Cambodian, Hmong, Laotian, and Bhutanese groups have even attended college.[9] Among Native Hawaiians and Pacific Islanders, 57.9% of Samoans, 56.8% of Tongans, 53% of Native Hawaiians, and 49.3% of Guamanians or Chamorros have not attended college.[10] Furthermore, Marshallese and Samoan adults are less likely to hold a bachelor's degree than any other racial group.[11] Based on data from 2018, AANAPISIs enroll one out of every 3 AA and NHPI students at four-year institutions and over half of all AA and NHPI students at two-year institutions. Despite this, AANAPISIs are severely underfunded and receive the least funding per capita of all Minority Serving Institutions.[12]

It is therefore critical that the Department of Education collect and release disaggregated data for AANHPI students, in order to facilitate educational equity. Similarly, noting that the threat of violence

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[5] https://www.cdc.gov/coronavirus/2019-ncov/covid-data/investigations-discovery/hospitalization-death-by-race-ethnicity.html

[6] https://www.cdc.gov/coronavirus/2019-ncov/covid-data/covid-net/purpose-methods.html

[7] https://www.commonwealthfund.org/publications/issue-briefs/2020/jul/gap-closed-aca-impact-asian-american-coverage

[8] https://www.searac.org/wp-content/uploads/2018/04/2015_ACA_policy_brief_v13_final.pdf

[9] https://www.pewresearch.org/fact-tank/2017/09/08/key-facts-about-asian-americans/
https://aapidata.com/infographic-education-aa-nhpi/

[10] https://apiascholars.org/wp-content/uploads/2019/12/NHPI_Report.pdf

[11] https://www.advancingjustice-la.org/sites/default/files/A_Community_of_Contrasts_NHPI_US_2014.pdf

[12] https://www.ncapaonline.org/wp-content/uploads/2020/10/NCAPA-AANAPISI-Brief.pdf

and harassment for Asian Americans have seen the largest rise during the COVID-19 pandemic,[13] it is necessary to properly assess its impact on students via the Department of Education's Civil Rights Data Collection (CRDC); additional reports measuring the impact of COVID-19 should be made accessible, similar to ED OCR's recent report, *Education in a Pandemic: The Disparate Impacts of COVID-19 on America's Student*s.

Housing and Economy

Income distribution among Asian Americans is the most unequal out of all racial and ethnic groups; Asian Americans in the 10th percentile make 10.7 times as much as Asian Americans in the 90th percentile.[14] Although the median annual household income of Asian Americans in 2019 was $85,800, this figure included incomes ranging from $44,000 per year for Burmese American households to $110,000 per year for Indian American households.[15] Similarly, among Native Hawaiian and Pacific Islander, the average household incomes for Guamians and Fijians in 2015 were slightly above the US median income average of $56,516, but "Other Micronesians" households made about $30,000 per year.[16]

12.3 percent of Asian Americans live below the federal poverty level but disaggregation shows the wide range masked by this single number, with 6.8 percent of Filipino Americans to 39.4 percent of Burmese Americans living in poverty.[17] NHPI communities experience poverty rates 20% higher than the national average but are often combined with AA groups, obscuring this significant and important difference.[18]

Homeownership among AA and NHPIs also reveals that while as an aggregate group, 58 percent of AA and NHPIs are homeowners, rates of homeownership vary widely with 25 percent of Samoan, 28 percent of Burmese, and 28 percent of Tongan Americans being homeowners, while 62 percent of Filipinos, 62 percent of Chinese Americans, 64 percent of Vietnamese, 64 percent of Japanese, and 68 percent of Taiwanese Americans are homeowners.[19] Among low-to-moderate income AA and NHPI households, 37 percent of Asian households and 22 percent of NHPI households owned homes compared to 53 percent of low-to-moderate income white households.[20]

Aggregated data on economic indicators like homeownership, credit score, and household income are unreliable for adequately identifying AA and NHPI needs. For example, Asian Indian and Chinese

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[13] https://www2.ed.gov/about/offices/list/ocr/docs/20210608-impacts-of-covid19.pdf

[14] https://www.pewresearch.org/social-trends/2018/07/12/income-inequality-in-the-u-s-is-rising-most-rapidly-among-asians/

[15] https://www.pewresearch.org/fact-tank/2021/04/29/key-facts-about-asian-americans/

[16] https://equitablegrowth.org/how-data-disaggregation-matters-for-asian-americans-and-pacific-islanders/

[17] https://www.urban.org/urban-wire/asian-americans-are-falling-through-cracks-data-representation-and-social-services

[18] https://www2.ed.gov/about/inits/list/asian-americans-initiative/what-you-should-know.pdf

[19] https://nationalequityatlas.org/homeownership_korean_ancestry

[20] https://www.nationalcapacd.org/wp-content/uploads/2021/03/NationalCAPACD_HousingCounselingReport_final_031221.pdf

borrowers are often welcomed by banks and offered low interest rates and closing fees, while other AA and NHPI groups such as Native Hawaiians, Filipinos, and Vietnamese often find themselves with higher-cost loans offered by mortgage companies.[21]

There is an urgent need for disaggregated data from all agencies collecting or providing data related to housing, earnings, wages, labor, banking, and other financial services. As mentioned earlier, Consumer Financial Protection Bureau's Home Mortgage Disclosure Act (HMDA) data has made great improvements in this direction and should be considered a model advancement in data equity that can be adopted by other agencies working with consumer financial data.

Immigration

Approximately 57% Asian Americans were born in another country, and Asian Americans are projected to become the nation's largest immigrant group by 2050. Predictably, immigration histories and patterns differ among the many Asian American ethnic groups and also frequently inform communities' unique needs and conditions. For example, only 27% of Japanese Americans are immigrants because significant waves of Japanese immigration occurred in the 19th century as laborers moved to Hawaiian plantations. By contrast, 85% of Bhutanese Americans are foreign born as many arrived recently as refugees.[22] Southeast Asian refugees from Vietnam, Cambodia, and Laos constitute the largest group to be resettled in American history. Immigration is also a complex issue for Pacific Islanders as many NHPIs are U.S. citizens but others are foreign-born or hold different types of immigration statuses. Some Pacific Islanders are considered US nationals because they come from US territories, and others are considered migrants and lawfully present non-citizens from Compact of Free Association (COFA) countries, which includes the Republic of the Marshall Islands (RFI), the Federated States of Micronesia (FSM), and the Republic of Palau. Other Pacific Islanders are foreign nationals and must apply for legal permanent resident status. Others still are undocumented.[23]

Disaggregated data on undocumented AA and NHPI can provide clarity about the needs of these particularly vulnerable immigrants in our communities. Of the estimated 1.7 million undocumented Asian Americans, 26 percent are Indian, 22 percent are Chinese, 14 percent are Filipino, 10 percent are South Korean, 7 percent are Vietnamese, 3 percent are Pakistani, and another disaggregated 17 percent are from other Asian countries.[24] Disaggregated data on undocumented Pacific Islanders is more difficult to find, creating roadblocks for community advocacy, but California data on deported Pacific Islanders can offer a glimpse into the disparities and urgent needs of NHPIs. Between 2001 and 2011, approximately 1,200 NHPI residents were deported from California to the Pacific Islands with approximately 80 percent of the people deported being sent to Fiji. Another 15 percent were deported to Tonga and 4 percent were deported to Samoa.[25]

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[21] https://ncrc.org/mortgage-lending-in-the-asian-american-and-pacific-islander-community/
[22] https://www.pewresearch.org/fact-tank/2021/04/29/key-facts-about-asian-americans/
[23] https://advancingjustice-la.org/sites/default/files/A_Community_Of_Contrasts_NHPI_CA_2014.pdf
[24] https://aapidata.com/undocumented/
[25] https://advancingjustice-la.org/sites/default/files/A_Community_Of_Contrasts_NHPI_CA_2014.pdf

Additionally, examining visa backlogs based on country can reveal which specific AA and NHPI communities are most impacted by waitlists, delays, and backlogs that have plagued our family-based immigration system for years. In FY 2021, immigrants from the Philippines, India, China, Vietnam, Bangladesh, and Pakistan make up the second, third, fourth, fifth, and seventh, and eighth largest numbers of backlogs respectively.[26]

Without disaggregated data on AA and NHPI communities on immigration and documentations status from Department of Homeland Security (DHS) and United States Customs and Immigrations Services (USCIS), these nuances of AANHPI community members immigration histories and related needs go undocumented and unmet.

Language Access

In 2019, 67.8 million people in the U.S. reported speaking a language other than English at home, and more than 25.5 million people—nine percent of the U.S. population—are LEP. Approximately 32 percent of AA and NHPIs in the U.S. are foreign born and more than 6 million AA and more than 100,000 NHPIs are limited English proficient. The federal government has recognized the importance of language access for LEP individuals. Federal law and regulations, including Title IV of the Civil Rights Act of 1964, Section 1557 of the Affordable Care Act, and Executive Order 13166 issued in 2000, establish civil rights obligations for the government to provide language access protections for LEP persons. The Stafford Act requires FEMA to "identify in coordination with State and local governments, population groups with limited English proficiency and take into account such groups in planning for an emergency or major disaster." The HHS Office of Minority Health created National Standards for Culturally and Linguistically Appropriate Services in Health Care as a guide for health care providers; and of the 14 standards, there are four that relate directly to language access.

These standards should be applied, where practicable, across the federal government, including language access in efforts to advance data equity for AANHPI communities. NCAPA recommends that all resources and materials developed by government agencies are translated into at least the 19 languages identified in the FEMA Language Access Plan. Data collection, analysis, and report should additionally include preferred language in addition to disaggregating by race and ethnicity.

Include Community Voices in Data Equity Process

To ensure the inclusion of community and scientific expert voices in all stages of federal statistical data collection, we will highlight some best practices and current challenges that can be addressed.

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[26] https://travel.state.gov/content/dam/visas/Statistics/Immigrant-Statistics/WaitingList/WaitingListItem_2020_vF.pdf

Create Advisory Committees and Stakeholder Engagement

The Census Bureau has created a number of institutional structures that create and support the ongoing engagement of community and scientific expertise. The Census Scientific Advisory Committee and National Advisory Committee provide a formal and regular process for external stakeholders to engage with Census Bureau staff around all Census Bureau data collection and processing efforts.[27] A similar structure for data equity and at other federal statistical agencies would help to build trust and familiarity among community organizations, researchers, and federal statistical agencies.

The Census Bureau also has programs that create opportunities for federal agency statistical staff and end users to interact on a regular basis. Examples include the Census Information Center,[28] State Data Center,[29] and Federal-State Cooperative for Population Estimates[30] programs at the Census Bureau. These programs provide the Census Bureau and stakeholders opportunities to learn about each others' work and to find areas to cooperate to make the Census Bureau data products more responsive to external data needs. We particularly single out the Census Information Center (CIC) network and encourage the Census Bureau to expand the network to include more geographic and demographic coverage. The CIC network aims to promote the use of Census Bureau data products and services among underserved communities, such as communities of color, rural communities, senior citizens, and children. There are currently 10 Asian American-serving CICs and one Native Hawaiian-serving CIC. The CICs provide vital feedback on Census data products and tools and provide examples of how Census Bureau data is used to help the communities they serve. The CICs also promote data accessibility and training to their communities.

Provide Sufficient Time and Support for Stakeholder Input

An additional advantage of the Census Bureau's stakeholder outreach is that the engagement gives external stakeholders the expertise of communicating with the Census Bureau including learning about the internal jargon and processes, so that comments and feedback that are provided can be most effective.

Without this level of pre-existing knowledge, public comment periods, like the 30-day comment period for this RFI, are often not sufficient to enable deep engagement with underserved community organizations. Most AA and NHPI community organizations are under-resourced and staff time is at a premium. Placing the burden on community organizations to come up with best practices and examples of successful engagement in isolation and with minimal guidance will inevitably result in low levels of engagement. For this RFI in particular, we recommend that if OSTP has not received significant input from AA and NHPI community organizations that a follow-up RFI accompanied by a substantial outreach effort to engage community organizations. By providing substantial guidance and with sufficient lead-time for community organizations to marshal their limited staff resources, OSTP will gain deeper

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[27] https://www.census.gov/about/cac.html
[28] https://www.census.gov/about/partners/cic.html
[29] https://www.census.gov/about/partners/sdc.html
[30] https://www.census.gov/programs-surveys/popest/about/fscpe.html

insights into the challenges of data equity for not just AA and NHPI communities but other under-resourced communities as well. Future data equity related public comment opportunities must include robust outreach and engagement plans that include detailed guidance and timelines, opportunities to interact with federal agencies, and sufficient time for community organizations to respond. For maximum impact, these outreach efforts should take place well-before the formal comment period begins and should be part of an ongoing engagement process, for example, through advisory committees or stakeholder engagement programs outlined in the previous section.

A successful outreach example was supplied by an NCAPA member, EPIC, a community organization that advances social justice by engaging Native Hawaiian & Pacific Islanders in culture-centered advocacy, leadership development, and research. The Office of Educational Technology at the Department of Education developed guidance to help local and state leaders reach and achieve digital equity in education. The office reached out to EPIC and other Native and Indigenous groups for feedback on their guidance. With EPIC, the office hosted a call with the wider Pacific Islander community to identify gaps and challenges that the community faces and to listen and follow the lead of the community. Ultimately, the guidance recommended continuous engagement of the community both to build awareness among federal agency staff on Pacific Islander concerns and also to build visibility of the federal government and its activities among community members. Through these interactions, the Office of Educational Technology was able to leverage trusted messengers to support their work.

Include AA and NHPI Issues in Equity Action Plans

In January 2021, Executive Order 13985, Advancing Racial Equity and Support for Underserved Communities through the Federal Government, tasked federal agencies with creating Equity Action Plans to assess department policies and identify barriers to equity and solutions for mitigating gaps. In an internal analysis of select federal agencies' Equity Action Plans, we found that several identified barriers that prevented closing gaps in equity. These barriers included a lack of equity assessments; lack of data or lack of analysis of collected data; infrastructure gaps, including in technology, personnel, and tools; and important policies that hinder data collection. Below, we provide a summary of some of these challenges as identified by the select agencies (*see Table 1*).

Table 1. EO 13985-Related data equity challenges identified by select federal agencies

Federal agency	**Challenges identified**
Department of Education	Onerous data requirements of FAFSA applications[31]
Department of Homeland Security	Lack of data to make conclusions about disparities[32]
Department of Labor	Missing and incomplete demographic data in Workforce Training

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[31] https://www2.ed.gov/documents/equity/2022-equity-plan.pdf

[32] https://assets.performance.gov/cx/equity-action-plans/2022/EO%2013985_DHS_Equity%20Action%20Plan_2022.pdf

	data; insufficient analysis of existing Workforce Training data[33]
Department of Treasury	Challenges in imputing demographic data; algorithmic bias[34]
Health and Human Services	Lack of data to identify inequities, including for Medicare and Medicaid[35]
Small Business Administration	Over-reliance on credit score (a barrier for small business owners with lack of banking/debt history); LenderMatch (matching platform for underserved borrowers) and Community Advantage Pilot (loan program to meet credit and technical assistance needs of underserved small businesses) do not optimize marketplace to match Community Financial Institutions (CFIs) and underserved borrowers[36]
Social Security Administration	Policy change in 1987 causing sharp decline in race and ethnicity demographic data[37]

It is worth noting that some agencies in our analysis did not engage in discussing challenges in these plans, including the Consumer Financial Protection Bureau (CFPB), Department of Commerce, Department of Justice, and the Federal Emergency Management Agency (FEMA).

To close data equity gaps, federal agencies across the board need to carry out equity assessments in full and develop plans that are accountable by including detailed short- and long-term indicators that can be tracked by the agencies and reported upon. Further, plans should aim to improve data quality by closing structural gaps in data collection and analysis, by aiming to disaggregate data.

Increase Data Dissemination and Outreach for AA and NHPI Communities

The last mile of data dissemination and outreach remains a significant hurdle to achieving data equity. For equitable data to be more accessible to members of the public, federal agencies must develop tools and training for data dissemination that are user-friendly and easy to access. For example, the new improvements to the Data.census.gov website, which is the primary data dissemination tool for Census

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[33] https://www.dol.gov/sites/dolgov/files/general/equity/DOL-Equity-Action-Plan.pdf

[34] https://assets.performance.gov/cx/equity-action-plans/2022/EO%2013985_USDT_Equity%20Action%20Plan_2022.pdf

[35] https://www.hhs.gov/sites/default/files/hhs-equity-action-plan.pdf

[36] https://assets.performance.gov/cx/equity-action-plans/2022/EO%2013985_SBA_Equity%20Action%20Plan_2022.pdf

[37] https://assets.performance.gov/cx/equity-action-plans/2022/EO%2013985_SSA_Equity%20Action%20Plan_2022.pdf

Bureau data products, have brought some user-friendly and natural language search features when searching for geography-based data. For example, a natural language search on Data.Census.Gov for poverty in Texas will call up both a highlighted statistic on the poverty rate for Texas and quick access to a user-friendly profile of key statistics for Texas based on ACS data. However, these improvements need to be extended to race and ethnicity data, particularly for underserved and smaller AA and NHPI communities. Current natural language searches on Data.Census.Gov for race and ethnicity data lead to a list of tables for users to go through on their own to find the exact data they are looking for and often the first few tables listed are not the relevant tables. This last mile of delivery of data remains a major challenge to increasing accessibility of data for underserved populations and the burden is falling on under-resourced community organizations or to academic institutions to fill the gap. An example of a community-led response to this last mile gap is AAPI Data's work to provide tools to access government data at aapidata.com.

Use Case Studies and Pilot Programs to Expand Availability of Data for AA and NHPI Communities

Case studies and pilot programs have been an important pathway to expanding the data available for AA and NHPI communities, particularly around the issue of health disparities. These case studies and pilot program demonstrate the importance and viability of various methods to increase availability of disaggregated data including increasing sample size, aggregating across multiple years, oversampling of specific small populations of interest in survey design, combining data sets across agencies, and using of administrative data and survey data to construct disaggregated datasets. Advocacy by NCAPA member organizations, including the Asian & Pacific Islander American Health Forum, resulted in the NCHS to oversample Asian Americans in both the National Health Interview Survey (NHIS) and the National Health and Nutrition Examination Survey (NHANES), the NHIS since 2006 and the NHANES since 2011.[38] For Native Hawaiians and Pacific Islanders, the National Center for Health Statistics (NCHS) conducted the first ever Native Hawaiian and Pacific Islander National Health Interview Survey (NHPI NHIS), a survey of 3,000 NHPI households using the 2014 NHIS survey instrument. Public use data from this survey was released in March 2017.[39]

Conclusion

Aggregated data masks wide disparities and urgent needs within Asian American, Native Hawaiian, and Pacific Islander communities that go undiscovered, unheard, and unchecked. A lack of disaggregated data across federal agencies presents an insurmountable barrier for advancing equity, including data equity, for AANHPI communities. We strongly urge OSTP to make data disaggregation a top priority for achieving data equity for AANHPI communities, and begin the necessary work of disaggregation across federal agencies.

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[38] Ponce, N.A., Bautista, R., Sondik, E.J., Rice, D., Bau, I., Ro, M.J., & Tseng, W. (2015). Championing Partnerships for Data Equity. Journal of Health Care for the Poor and Underserved, 26(2), 6-15. https://doi.org/10.1353/hpu.2015.0058

[39] National Center for Health Statistics. (2022). Native Hawaiian and Pacific Islander (NHPI) National Health Interview Survey (NHIS). Retrieved from https://www.cdc.gov/nchs/nhis/nhpi.html

In closing, we would also like to register the dismay and frustration of our communities in being asked to provide the same evidence for data equity for our communities as we have for several decades. It is concerning that the federal government needs further convincing of the pressing need for disaggregated data for AANHPI communities in almost all areas. In particular, placing the onus to provide evidence upon communities, when the federal government commands limitless resources in comparison, further exacerbates the inequity our communities face as our organizations struggle to meet our communities' needs with already constrained resources.

Sincerely,

Gregg Orton
National Director
National Council of Asian Pacific Americans

Karthick Ramakrishnan
Founder and Director
AAPI Data

Attached: Report - *2022 Asian American, Native Hawaiian, and Pacific Islander (AA and NHPI) Roadmap for Data Equity in Federal Agencies*

www.ncqa.org

October 3, 2022

Denice Ross
U.S. Chief Data Scientist
Office of Science and Technology Policy
Attn: NSTC Subcommittee on Equitable Data,
[redacted]logy Policy, Eisenhower Executive Office Building

Washington, DC 20504

RE: Engagement and Accountability RFI

Dear Ms. Ross,

The National Committee for Quality Assurance (NCQA) thanks you for the opportunity to provide feedback on advancing equity through community data partnerships. NCQA is a private, 501(c)(3) not-for-profit, independent organization dedicated to improving health care quality through our Accreditation and measurement programs. We are a national leader in quality oversight and a pioneer in quality measurement. Our mission to improve the quality of health for all Americans, with an intentional focus on health equity, propels our daily work. Leveraging our strengths as a trusted third party, we are committed to helping organizations move toward a more equitable health care system through accountability, transparency and measurement.

We are pleased to provide comments on the opportunities for data to support the federal government's efforts to identify inequitable health outcomes and establish systems for measuring health-related social needs.

#3: What policies, resources, programs, training, or other tools can facilitate increased data sharing between different levels of government (Tribal, territorial, local, State, or Federal) around equitable data?

The COVID-19 Pandemic has exacerbated our nation's health inequities, and our ability to capture the magnitude of disparities has been hindered by incomplete or missing data. We encourage the Administration and HHS to establish policies to leverage national Accreditation standards to enhance health care organizations' capacity to collect data to identify and address health inequities. Accreditation standards help align data collection across the health care system, including social/ community services, with a common set of consensus-driven principles.

During the pandemic, policymakers have turned to NCQA's Health Equity Accreditation to establish requirements to close inequitable gaps in health outcomes by focusing on data collection and core quality-improvement standards. NCQA's Health Equity Accreditation is a rebranding and update to our Multicultural Health Care Distinction program, in place for over a decade and based on the HHS Office of Minority Health's CLAS Standards.

To date, 154 organizations have either achieved Health Equity Accreditation or have a survey scheduled. Ten states are leveraging Accreditation in their Medicaid or state-based Marketplace/ Exchange programs, and CMS is considering the benefits of Health Equity Accreditation for all Marketplace/Exchange plans in recent health equity RFIs. While the program's historic use has been with insurers, we designed the latest update to ensure that ACOs, FQHCs and health systems/hospitals are able to work with their partners on aligned standards.

Additionally, after a successful pilot with nine leading health organizations, including two health systems, this month we launched Health Equity Accreditation Plus. This program emphasizes the role of community and cross-sector partnerships in improving and addressing health-related social needs, and includes standards for data collection, data sharing and building and strengthening cross-sector partnerships.

Important to note, Health Equity Accreditation and Health Equity Accreditation Plus purposefully align with existing industry efforts, like the Gravity Project, and with federal efforts, like USCDI, to standardize data for a more equitable American health care system. Accreditation provides an additional level of adoption and oversight that is not built into existing federal programs.

#6: What policies, resources, programs, training, or tools can make equitable data more accessible and useable for members of the public.

Advancing equity requires an appropriate level of data that can be disaggregated by demographic, geographic and other variables to enable insights on health disparities. For over 30 years, HEDIS® has been one of health care's most widely used performance improvement tools—over 200 million people are enrolled in health plans that report HEDIS results. States and the federal government use HEDIS for public transparency and accountability of contracted health plan and provider partners.

Better transparency of performance by race and ethnicity will illuminate and aid investigation of care gaps and inequitable care. As of August, NCQA has released 13 measures that can be stratified reliably by race and ethnicity (NCQA Updates & Releases New Quality Measures for HEDIS 2023 with a Focus on Health Equity). This effort will ensure that federal programs can benchmark and make apples-to-apples comparisons based on organizational performance for reducing unequal gaps in health outcomes.

We recently released the *Social Need Screening and Intervention* measure, which assesses screening for unmet food, housing and transportation needs, and includes referral to intervention after a positive screen. Because these data can be captured in a variety of electronic data sources (e.g., EMRs, resource referral platforms, case management systems), this measure is specified for Electronic Clinical Data System (ECDS) reporting. To reduce burden, state and federal agencies should evaluate available tools for aligning data collection and sharing, and the federal government should encourage alignment with national data standards. For example, NCQA supports aligning measures and data elements with the Gravity Project's work to standardize interoperable social needs data.

We thank the Administration for its commitment to rectifying historic health inequities. Our team remains dedicated to supporting federal, state and local communities to ensure that every American has a health system that meets their cultural, language and social needs.

As the OSTP considers policies across the federal government, we invite you to visit our Health Equity Resource Hub, which contains publications relevant to your exploration, including our recent reports, Federal Action Is Needed to Improve Race and Ethnicity Data in Health Programs and Improving Data on Race and Ethnicity: A Roadmap to Measure and Advance Health Equity.

Thank you again for the opportunity to comment. We welcome the chance to discuss our experience and findings, and we look forward to working with the Biden-Harris Administration to build a more equitable, sustainable and responsible American health care system. If y [redacted] ions, please [redacted], NCQA Assistant Vice President of Federal Affairs, a [redacted] r at

Sincerely,

[redacted]

Margaret E. O'Kane
President

NFHA NATIONAL FAIR HOUSING ALLIANCE

October 3, 2022

NSTC Subcommittee on Equitable Data
Office of Science and Technology Policy
Eisenhower Executive Office Building
[redacted]
Washington, DC 20504

RE: Document No. 2022-19007, Engagement and Accountability RFI

To Whom It May Concern:

These comments are submitted on behalf of the National Fair Housing Alliance (NFHA) in response to the RFI issued by the Office of Science and Technology Policy seeking input on how Federal agencies can better support collaboration with other levels of government, civil society, and the research community around the production and use of equitable data and to support Federal equitable data efforts described in the Executive Order on Advancing Racial Equity and Support for Underserved Communities Through the Federal Government (E.O. 13985), including the *Vision for Equitable Data* issued to the President in April 2022.

Founded in 1988 and headquartered in Washington, D.C., NFHA leads the fair housing movement. NFHA works to eliminate housing discrimination and ensure equitable housing opportunity for all people and communities through its education and outreach, member services, public policy, advocacy, housing and community development, tech equity, enforcement, and consulting and compliance programs.

NFHA fully supports the policy laid out in E.O. 13985, which acknowledges the racial inequities that pervade our society, many created and perpetuated by policies of the federal government itself. Importantly, the EO also recognizes the benefits that will accrue to all from expanding access to opportunity for historically underserved and marginalized communities, affording everyone the opportunity to reach their full potential. Indeed, this goal aligns with the provisions of the 1968 Fair Housing Act, which require all federal agencies to administer their programs and activities relating to housing and urban development in a manner affirmatively to further fair housing.[1] This means federal agencies must ensure that their programs do not discriminate based on race, national origin, or other protected characteristics. Equally important, it requires agencies to design and implement their programs to eliminate the barriers and disparities caused by residential segregation, enabling equitable access to resources and amenities for all communities.

Our comments respond to questions 3-7 in the RFI.

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[1] See 42 U.S.C. §3608(d) and (e).

Fair housing is central to racial equity

Because where a person lives determines, to a very large degree, the resources and opportunities available to them and their ability to achieve their full potential, fair access to housing must be a central component of any effort to advance racial equity and support underserved communities. NFHA's comments focus on several key areas where the federal government can play an important role in facilitating access to the data needed to advance racial equity.

For most families in this country, homeownership is a key to the middle class, providing housing and financial stability and a means to build wealth. Access to homeownership is one area where inequitable policies and practices have led to significant racial and ethnic disparities. The Federal Reserve Bank of St. Louis reports that, as of the second quarter of 2022, the homeownership rate for White households is 74.6 percent, compared to 48.3 percent for Hispanic or Latino households and 45.3 percent for Black households. The Black-White homeownership gap is as big as it was before the Fair Housing Act was passed and even 1890. These disparities in homeownership rates are a driving factor in our country's racial wealth gap: for every $1 in wealth held by the median White household, the median Hispanic or Latino household has $0.21 in wealth, and the median Black household has only $0.12.[2] Disparities in homeownership continue to drive wealth disparities, and federal housing policies during the pandemic contributed to the widening of the Black-White wealth gap by $20 trillion.[3]

Data needed to monitor mortgage loan performance and foreclosure activity

These stark disparities underscore the importance of rooting out discrimination in our housing markets and preventing the loss of homeownership among households of color. We cannot accomplish these goals without data to monitor trends in the marketplace and intervene early to resolve any that are problematic. The Home Mortgage Disclosure Act (HMDA) provides public access to reasonably comprehensive data, at a geographically granular level (census tract) and including demographic information (race, gender, national origin) on applicants for mortgage loans. It has been a fundamental tool for spotting potential discrimination in the mortgage origination process.

However, we lack similarly granular and comprehensive data, widely available to the public and policymakers alike, to spot problematic trends in the mortgage market post-origination, understand their impact on homeowners and communities of color, and develop effective interventions to advance racial equity.

The foreclosure crisis spurred by the boom in abusive subprime mortgage lending targeted at communities of color over a decade ago provided a wake-up call about the critical need for such data on mortgage performance and foreclosures. Although advocates called attention early on to the alarming rise in delinquencies and foreclosures in communities of color, in the absence of comprehensive data to document the problem, policy makers failed to intervene in a timely manner and the problem spiraled,

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[2] Kent, Ana Hernandez and Lowell Rickets, "Wealth Gaps Between White, Black and Hispanic Families in 2019," On the Economy Blog, Federal Reserve Bank of St. Louis, January 5, 2021. Available at https://www.stlouisfed.org/on-the-economy/2021/january/wealth-gaps-white-black-hispanic-families-2019.

[3] Shawn Donnan, Ann Choi, Hannah Levitt and Christopher Cannon, "Wells Fargo Rejected Half Its Black Applicants in Mortgage Refinancing Boom," Bloomberg, (March 11, 2022), https://www.bloomberg.com/graphics/2022-wellsfargo-black-home-loan-refinancing/.

ultimately throwing our entire economy into crisis. To avoid a repeat of this problem, Congress included a provision in the 2010 Dodd-Frank Act requiring the new Consumer Financial Protection Bureau (CFPB) to create a national database of mortgage delinquencies and foreclosures and make that available to the public.[4]

Early in the COVID-19 pandemic it became evident that it, too, would cause significant disruption in the mortgage market, as the shut-down of the economy meant the disruption of people's incomes and ability to make their mortgage payments. These impacts fell disproportionately on people of color, as did the health impacts of COVID-19, raising concerns that they would bear the brunt of foreclosures and loss of homeownership. To stave off another foreclosure crisis, as part of the American Rescue Plan Act, Congress allocated nearly $10 billion for the Homeowner Assistance Fund (HAF), enabling states, tribes and territories to set up programs designed to enable homeowners to avoid foreclosure and displacement. HAF is administered at the federal level by the U.S. Department of the Treasury.

HAF includes a provision targeting some of the funds to people deemed to be "socially disadvantaged individuals." This provision is intended to ensure that people of color, who had been hit hardest by the foreclosure crisis more than a decade ago and suffered disproportionate losses, have equitable access to foreclosure prevention resources in the COVID pandemic. To implement this provision, and to ensure that HAF is designed and administered in a manner that advances racial equity, state program administrators and the Treasury Department needed access to geographically and demographically granular data on people who were falling behind on their mortgages. Unfortunately, such data were not readily available.

Researchers at the Urban Institute have identified nine major sources of information on mortgage performance. Some of these cover large portions of the mortgage market, others are more limited. Most are reported at either the state or national level and lack the kind of detailed geographic data that would have been most helpful to state administrators designing their HAF programs. None of the large datasets that cover most of the market include the demographic data needed to advance racial equity, and most are available only at the state or national level and lack the necessary geographic granularity. The majority are available only for a fee and some are not available at all to parties outside the federal government. This latter category includes the National Mortgage Database, a joint project undertaken by the CFPB and FHFA, in part, to fulfill the mandate from the Dodd-Frank Act to create a publicly available, national database of mortgage delinquencies and foreclosures.

The result is that state HAF administrators have lacked the data they need to ensure that their programs are designed in a manner that would best advance racial equity and against which they can measure program performance. Similarly, the Treasury Department lacks the data needed to carry out its oversight responsibilities effectively, and the public lacks the contextual data that would give them confidence that their state HAF programs are functioning in a racially equitable fashion.

Recommendation: NFHA recommends that the federal agencies that insure or guarantee mortgages, and those agencies with oversight responsibilities for various segments of the mortgage market, work together to create a comprehensive, national database on mortgage performance, including delinquencies, forbearances, loss mitigation solutions and foreclosures. Like the HMDA data, this

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[4] Dodd-Frank Wall Street Reform and Consumer Protection Act, Public Law 11-203, Section 1447, DEFAULT AND FORECLOSURE DATABASE. July 21, 2010.

database should be readily available to the public, include critical demographic information about borrowers, and be reported at a geographically granular level, preferably census tract.

Data needed to evaluate borrowers' ability to repay mortgage loans

The Truth in Lending Act's Ability to Repay/Qualified Mortgage loan rule (ATR/QM Rule) (12 C.F.R. Part 1026) requires a creditor to make a reasonable, good faith determination of a consumer's ability to repay a residential mortgage loan according to its terms. Loans that meet the ATR/QM's rules for qualified mortgages (QMs) obtain certain protections from liability. Over time, different proposals have been issued to determine the definition of a QM. For example, at one point, the QM threshold was based on a debt-to-income ratio of 43 percent.

Recommendation: We recommend that the CFPB be required to disclose mortgage data (including GSE data) related to loans with debt-to-income ratios above 43 percent, which borrowers of color utilize to access mortgage credit. These data are needed to help shape any future discussions on QM and ensure equitable access for underserved borrowers of color.

Data needed to detect algorithmic bias

Lenders often use data-driven automated underwriting systems (AUS[5]) to predict loan delinquency risks conditioned on borrowers' data known at the time of loan application when making a mortgage underwriting decision. Traditional fair lending testing of underwriting decisions focuses on the output of an AUS to decide if the system causes an adverse impact on any protected classes under the Fair Housing Act (FHA) and, if so, whether there are less discriminative alternatives (LDA) that could be adopted. Whereas evaluation of snapshot outcomes from an AUS could help assess the potential of the system to perpetuate statistical and/or practical significant approval disparities which may suggest violation of a fair lending law, access to the performance data of loans approved by the AUS or any other underwriting system is a critical step for equitable access to mortgage credit and other lending opportunities for consumers.

Access to performance data will help researchers and advocacy groups conduct analyses[6] to 1) assess consumer risks, not just model risks, associated with lenders' (automated) underwriting systems; 2) evaluate the bias in how lenders label good and bad loans; 3) make reasonable judgments on how lenders' portfolio risks are distributed across classes protected under the Fair Housing Act; and 4) propose viable less discriminatory alternatives (LDA) that can reverse the persistent racial homeownership wealth gaps and mitigate nascent risks associated with emerging algorithmic solutions in the lending market.

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[5] AUS or Automated Underwriting System is often used to mean automated systems like the GSEs' Desktop Underwriter (DUP), Loan Prospector (LP), or Technology Open To Approved Lenders (TOTAL). However, in this comment letter AUS has a broader scope that includes any automated system driven by business rules, business logic, data, statistical models, machine learning models, or artificial intelligence (AI).

[6] Joshua White et al., "Qualified residential mortgage: background data analysis on credit risk retention," August 2013. Accessed at https://www.sec.gov/dera/staff-papers/white-papers/qrm-analysis-02-2015.pdf.

Privacy concerns have been expressed when researchers, advocacy groups, and the public request access to granular data to support the Federal Government's equitable housing data efforts. These concerns are reasonable[7] in a world of big data with sophisticated algorithms and hardware innovations that can join forces to undermine consumer privacy and enterprise security.[8] However, there are modern software and hardware solutions that embody fundamental data protection principles that minimize personal data use, maximize data security, and empower data analysts to obtain insights from datasets without compromising personal privacy. Privacy-enhancing technologies[9] (PETs) like homomorphic encryption (HE), secure multiparty computation (SMPC), trusted execution environments (TEE), or robust synthetic data solutions can be used to eliminate data silos among various levels of government and foster productive collaboration among government agencies, civil society, and the research community without compromising consumer privacy and data security.

Recommendations: We ask the CFPB to release performance data on mortgage loans. In addition, we ask federal banking regulators, including the CFPB, to explore the privacy protection technologies described above so that they can provide access to data required to remove data-related impediments to homeownership and other economic opportunities.

Data needed to monitor appraisal practices

Evidence continues to mount that the real property appraisal and valuation system in this nation is broken. Reports from the Biden Administration's Property Appraisal and Valuation Equity (PAVE) Task Force, the National Fair Housing Alliance Consortium, and the Philadelphia Home Appraisal Bias Task Force documented systemic challenges that drive appraisal bias. For example, these reports highlight that Fannie Mae and Freddie Mac (collectively, the "Government-Sponsored Enterprises" or "GSEs"), FHFA, HUD/FHA, VA, and USDA each maintain a comprehensive database of historical appraisal reports, but those databases generally are not available to government agencies or the public for research, supervision, enforcement, or compliance management.

Recommendations: Consistent with the findings and recommendations in these reports, we recommend that the Administration act quickly to:

- Develop data-sharing arrangements among all relevant government agencies and pursue joint strategies to make the appraisal-related data more widely available, foster federal research, and better enable enforcement related to appraisal bias. (PAVE Action Item #5.1)
- Establish the public sharing of a subset of historical appraisal data, including that collected by the GSEs, HUD/FHA, VA, and USDA. (PAVE Research Effort #4)
- Provide public support for Congressional action to amend HMDA to provide the CFPB with the rulemaking authority to require mortgage lenders to provide valuation data, to develop a

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[7] Anthony Yezer, "Personal privacy of HMDA in a world of big data," October 2017. Accessed at https://www2.gwu.edu/~iiep/assets/docs/papers/2017WP/YezerIIEP2017-21.pdf.

[8] Nicolas Papernot, Patrick McDaniel, Arunesh Sinha, and Michael P. Wellman. " SoK: Security and Privacy in Machine Learning." In 2018 IEEE European Symposium on Security and Privacy. Accessed at https://oaklandsok.github.io/papers/papernot2018.pdf.

[9] See the following blog post that reviews tools and techniques that use computational methods to implement privacy methodologies, https://www.priv.gc.ca/en/opc-actions-and-decisions/research/explore-privacy-research/2017/pet_201711/

publicly available database (which may need to suppress/modify certain fields for privacy), and to create a Trusted Researcher Program. “Trusted Researchers” would have access to the fields not provided to the general public due to privacy concerns.

Data needed to coordinate across programs and agencies

Consistent with E.O. 13985, the Biden-Harris administration is launching a number of efforts to incorporate racial equity considerations into federal programs with significant impacts on communities in the U.S. These programs span areas including housing, transportation, the environment and many others, and involve a host of federal agencies. For example, the Department of Transportation recently entered into a memorandum of understanding with the Departments of Housing and Urban Development and Energy and the Environmental Protection Agency to work together to ensure the development of a transportation system that is both equitable and decarbonized. DOT and HUD are partnering on the Thriving Communities Initiative to improve and foster thriving communities through transportation initiatives. HUD is in the process of promulgating a new Affirmatively Furthering Fair Housing regulation, which will direct its grantees to assess their programs to ensure they are not discriminatory and take action to eliminate any barriers to fair housing for members of protected classes. This analysis should include consideration of the access to transportation, educational, environmental, employment and other resources available to residents in different neighborhoods.

Many of these programs affect the same communities, and people living in those communities do not experience these as distinct issues. Rather, these different programs and issues impact various aspects of life in their neighborhoods: the quality of the air they breathe, the availability of safe, affordable housing that is suitable for their families, and the transportation systems upon which they rely. In other words, considerations of racial equity are intersectional. Each issue affects other issues, and their collective impact may be greater than the sum of their individual impacts. They cannot be addressed through siloed analyses and programs but must be understood as a whole.

This kind of holistic understanding depends on the availability of data for each of its elements; data that can be compared, compiled, cross-tabulated and overlaid to understand the totality of the impacts on a particular place. This can best be accomplished when data are compiled and reported in a consistent format, so that data from one federal agency is compatible with data from other agencies.

Recommendations:

NFHA recommends that OMB explore ways to standardize data reporting throughout all federal agencies to enhance compatible of federal datasets. To further enhance racial equity efforts, whenever possible, data should be reported at the census tract level. This would enable analyses at scales ranging from the neighborhood level up through the state or national level. In addition, data should be made available in formats that are readily accessible to and usable by people with limited resources, not just researchers with sophisticated tools available. It should also be accompanied by tools to enable data visualization, including mapping and other visualization techniques.

Conclusion

NFHA commends the Biden-Harris administration for its efforts to advance racial equity and its recognition of the important role that data plays in those efforts. We appreciate the opportunity to respond to this RFI and would be happy to answer any questions or discuss our recommendations further. For additional information, please contact Debby Goldberg [redacted] Maureen Yap (MYa [redacted] ing.org), or Dr. Michael Akinwumi [redacted]

October 3, 2022

NSTC Subcommittee on Equitable Data
Office of Science and Technology Policy
Eisenhower Executive Office Building
[redacted]
Washington, DC 20504
Submitted electronically through www.regulations.gov

Re: Docket No. 2022-19007 Request for Information; Equitable Data Engagement and Accountability

The following comments are submitted on behalf of the National Housing Law Project (NHLP), the National Consumer Law Center (NCLC) and the undersigned organizations regarding the White House Office of Science and Technology Policy (OSTP) request, on behalf of the Subcommittee on Equitable Data of the National Science and Technology Council, for information about how Federal agencies can better support collaboration with other levels of government, civil society, and the research community regarding the production and use of equitable data.

The National Housing Law Project (NHLP) is a legal advocacy center focused on increasing, preserving, and improving affordable housing; expanding and enforcing rights of low-income residents and homeowners; and increasing housing opportunities for underserved communities.

Since 1969, the nonprofit National Consumer Law Center® (NCLC®) has worked for consumer justice and economic security for low-income and other disadvantaged people in the U.S. through its expertise in policy analysis and advocacy, publications, litigation, expert witness services, and training.

Thank you for your engagement of the public on the production and use of equitable data.

1. What are *examples of successful collaborations* involving equitable data between the Federal government and (a) Tribal, territorial, local, and State governments, or (b) local communities?

The American Rescue Plan Act provides up to $9.961 billion for states, the District of Columbia, U.S. territories, Tribes or Tribal entities, and the Department of Hawaiian Home Lands to provide relief for our country's most vulnerable homeowners. The program, the Homeowners Assistance Fund (HAF), involves several aspects of data collection, analysis and reporting that have resulted in some successful federal/local collaboration, but HAF also starkly highlights the lack of federal data on the mortgage market, the atomized nature of existing data, and the reliance of government entities on the private sector for such information.

The statute required the Department of the Treasury to make allocations for each state, the District of Columbia, and Puerto Rico based on homeowner need, determined by reference to (1) the average number of unemployed individuals; and (2) the number of mortgagors with mortgage payments that are more than 30 days past due or mortgages in foreclosure.[1] In order to determine the number of delinquencies, Treasury had to rely upon data provided by the Mortgage Bankers Association and Haver Analytics.[2]

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[1] U.S. Department of Treasury, Homeowner Assistance Fund, Data and Methodology for State and Territory Allocations

[2] Id.

Treasury then required eligible entities[3] ("entities") to submit a plan for their use of HAF funding describing in detail the needs of homeowners in their jurisdictions.[4] More specifically, entities needed to provide data about financial hardships of targeted homeowners and socially disadvantaged individuals, including data on mortgage delinquencies, defaults, foreclosures, post-foreclosure evictions, and the loss of utilities or home energy services, containing trends over time disaggregated by demographic categories and geographic areas.[5] The plans were also required to include a review of quantitative data or studies regarding which demographic segments in the respective jurisdictions have historically experienced discrimination in the housing or housing finance market.

The submitted plans relied upon a wide range of data sources including other governmental entities.[6] The majority of entities[7] relied upon the Federal Reserve Bank of Atlanta's Mortgage Analytics and Performance Dashboard (MAPD) to estimate forbearance rates.[8] The data set went into effect in March 2021, but received its final update in December 2021.

Many entities had to rely upon data from non-profit organizations,[9] researchers,[10] academic institutions,[11] mortgage servicers,[12] industry groups,[13] or private data providers,[14] or conduct their own surveys. For example, Alaska Housing Finance Corporation conducts the Survey of Lenders to collect and compile mortgage data as well as the Alaska Housing Unit Survey, a survey of local governments and housing agencies.[15]

For information on demographic segments in their jurisdictions have historically experienced discrimination in the housing or housing finance market, entities relied on a wide array of studies rather than any particular data source. While these efforts allowed the entities to develop their programs, they also revealed glaring gaps in the government's collection and provision of relevant data.

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[3] Eligible entity means (1) a State, (2) the Department of Hawaiian Home Lands, (3) each Indian Tribe (or, if applicable, the tribally designated housing entity of an Indian Tribe) that was eligible for a grant under Title I of the Native American Housing Assistance and Self Determination Act of 1996 (25 U.S.C. 4111 et seq.) for fiscal year 2020, and (4) any Indian Tribe that opted out of receiving a grant allocation under the Native American Housing Block Grants program formula in fiscal year 2020.

[4] U.S. Department of the Treasury, Homeowner Assistance Fund Guidance

[5] Id. at 8.

[6] Centers for Disease Control and Prevention Indexes, Congressional Research Service, Consumer Financial Protection Bureau, U.S. Treasury, U.S. Census Bureau American Community Survey and Participant Analysis, U.S. Bureau of the Census' Household Pulse surveys, U.S. Bureau of Labor Statistics, U.S. Department of Housing and Urban Development, National Mortgage Database

[7] California, Colorado, Connecticut, Delaware, Georgia, Idaho.

[8] MAPD utilizes Black Knight's McDash Flash daily mortgage performance data to identify forbearance as well as Equifax and Black Knight McDash Credit Risk Insight Mortgage Servicing data set to estimate forbearance rates. This dataset comprises roughly two-thirds of mortgage markets and includes flags for delinquency and forbearance. Data is filtered for active loans for owner-occupied residences that are secured by first liens. Zip codes with under 50 active loans are excluded from the sample.

[9] Center for Heirs Property Preservation, National Fair Housing Alliance (NFHA) 2020 Fair Housing Trends Report, National Consumer Law Center and NeighborWorks.

[10] Policy Institute, Social Science Research Council, Urban Institute.

[11] Owner Vulnerability Index (OVI) by UCLA; census microdata from the University of Minnesota; Joint Centers for Housing Studies of Harvard University; University of Pennsylvania, Department of City Planning.

[12] AFV Loan Portfolio, Banco Popular, CELINK, Champion, Dovenmuchle Mortgage, Inc., First Bank of Virgin Islands, Freedom Mortgage, Oriental Bank, ServiSolution, US Bank, Wells Fargo.

[13] National Association of Realtors Research Group, National Council of State Housing Agencies, Mortgage Bankers Association, State Mortgage Market Profiles, Federal Financial Institutions Examinations Council, National Reverse Mortgage Lenders Association.

[14] CoreLogic MarketTrends, Data Dynamics, First American Data Tree, Lereta Tax Services, MAPD, The Warren Group.

[15] HAF Grantee Plan - HAFP-0197 - Alaska Housing Finance Corporation p. 4

2. Among examples of existing Federal collaborations with (a) Tribal, territorial, local, and State governments or (b) local communities involving equitable data, *what lessons or best practices have been learned from such collaborations*?

The submitted HAF plans demonstrate the needs of entities, the federal government, and the public, to have more and better data. Many entities were unable to obtain quantitative data from authorities charged with assessing and collecting property taxes,[16] which was essential for determining how best to serve eligible homeowners at risk of displacement. Colorado had to consult with stakeholders in focus groups and in a survey.[17] Many states, including Kentucky, had to gather the raw data of delinquent property taxes.[18] South Carolina tried to do the same but could get responses from only 41 out of 46 counties and Michigan obtained delinquency data from only 64 of 83 counties.[19] New York determined that property tax foreclosure data was not collected or compiled centrally, and data available varied greatly by county.[20]

Entities also had difficulties obtaining data on reverse mortgages[21] and contracts for deed,[22] which directly impacted program design. For example, the Arkansas HAF Plan excluded reverse mortgages and contracts for deed stating it would "assess the need for any exclusions and propose a modification to program types if data becomes available indicating significant needs in excluded programs."[23] Reverse mortgage data is challenging to obtain and is often not included in the private data sources because reverse mortgages accounts are not furnished to credit reporting agencies. Kentucky chose to exclude land contracts or contracts for deeds in its HAF program stating it would be a "great challenge to document past due/arrearages and could lead to fraud."[24]

Data challenges identified by entities included homeowner association fee delinquencies[25] as well as data on manufactured housing loans.[26] Due to the lower barrier for entry to ownership of manufactured homes compared to site-built homes, chattel loans for manufactured homes are disproportionately used by Black, Indigenous, people of color, and lower income home buyers. The demographics of manufactured home ownership and those who experienced negative economic impacts have significant overlap and are much less likely than traditional mortgages to be refinanced.[27] Yet, Vermont had to rely on a 2011 academic survey of nine mobile home parks to assess its homeowners' needs.[28]

In addition to the challenges obtaining these specific data points, the data collection process highlighted the glaring lack of public data on mortgage performance and demographics. The lack of data

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[16] Alabama, Colorado, Hawaii, Louisiana, Massachusetts, Minnesota (sample), Montana, Nevada, New Hampshire, Oregon (sample), Pennsylvania, Rhode Island, South Carolina (sample), South Carolina, South Dakota, Tennessee, Texas, Virgin Islands, Virginia, Washington, West Virginia, Wyoming.

[17] HAF Grantee Plan - HAFP-0081-State of Colorado p. 4

[18] HAF Grantee Plan - HAFP-0062-Kentucky Housing Authority

[19] HSF Grantee Plan - HAFP-0111-SC State Housing Finance and Development Authority p. 3, HAF Grantee Plan - HAFP-0075-State of Michigan Department of Treasury p. 3.

[20] HAF Grantee Plan – HAFP-0066-New York State p. 3.

[21] Alabama, Arkansas, Vermont.

[22] Arkansas, Hawaii.

[23] HAF Grantee Plan - HAFP-0066-New York State p. 11

[24] Kentucky, supra note 18.

[25] Colorado, Minnesota, Texas.

[26] Arizona, Idaho, Iowa, Louisiana, Montana, North Carolina, Vermont, Wyoming.

[27] HAF Grantee Plan - HAFP=0040-Agency of Commerce and Community Development

[28] Baker, Hamshaw & Beach, Journal of Rural and Community Development 6, 2 (2011) 53-70. Virginia relied upon VA DOT Manufactured Homes, Locality, July 2021

undermined efforts to assess loss risks presented by the COVID national emergency and to develop policies that could serve homeowners and communities most vulnerable to foreclosure.

As part of their HAF plan submission, each entity was able to identify what ongoing data was most needed and the most cited request was monthly data on loan delinquency.[29] The many sources of mortgage data currently available, private and federal, offer a varied range of information, making it difficult to put together a comprehensive picture of the problems facing homeowners.[30] First, some data is only available for purchase, limiting access. Other data is difficult to access, organize, and analyze. Mortgage performance and borrower demographic data is largely absent from freely available data sources, making an assessment of disparate impact and specific challenges faced by homeowners of color difficult to accomplish.

Regulators and policymakers, along with the public, need to know the particularities of mortgage challenges faced by homeowners of color to better stem the tide of foreclosures and address the racial homeownership and wealth gaps. However, most publicly available data sources do not include any demographic information on borrowers, making it impossible to assess the extent of the problem and the special efforts needed to prevent avoidable foreclosures in communities of color. As widely documented, Black and Latinx communities were hardest hit by the foreclosure crisis of a decade ago, and have been disproportionately impacted by the COVID-19 pandemic, both with regard to physical health and economic stability.

The lack of uniform reporting requirements affects data quality as well. For example, though mortgage delinquencies rose sharply, servicers reported markedly different delinquency statistics, in part due to differences in defining and classifying mortgages in forbearance. Wells Fargo, which counts loans in forbearance as delinquent, reported a delinquency rate *eight times* higher than Chase, which does not count loans in forbearance toward the reported delinquency rate.[31] Other sources of data, such as the Census Household Pulse Survey, make no distinction between mortgages that are delinquent and not in a forbearance plan and those in forbearance (although it does provide demographic insights based on a randomly sampled survey of consumers, the kind of information that is sorely lacking as described below). There is also very limited public data about the nature of post-forbearance "solutions" homeowners have accepted. Without consistent, more comprehensive loan-level reporting it is difficult to determine how many borrowers are accessing forbearance and the adequacy of loss mitigation options available to them.

In some cases, data collected by the government is not shared publicly or at the loan level, such as, it appears, much of the data collected on GSE loan performance. Further, while the National Mortgage Database created by Dodd-Frank provides some information, it is only a sample and lacks certain critical information. FHA's Neighborhood Watch data does provide helpful insights into FHA loan performance. However, the data is refreshed each month, making it difficult to track trends, and it lacks detail on what types of loss mitigation offers homeowners receive or analysis of what trends are

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[29] Alaska, Arizona, Arkansas, District of Columbia, Georgia, Idaho, Iowa, Louisiana, Maine, Massachusetts, Montana, Minnesota, Missouri, Montana, Nebraska, Nevada, New Mexico, North Carolina, Oklahoma, Pennsylvania, Puerto Rico, South Carolina, South Dakota, Texas, Utah, Vermont, and Wyoming. Maryland entered into a MOU with its state division of financial regulation to obtain real time data on Notices of Intent to Foreclose. See HAF Grantee Plan – HAFP-0034 p. 4.

[30] HAF Grantee Plan - HAFP-0096 - Texas Department of Housing and Community Affairs, p. 4 "Due to challenges posed by a lack of data compatibility among various sources and the difficulty locating reliable data for non-traditional mortgage loans in Texas (outside the traditional channels of FHA, VA, USDA-RD, Freddie Mac, and Fannie Mae), assumptions were made." Maryland HAF Grantee Plan – HAFP-0034: "DCHD retained the services of a consultant to perform a multi-variant data analysis."

[31] Brandon Ivey, "Delinquency Trends Far From Uniform Among Servicers, Loan Types," *Inside Mortgage Finance* (Aug. 20, 2020).

developing. Data is also limited or unavailable on sales of non-performing loans (limited) or reperforming loans (unavailable) by FHFA and FHA.

3. What resources, programs, training, or other tools *can facilitate increased data sharing between different levels of government (Tribal, territorial, local, State, or Federal) related to equitable data*?

There are many government sources of mortgage data, including those described below. The Consumer Financial Protection Bureau ("CFPB") should combine data, add additional collection and reporting, and provide comprehensive loan-level mortgage performance data that can be linked to HMDA and be made available in the aggregate to the public and at the loan level for government analysis and to researchers along the lines of how social security data is used for research and closely monitored for security and privacy.

HMDA Data Publication: This federal database is freely accessible and offers detailed data on individual loans from 2017 to the present. Loans are reported both by institution and nationwide by borrower characteristics. This database focuses on loan applications and origination. Some borrower demographic data is included. Furthermore, HMDA data files are difficult to work with.

The National Mortgage Database is a random sample of mortgages in the US tracking the credit scores, mortgage performance, and non-mortgage credit performance of sample borrowers, including household demographic data and borrower income.

The Census Household Pulse Survey began April 23, 2020 and provides a weekly report on a sample size of thousands of households, reporting mortgage status by race, income, and education. It does not distinguish between mortgages in forbearance and not in forbearance.

The FHFA Foreclosure Prevention & Refinance Report, released quarterly, reports foreclosure prevention actions, forbearance plans, loan modifications, refinances, delinquencies, and foreclosures. Delinquency rates are reported by state.

Making Home Affordable reported HAMP data and other loan modifications by servicer, by state, by year, by metropolitan statistical area, but provides no demographic data. The project is now closed; the latest report is from 2017, but some HAMP performance data is still updated by servicers.[32]

The OCC Mortgage Metrics Report provides quarterly data on mortgage performance, foreclosures, and modifications, as well as a "borrower risk category." Some data is available by state, but no demographic data is included. Unlike the OCC reports provided a decade ago, the current reports lack details about how loss mitigation is working.

The Mortgage Analytics and Performance Dashboard ("MAPD"), maintained by the Federal Reserve Bank of Atlanta, was updated monthly and used a servicer data set developed in part by Black Knight. Forbearance and delinquency rates were tracked by state, county, and zip code. No other borrower information is available and it has not been updated since December 2021.

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[32] Troubled Assets Relief Program.

However, most discussions of mortgage performance rely on private sector data, including a significant amount of analysis published by agencies such as the Federal Reserve Bank of Philadelphia.[33] The government needs to collect, analyze and publish its own data.

4. What resources, programs, training, or other tools *can expand opportunities for historically underrepresented scholars and research institutions to access and use equitable data across levels of government*?

Many of the HAF plans relied upon academic studies to determine homeowner needs and develop their program plans. In fact, Colorado stated it would be helpful to have academics study the efficacy of programs funded through HAF.[34]

Without access to free data sources, academics must purchase data from private entities. For example, Hawaii is collaborating with the University of Hawaii Economic Research Organization (UHERO) to analyze data for implementation and subsequent updates to the state's HAF plan. However, UHERO had to contract with Black Knight to receive high-frequency microdata on mortgage delinquencies and forbearance. Purchasing this data is costly.[35] Until the federal government collects its own comprehensive mortgage performance data, as it does under HMDA, these problems will remain.

5. What resources, programs, training, or tools *can increase opportunities for community-based organizations to use equitable data to hold government accountable to the American public*?

The public availability of mortgage market data is too limited. Available data, primarily generated in aggregate data tables produced by private industry, provides certain key metrics about mortgage performance but leaves many unanswered questions about who is facing the greatest challenges and the nature of the problems they face. As discussed further below, the federal government, through the CFPB, must collect, analyze and publish comprehensive, timely data on mortgage/chattel loan/property tax performance, including foreclosure status and loss mitigation options, at a sufficiently granular geographic level and with important demographic data included.

In the context of HAF, without a robust data set, entities had to consolidate variables from the above-described data sets into a single iterative index to align with program goals and eligibility criteria.[36] For example, California combined MAPD, Notices of Default, and other court records from pay-to-use datasets, all of which needed to be updated regularly, with Census Tract income information to determine potential eligibility for the program.[37] The full extent of the challenges facing homeowners is obscured both by missing data and by differences in how metrics are used and defined in data collection.

6. What resources, programs, training, or tools *can make equitable data more accessible and useable* for members of the public?

See previous response.

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[33] Relies on Black Knight Data

[34] https://home.treasury.gov/system/files/136/HAFP-0081-Colorado-GranteePlan.pdf page 8

[35] One private data provider charges $36,000 per year to purchase foreclosure and neighborhood data for one state, quote on file at National Housing Law Project.

[36] https://home.treasury.gov/system/files/136/HAFP-0108-California-Submitted-Plan-Narrative.pdf page 12

[37] https://home.treasury.gov/system/files/136/HAFP-0108-California-Submitted-Plan-Narrative.pdf at 15.

7. In which agencies, programs, regions, or communities *are there unmet needs, broken processes, or problems related to participation and accountability* that could be remedied through stronger collaborations and transparency around equitable data?

The CFPB should collect loan-level data and provide aggregate reporting free to the public regarding market-wide mortgage performance and loss mitigation, including demographic data and property location, to better monitor developments, develop policies and identify impacts on homeowners. Loan-level data with protections for individual privacy should also be publicly available to allow researchers to engage in further examination. Data published by the private sector is helpful but incomplete and does not provide universal access to key information.

The CFPB should work with federal banking and housing regulators and the Government Sponsored Enterprises to conduct and make public fair lending analyses related to the availability of loss mitigation and studies to better understand demographic differences in mortgage performance. In-depth analysis is needed of how policies affect populations and localities, including immigrant borrowers and homeowners with limited English proficiency, as well as Black, Latinx, Asian and Indigenous communities.

Policies must respond to data findings to ensure hard-hit communities and homeowners can increase their access to sustainable homeownership and exercise all available options for loss mitigation. Regulators also would be able to use this data to step up oversight of the mortgage market and to improve protections for homeowners and communities. Over a decade after the Great Recession's foreclosure crisis and as COVID hardships for homeowners linger, quality data on key aspects of mortgage performance is still unavailable to the public, keeping shrouded key questions about the loss mitigation system and impacts in communities of color.

Thank you for your consideration of our comments and recommendations. We look forward to working with OSTP and are happy to further discussion our suggestions. Please contact Stacey Tutt [redacted] should you wish to clarify our position on these important issues.

Respectfully submitted:

National Housing Law Project
National Consumer Law Center
Americans for Financial Reform Education Fund
Consumer Action
Consumer Credit and Budget Counseling, Inc. d/b/a National Foundation for Debt Management
Jacksonville Area Legal Aid, Inc.
SeniorLAW Center
Woodstock Institute

NNAAC
NATIONAL NETWORK FOR
ARAB AMERICAN COMMUNITIES

www.nnaac.org

October 3, 2022

Office of Science and Technology Policy
Attn: Public Comments

Re: Request for Information; Equitable Data Engagement and Accountability Engagement and Accountability RFI

Dear Ms. Ross,

On behalf of the National Network for Arab American Communities (NNAAC), a consortium of 30 community-based organizations across 13 states, I am pleased to submit this comment regarding the Vision for Equitable Data (VED).

“Equitable data are those that allow for rigorous assessment of the extent to which government programs and policies yield consistently fair, just, and impartial treatment of *all* individuals. Equitable data illuminate opportunities for targeted actions that will result in demonstrably improved outcomes for underserved communities [emphasis mine],” begins the VED report. The first component listed in the VED document is disaggregation of data. Though there have been steps at local and state levels—including in health care and education—to remedy the federal government’s lack of data disaggregation, the MENA community is functionally erased in federal data collection. The group, listed as White on the US Census and across federal data collection forms, is not represented in federally conducted or supported data collection and research activities, as well as federal programs intended to address underserved communities.

Without a MENA category, we are significantly limited in our ability to assess the needs in our communities and provide relief. It is worth briefly considering the source of this exclusion. The Office of Management and Budget (OMB) coordinates the federal statistical system, which comprises a set of principal statistical agencies which either conduct or support data collection activities across all levels of government, civil society, and the research community. The OMB coordinates statistical activity through a set of Statistical Policy Directives. Statistical Policy Directive Number 15 (SPD No. 15) concerns the minimum standards for data collection on racial and ethnic groups for all institutions across government, civil society, and the research community. According to the latest guidance, data on MENA Americans is aggregated into and disarticulated by the White reference category. SPD No. 15 disarticulates the MENA community. To the extent that federal agencies rely upon data collected through the standards set forth in SPD No.15 to design programs for underserved communities, MENA Americans are limited in their access to such programs.

Without data to indicate the needs of MENA Americans, agency officials are ill-equipped to incorporate an understanding of MENA communities into the design of federal programs that alleviate culture or linguistic barriers to access of appropriate, high-quality, effective, and appropriate health care services. The same is true of MENA community access to programs targeted at specific risk behaviors or chronic health conditions, which tend to implicate individuals with similar cultural backgrounds and migratory histories. In these ways, MENA exclusion is felt in the statutory guidelines for federal programs, which determine availability of and eligibility for federally conducted and supported programs.

Through the data conducted through the American Community Survey, the Census Bureau produces data that provides a significantly representative account of the quality of life and well-being indicators for MENA Americans. MENA Americans face higher levels of poverty, are significantly more likely to have limited English proficiency, are less likely to have a high school degree, and are almost four times as likely to not have insurance than non-Arab Whites.[1] Further, private research suggests MENA residents face lower life expectancies and higher rates of cancer, hypertension, diabetes, and mental health disorders than non-Arab Whites.[2]

To alleviate these problems and truly move toward health equity, MENA Americans must become part of the data collection efforts. Congress imposes no limit on the authority of agencies to collect information on additional groups not articulated in SPD No.15, where doing so makes for better policy. In fact, the *Foundations for Evidence-Based Policymaking Act* authorizes the Department of Health and Human Services (HHS) Data Council to submit on an annual basis a list of the "data the [HHS] intends to collect, use, or acquire to facilitate the use of evidence in policymaking."

As it is established in the request for information posting, "[e]quitable data can illuminate opportunities for targeted actions that will result in demonstrably improved outcomes for underserved communities." Having no data, research, or statutory recognition as either an underserved community or racial and ethnic minority group, MENA Americans are excluded from available pathways to improved well-being and quality of life. NNAAC submits these comments as potential ways for the Office of Science and Technology Policy, to collaborate on inclusion of the MENA community.

Within the RFI is a series of questions. Here, I will respond to inquiries three, four, and five.

3. What resources, programs, training, or other tools can facilitate increased data sharing between different levels of government related to equitable data?

A good example of successful data sharing is with the Center for Disease Control's Environmental Justice Index. This tool has information on how the data is collected and analyzed, as well as an interactive map that shows specific information per Census tract. Public health departments rely heavily on this information to address environmental health issues. If this information cannot identify MENA populations, then the MENA populations served through the NNAAC network suffer from a limited access to representation in federally conducted or supported programs intended to address environmental justice concerns. The same holds true for other programs and initiatives which rely upon demographic data that does not disaggregate. Additionally, the Department of Housing and Urban Development's Public Housing Dashboard and Low-Income Housing Tax Credit Dataset provide in-depth and intuitive information on demographic information. To provide meaningful and accessible information to the public, we must fully establish demographic categories—including data on the MENA group—and be able to reconcile these categories with Census information.

4. What resources, programs, training, or other tools can expand opportunities for historically underrepresented scholars and research institutions to access and use equitable data across levels of government?

Currently, there is no government-sponsored research or data on the MENA community at the federal level. Although states, such as Illinois and California, have taken steps toward equitable collection, truly meaningful data would require a top-down approach. The Arab Community Center for Economic and Social Services (ACCESS), the nation's largest Arab American nonprofit, hosts a body of private research. This research capacity, however, has its limitations. First, it is often outdated. A large portion of the research was conducted 10 to 20 years ago, creating a gap in current knowledge and trends. Second, much of this research took place in hyper-specific areas: we do not have any data on MENA residents nationally. Finally, much of this information is simply on Arab Americans instead of MENA Americans. Though Arab Americans make up most MENA residents, it is not a one-to-one comparison. To truly address a community in virtue of their cultural and linguistic affinities, which corresponds with inclusion within the federal programs' authorizing statutes, data on MENA Americans must be aggregated, analyzed, and visualized in federally conducted or supported data collection activities. Opportunities for research communities and civil society organizations to utilize federal grants and data products in areas where enclaves of MENA communities reside would allow for more sustainable and scalable approach to MENA inclusion under the current OMB standards.

5. What resources, programs, training, or tools can increase opportunities for community-based organizations to use equitable data to hold government accountable to the American public?

Opportunities include supporting platforms and collaborative partnerships that allow the public to easily find meaningful data about the well-being of their communities and the services that are available to them. The Census Bureau's Community Resilience Estimates is a good example of this. To improve accountability and credibility with the American people, the government must provide tools that enable communities to not only visualize data but also track the government's progress toward equitable outcome. Section five of President Biden's "Executive Order On Advancing Racial Equity and Support for Underserved Communities Through the Federal Government" focuses on equity assessment, but there is no approach to providing any data to the public that can demonstrate the government's progress in increasing equity.

For questions, contact Adam Beddawi at [redacted]

Respectfully submitted,

NNAAC
NATIONAL NETWORK FOR
ARAB AMERICAN COMMUNITIES

www.nnaac.org

Adam Beddawi
Federal Policy Manager

Abstract

With support from the Improving Undergraduate STEM Education: Hispanic-Serving Institutions (HSI Program), this conference project entitled, *"HSI Intersectionality Community of Practice for Student Success (HSI-ICPSS),"* will bring together 25 HSIs for a year-long community of practice through a virtual conference series. Institutions of higher education generally define underserved student populations using one-dimensional metrics, such as first-generation college status, PELL recipient, race and gender. Yet, research shows that reporting higher education outcomes by one dimension of inequality, whether race alone, gender alone or class alone, is insufficient for documenting and eliminating inequities. *One thing is clear*: Intersectionality or attention to the co-constitution of race, gender, class, and other axes of inequality *as both analytically distinct and simultaneous* systems of oppression/resistance in a given sociohistorical context is a powerful tool for making inequities visible and helping institutions of higher education create effective actions for advancing undergraduate student success. Yet, the power of intersectionality for system-level equity transformations has not been brought to scale for catalyzing enduring and system-wide equity transformations in equity metrics and distribution of resources in higher education. We will convene participating HSIs for four half-day conferences. Key stakeholders, including faculty, staff and other leaders with expertise in equity and inclusion and undergraduate success initiatives focused on undergraduate STEM student success will be invited. A key goal of the virtual conference series is to share state of the art scholarship and policy on the use of intersectionality in higher education and the transformative potential of intersectionality as inquiry and praxis for equity metrics and developing effective strategies for advancing student success. This will lead to new inquiry and effective equity-focused actions that illuminate intersectional inequities (e.g., outcome metrics such as odds of graduation in STEM for first generation-college Latinx men, women and others, grew up in a households where no parent/guardian earned a four-year year degree compared to their continuing generation counterparts, etc.). To cultivate communities of practice, each participating HSI will create:

1. Data Policy Brief (1-2 pages) outlining institutional consensus values, current data collection and analytical strategies and alternatives that center intersectionality inquiry for equity impact.
2. Action Plan (1-2 pages) describing their theory of change, stakeholder engagement, anticipated roadblocks, as well as practical solutions in their intersectional community of practice.
3. Communication Strategy (1-2 pages) outlining updates to websites and other social media (e.g., twitter, blogs, university-wide institutional equity reports on admissions, retention, graduation, including undergraduate STEM degrees etc.)

Each of these products will be posted on the website for The Institute for the Study of “Race” & Social Justice (race.unm.edu) and archived in the UNM digital repository, tagged under the following subjects: “Hispanic Serving Institutions (HSIs),” “Intersectionality,” “Equity,” “Higher Education,” “Student Success,” “Metrics.” The UNM Digital Repository is free and accessible to anyone with internet access. Our long-term goal is to build capacity for intersectionality as inquiry and praxis as a new gold standard in higher education equity metrics for distribution of resources.

NATIVE
FARM BILL
COALITION

October 3, 2022

Denise Ross
U.S. Chief Data Scientist
White House Office of Science and Technology Policy

Executive Office of the President
Eisenhower Executive Office Building
[redacted]
Washington, D.C. 20504

Dear Chief Data Scientist Ross,

On behalf of the Native Farm Bill Coalition, an organization of over 270 member Tribes, intertribal/tribal organizations, and allies representing over 80,000+ Native food producers across Indian Country, we are submitting responses to the Subcommittee on Equitable Data of the National Science and Technology Council's requests on how Federal agencies can better support collaboration with other levels of government, civil society, and the research community around the production and use of equitable data.

Tribal peoples and their governments are often the least represented in traditional American information and data gathering practices, resulting in undue harm and policy shortfalls due to a lack of adequate and timely information. We have identified several problem areas and suggested remedies below.

<u>1. What are *examples of successful collaborations* involving equitable data between the Federal government and (a) Tribal, territorial, local, and State governments, or (b) local communities?</u>

The absence of accurate data about American Indians and Alaska Native (AI/AN) peoples continues to be a barrier to clear federal understanding of the gaps in opportunities, programs, and services in Indian Country, and as a result, there are few examples of such successful collaborations between federal entities and Tribal governments or communities. While there is still a lot of work to be done, there are examples of positive steps taken towards obtaining equitable data.

In response to a recommendation that originated from the Secretary of Agriculture's Advisory Committee on Agriculture Statistics for the 2002 census, the National Agricultural Statistics Service (NASS) implemented the following activities for the 2017 Census of Agriculture:

- Obtained mailing lists from organizations likely to contain names and addresses of American Indian and Alaska Native farm and ranch producers;
- Conducted pre-census promotion activities that targeted American Indian and Alaska Native farm and ranch producers;
- Worked with community-based organizations to promote the 2017 Census of Agriculture to their members.

Specifically, NASS worked directly with the Intertribal Agriculture Council (IAC), a national Native-led intertribal organization providing direct service to Native food producers across Indian Country. This direct partnership with a trusted Indian Country partner yielded significant results in terms of increased counts of Native producers in this critical dataset at USDA.

It's also important to note that the 2002 recommendation that spurred this change would not have happened had that NASS advisory council not included Native representation on the board. Without Native leadership and representation at all levels of federal service, from political appointments to career staff to service on federal advisory bodies, there will continue to be gaps in equitable partnership between Tribal governments and communities and the federal actors that generate datasets.

2. Among examples of existing Federal collaborations with (a) Tribal, territorial, local, and State governments or (b) local communities involving equitable data, *what lessons or best practices have been learned from such collaborations?*

Survey fatigue is very real when it comes to studies being done on and in Indian Country. Outside researchers leading the way to obtaining data about Native communities comes across not as collaboration, but as exploitation and does not lead to best collection of data. There needs to be a paradigm shift in studying or obtaining information about Indian Country. This shift should reflect some, if not all, of the following steps identified in a recent webinar for SNAP-Ed outlining the Role of Racial Equity in SNAP-Ed:

- Provide a clear explanation of how data is being collected and used
- Make space for community driven concerns
- Provide appropriate incentives to encourage participation
- Develop "Data Use Agreements"
- Engage community facilitators

The use of pre-consultation "framing papers" is a best practice that aligns with the steps identified in this SNAP-Ed webinar. Framing papers focus the consultation process–a process that should always occur when there could be an impact to Tribal communities–and enable Tribal Leadership to prepare the necessary information needed for the meeting. To the extent allowable by law, agencies should also share materials about pending decisions with Tribal leaders in advance, as well as requiring agency personnel empowered to change policy to be at the table, so that the time and energy of both tribal leaders and federal officials are used effectively.

Federal actors need to recognize that obtaining true and honest data comes from meaningful dialogue and consultation with Tribal Nations in order to have comprehensive information on a topic.

3. What resources, programs, training, or other tools *can facilitate increased data sharing between different levels of government (Tribal, territorial, local, State, or Federal) related to equitable data?*

The effectiveness of training or research tools depends not only on the tools themselves, but also on the way the tools are administered. Outside of offering more Native-led training sessions, all USDA agencies and employees need training on how to fulfill the requirements of government-to-government consultation. This training should include both a cultural competency component and general training on the federal trust responsibility. The Office of Tribal Relations should lead on that training, and it should be required for all USDA employees who will attend consultations or work with Tribal Nations. If OTR does not have the capacity to deliver the training, Native-led organizations that have established and trusted relationships with Tribal communities could be contracted.

The differences between Western research methodologies and Indigenous methodologies should not be underestimated. The path towards obtaining equitable data from Indian Country requires an investment in time and resources that cannot be achieved by simply asking Tribal members to fill out a survey; much less, aggregating American Indian and Alaska Native populations into an "other" category to address smaller sample sizes.

A concerted effort to create a sense of community, emphasize individual stories, and utilize cultural ways of imparting knowledge must be at the core of surveying Indian Country. USDA should support researchers from Native-led organizations and Tribal governments and engage Native communities in design, planning, and implementation of data collection. Anything less will likely fail to build the trust necessary to obtaining comprehensive and accurate information.

4. What resources, programs, training, or other tools *can expand opportunities for historically underrepresented scholars and research institutions to access and use equitable data across levels of government?*

USDA can continue the positive work initiated by the 1994 Equity in Educational Land-Grant Status Act. This Act gave land grant universities at Tribal Colleges and Universities (TCU) the same status as other land grant institutions. The legislation initially included a $1.7 million agriculture and natural resources grant program and $50,000 per tribal college for agriculture and natural resources postsecondary programs. This legislation also authorizes $5 million to the Cooperative Extension Service in states that have both 1862 land grant colleges and 1994 tribal land grants[1]. However, the 35 TCUs remain woefully underfunded and supported compared to more "historical" land grant institutions.

Supporting educational institutions such as TCUs that directly serve tribal communities, assuring access to research, and building adequate research systems are all vital to Tribal agriculture and food systems in addition to supporting our Tribal producers and Tribal communities. USDA must provide the support and funding necessary for our technical assistance networks and institutions that are on the ground every day in Indian Country and working to support traditional knowledge, which is best done at tribally owned and managed organizations and institutions.

Research and education programs at USDA must allow for educating the next generation of Tribal producers, scientists, technical specialists, business managers, engineers, lawyers, and related professionals who advise and support the agriculture and food sectors. There are many Native youth who aspire to these career paths, and the USDA must support these youth through expansion of agriculture-related program funding at TCUs.

Because only a small number of tribal citizens in higher education attend these 35 institutions[2], USDA must dedicate itself to increased funding *and outreach* that engages tribal citizens attending the country's other land grant institutions. Non-competitive funding allocations for programs like the New Beginnings for Tribal Students program, should be a component of this effort. Ensuring non-competitive funding availability to tribes and tribal students is vital. Competitive funding pits Tribal Nations and Tribal-serving institutions against one another, undermining progress and creating turmoil. Non-competitive funding circumvents this inequity.

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[1] The Land Grant Tradition

[2] As of the 2019-20 school year, there were approximately 23,000 enrolled students at 35 TCUs nationwide.

USDA should make all efforts possible to cement attainable pathways for tribal agriculture students, then professionals, to utilize traditional farming practices and ecological knowledge to improve the diversity, resiliency, environmental and economic sustainability, and productivity of our food systems. Research regarding this knowledge should be handled respectfully and with the consent and guidance of the communities and individuals from which it originates. TCU students and staff, alongside tribal citizens enrolled or graduated from other land grant universities are vital cogs in this knowledge pathway. These individuals retain the knowledge of respecting tribal data sovereignty and opacity considerations, along with cultural sensitivities unclear to researchers from outside of Indian Country. This is especially prescient considering the historical exploitation of Indigenous science, the trauma of the colonial education system as imposed on Indigenous people for generations, and the continued inequality of access to agricultural research and extension services. Along with authentic relationships and partnerships required for research, reciprocity should be considered.

USDA should also closely collaborate with United States Department of Health and Human Services (HHS) to create set-asides in all current funding sources to support Native American scholars conducting nutrition and food security research. Native Americans and Alaska Natives are often missing when viewing federally-gathered data on food and nutrition statistics used to shape policies impacting the very people they're designed to serve. This "blind spot" hampers policymakers' ability to craft effective and sensible policy solutions and social programs that effectively target and benefit Native communities. Native American scholars are best positioned to carry out research in Tribal communities. It is crucial to understand local perspectives and engage with the Tribal communities on their terms, not the other way around. By creating set-asides to fund research done by Native scholars, HHS and USDA can help to fill this gap in Tribal-specific data and do so in a way that is respectful of Tribal communities.[3]

5. What resources, programs, training, or tools *can increase opportunities for community-based organizations to use equitable data to hold government accountable to the American public* ?

USDA must emphasize – through Tribal consultations and training of the USDA workforce – a wholehearted respect for Tribal data sovereignty, or the right of Native Nations to govern the collection, ownership and application of their own data, an extension of the rights codified through four centuries of treaties and other legal agreements negotiated on a Nation-to-Nation basis.[4]

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[3] White House Consultation briefing doc

[4] Rodriguez-Lonebear D & Rainie SC. (2016). US Indigenous Data Sovereignty Network: About Us. Retrieved 5 December 2017 from http://usindigenousdata.arizona.edu/about-us

As previously stated, the most effective surveys of the specific needs and circumstances impacting Tribal communities are generally scholars who come from those communities. For too long, Tribal communities and governments have remained dependent on external actors – mainly from the settler-colonial academic community – to glean information concerning their own economic circumstances, environmental conditions, and health outcomes. While there is often data about Tribes and their citizens, it has historically been collected without their input respecting how and why it was gathered, and has until recent decades been difficult to access. According to the University of Arizona's Native Nations Institute[5], the result of this has been:

- the collection, ownership, and application of Indigenous data are controlled by external entities;
- an extensive history of exploitative research and policies has left a legacy of mistrust of data; and a lack of data infrastructure and capability cripples tribal efforts to overcome these obstacles.

In practical terms, USDA's respect for Tribal data sovereignty begins with consultations, but must extend to mandatory and thoughtful training for staff members at all levels of interaction with tribal information gathering activities. The Office of Tribal Relations (OTR) is well placed to provide insight on how best to formulate said training, and will have access to external resources retaining expertise in these areas.

Most assuredly, what this training cannot be is a time-marking exercise, completed online and with minimal preparation or thought put into it. Additionally, the training must be led or have been designed by Native people who understand tribes and communities. Too often, the federal government relies on instruction from non-Natives and those who, though perhaps tangentially familiar with Indian Country, have not been born, lived and worked in it. Consulting with the OTR or other well established Tribal scholars and organizations in the data sovereignty sector would be a positive step towards honoring the nation-to-nation status between the federal government and tribal governments.

6. What resources, programs, training, or tools *can make equitable data more accessible and useable* for members of the public?

Real time and uniform tracking information is hard to come by when it comes to Indian Country and indigenous agriculture producers. For one, a drastic increase in transparent data must be available across the breadth of USDA programs and its subagencies with regard to AI/AN producers. This must extend to concise, accessible and uniform datasets that include up-to-date information from all federally recognized tribes and regional level datasets. These regional data sets must include all of Indian Country,

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[5] Indigenous Data Sovereignty in the United States – NNI University of Arizona

with the information able to contextualize the vast differences in tribal communities across the U.S. It is wholly purposeless to gather data on these diverse entities without respect the localized circumstances that help shape the data retained by USDA.

Take for example the generalized data collection methods of state and federal governments for minority populations[6]. Generally, five broad categories consist of the data collected – Black, White, American Indian/Alaska Native, Latinx, and Asian American/Pacific Islander. This example is repeated over a wide array of topics and issues collecting data in the U.S.[7] These ignore entire populations and consequently perpetuate systemic approaches to funding that are wholly ineffective at addressing their intended goals. A superior return on investment of time, money and human capital would be to disaggregate over such issues socio-economic level, age, and geography.

The collection must be done *following* a dedicated consultation with the tribal community/people being surveyed, with the gatherers providing utmost respect to tribal data sovereignty.

7. In which agencies, programs, regions, or communities *are there unmet needs, broken processes, or problems related to participation and accountability* that could be remedied through stronger collaborations and transparency around equitable data?

Unfortunately the whole of Indian Country suffers from unmet needs, broken processes and further complications with regards to proper data. At the micro level, there are several USDA agencies interacting with tribal communities and producers where stronger and transparent collaboration on equitable data can be readily identified.

Foremost, as previously mentioned, the entirety of USDA and its subagencies must make accurate and transparent data available to tribes and tribal researchers. This data must be disaggregated wherever applicable in statute without delay and encompass specific micro-level details down to the tribal government and regional levels.

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[6] Health Equity Cannot be Achieved without Complete and Transparent Data Collection and the Disaggregation of Data - Jan 2021;

[7] Pew Research Center. (2015). Multiracial in America: Proud, diverse and growing in numbers. http://www.pewsocialtrends.org/2015/06/11/multiracial-in-america/.

Further sub-agencies include:

- National Agriculture Survey Service (NASS) must develop improved census questions and farm definitions. Current questions and definitions lack the breadth of nuance encompassing all of indigenous agriculture.[8]
- Farm Service Agency (FSA) must prioritize and initiate the reporting of Native producers who apply for their programs. To date, FSA only reports out the number of Native American agriculture producers who are successful in loan applications to the agency, giving no wider picture of the numbers of those who may have been rejected from financial support. FSA previously reported out this information, but now says it can only report on successful loan applications from tribal producers due to a change in computer systems and procedures. By not listing the number of those rejected compared to those approved, FSA is able to claim credit for supporting tribal farmers and ranchers while only showing half the evidence. Coming from an agency with historic and documented discriminatory behavior towards Indian Country agriculture producers, the omission appears highly dubious.
- Natural Resources Conservation Service (NRCS) must make a demonstrable effort at increasing outreach and transparency through its staff-level employees to tribal producers concerning conservation programming data. Often, due to the unique jurisdictional challenges facing American Indian producers working in tribal jurisdictions, NRCS programs remain increasingly challenging to bid out, initiate and complete. A lack of clear communication and outreach by local NRCS staff, who either do not understand or do not want to deal with on-reservation conservation projects, hampers some of the country's most vulnerable producers ability to manage topsoil erosion and other issues.
- Food and Nutrition Service datasets must become more uniform to truly be useful for the patchwork of nutrition programs large swaths of Indian Country rely on. While datasets from programs like Supplemental Nutrition Assistance Program and Women, Infant Children do disaggregate some data, The Food Distribution Program on Indian Reservations (FDPIR) can only be accessed through National Data Bank resource. When researching such unique and dense information, the access and proximity of all three datasets should be easily attainable and searchable.

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[8] National Agricultural Statistics Service, 2017 Census of Agriculture Highlights - American Indian/Alaska Native Producers, Oct. 2019, available at: https://www.nass.usda.gov/Publications/Highlights/2019/2017Census_AmericanIndianAlaskaNative_Producers.pdf

Thank you for the opportunity to provide these comments as part of USDA's efforts at supporting Federal equitable data efforts as described in Executive Order on Advancing Racial Equity and Support for Underserved Communities Through the Federal Government (E.O. 13985) and President Biden's April 2022 *Vision for Equitable Data.* It is important the federal government considers the aforementioned responses in hopes of remedying centuries of misclassification and underserving Tribal governments and agriculture producers. We remain ready to assist in any efforts to remedy these shortfalls and look forward to the recommendations and policies that come from this effort.

Sincerely,

[redacted]

CC:

Dr. Alondra Nelson, Director of the White House Office of Science and Technology Policy

Honorable Tom Vilsack, Secretary of Agriculture

Janie Simms Hipp, USDA General Counsel;

David Grahn, USDA Deputy General Counsel;

Heather Dawn Thompson, Director, Office of Tribal Relations

RFI Response: Equitable Data Engagement and Accountability

To: The White House Office of Science and Technology Policy (OSTP), on behalf of the Subcommittee on Equitable Data of the National Science and Technology Council

Submitted by:
Shannon Dosemagen, Director, Open Environmental Data Project
[redacted]
Katie Hoeberling, Director of Policy Initiatives, Open Environmental Data Project
Emelia Williams, Research and Policy Associate, Open Environmental Data Project

As urgency grows around climate change and other environmental crises, so too does the need for environmental datasets to be opened up to support equitable decision-making and accountability. Open data policies such as the OPEN Government Data Act enacted in 2019 and efforts like the Open Government Partnership have set a foundation for data transparency and availability in the US. Still, they often fall short of making data equitable, accessible, and usable. Incentive structures, standards and privacy, and rules and regulations related to environmental data are failing communities collecting and using data, as well as government stakeholders who could benefit from this data in their policy and decision-making structures.

Inclusive, interactive data systems can become a foundation for increasing environmental equity in communities, especially those dealing with historical or ongoing environmental injustices. Socializing government and the public to the value of community data and the concept of environmental data as a public good will be critical to building equitable and effective data systems. Open dialogue and participatory infrastructure development can help identify the political push points and necessary changes in the social behavior of Federal agency staff and researchers, to ensure adoption and use of inclusive data systems.

The Open Environmental Data Project (OEDP) builds spaces to grow the global conversation on environmental data access and use to increase the flow of usable information between communities, researchers, lawmakers, and enactors seeking to actively address environmental and climate injustices that impact the quality of life and health of our communities. Informed by our research and programming, we offer recommendations for Federal agencies to better support collaboration with other levels of government, civil society, and the research community around the production and use of equitable data. Responses to each of the RFI's questions are provided under their headings below.

Q1-2: What are examples of successful collaborations involving equitable data between the Federal government and (a) Tribal, territorial, local, and State governments, or (b) local communities? Among examples of existing Federal collaborations with (a) Tribal, territorial, local, and State governments or (b) local communities involving equitable data, what lessons or best practices have been learned from such collaborations?

In our work, we have encountered several successful collaborations involving equitable environmental data between the Federal government and other governance levels. ***Two significant examples include the Environmental Information Exchange Network and the Internet of Water.***

The Environmental Information Exchange Network (EIEN) demonstrates the social, technical, and capacity-building elements required to keep data management and sharing initiatives effective and accountable to those involved. The EIEN facilitates data sharing among the Environmental Protection Agency (EPA), states, Tribes, and territories through shared, reusable, and streamlined data collection and exchange services. This work is done largely through partnerships with the Exchange Network (EN) and the Tribal Exchange Network Group (TXG), the maintenance of the Central Data Exchange and topic data exchanges, and grant funding for eligible states, federally-recognized tribes, and US territories.

The EIEN leverages its partnerships to focus on continuous maintenance of data infrastructure, enabling it to update its tools in response to local partner needs. The TXG comprises tribal professionals working on various aspects of the EN whose primary purpose is to ensure tribal representation and participation, promote tribal sovereignty, facilitate access to resources and tools, and communicate and collaborate with the EPA to increase understanding of unique tribal cultural values and environmental concerns. The EN assists 51 state nodes, 14 Tribes, and 3 territories in sharing data, using standardized data structures, and offering automation services. The purposeful and deliberate collaboration across governance levels allows the EIEN to support local data initiatives with technical and non-technical support, decrease data sharing errors, and cultivate a group of interested environmental professionals who use and support this data and work.

The EIEN also distributes capacity-building grants, supporting local and state projects in creating, piloting, and maintaining environmental data systems designed by those localities. For example, MassBays builds tools to support community-based monitoring and decision-making. EIEN also provides support and peer-to-peer partnership and data-sharing options throughout and after the duration of the grant cycle. This granting and support structure can serve as a model for other data collaboratives and foundations for designing capacity-building grant programs.

The Internet of Water's (IoW) work is another example of equitable data collaboration between a coalition of organizations working with Federal, state, and local government partners to build foundational water data infrastructure across the US, and create a community using water data to inform decisions. With funding support from the Infrastructure Investment and Jobs Act, the EPA will grant $15 million to projects aimed at more easily sharing information on water quality (including IoW), water infrastructure needs and water technology between state and local agencies.

The IoW's Online Resource Library and Service Provider Directory is regularly updated, providing up-to-date and high-quality training, resources, and referrals for community scientists. One standout feature is the Water Data Assessment Tool, which helps data producers improve their data's discoverability, accessibility, and usability. Other sectors of environmental data could learn from this model, in that providing actionable online and easy-to-use tools allow for greater participation and efficacy at local levels.

IoW also creates hub structures that can be customized and designed to fit diverse needs, allowing developers to compare and contrast hub types and their advantages, limitations, and barriers. Importantly, their data governance practices are based on user needs and limitations, focusing on creating standardized but customizable metadata catalogs. Good examples of IoW hubs include New Mexico Water Data and the Western States Water Council. Best practices that other sectors could replicate include IoW's clear representation of the standard technical management system with customizable models depending on the collaborative's needs and priorities.

IoW also cultivates a peer-to-peer network to connect members from across the nation. To support this network, IoW provides an online directory, regular webinars, and technical matchmaking where community scientists and small watershed monitoring programs are matched with technical service providers. By providing active participation points in network activities, IoW enhances credibility and utilization of tools that integrate community science into decision making, and helps to spread adoption and uptake of best-recommended technologies and monitoring practices.

Q3. What resources, programs, training, or other tools can facilitate increased data sharing between different levels of government (Tribal, territorial, local, State, or Federal) related to equitable data?

Coalition building, statewide data policies, and training programs that build up capacity for effective use of data can facilitate increased equitable data sharing between different levels of government. Coalition building is key to creating sustainable data-sharing programs. Coalitions of Federal agencies and programs can raise awareness, and direct spending towards improved bi-directional data flows between different levels of government and communities. The Federal Equitable Data Working Group could design a model that values community data during various decision-making processes and works for agency QA/QC needs.

Additionally, Federal agencies and states have a major role to play in managing and sharing data both with public agencies at various levels and those outside of government. Master Data Sharing Agreements, collaboratively designed with other agencies, states, and communities, can set data management standards and establish processes for safely sharing fine-grained and de-identified datasets with the public. Relatedly, Federal and statewide data policies can drive a culture of sharing by creating a presumption of openness among agencies, and by providing guidance for agencies to share data openly in usable formats and publish data dictionaries and useful metadata. States (as well as cities, counties, and universities) can also look to models such as the Western Pennsylvania Data Center, which leverages digital and legal infrastructure to support sharing between public agencies and community engagement with government data.

To increase data sharing between different levels of government, departments and agencies at every scope of government need access to relevant data literacy training to expand their capacity. Examples include programs like Georgetown's Data Labs, which offer long-term training on open and responsible data governance. In addition, governments can employ data intermediaries or ombudspeople who can liaise between communities and agencies, help users find and access data, and advocate for system improvements. At Federal and state levels, Chief Data Officers (CDOs) and agency data officers with backgrounds and expertise in library science and curation, rather than solely data analysis or IT, can be hired to improve government capacity to provide more accessible and usable data. Such officers would ensure that data practices meet standards set in Master Sharing Agreements and data policies, and establish collaborative data governance practices. They could also offer guidance and technical assistance to agency staff regarding data quality, curation, and sharing.

Q4. What resources, programs, training, or other tools can expand opportunities for historically underrepresented scholars and research institutions to access and use equitable data across levels of government?

Communities most affected by environmental harms and climate change tend to be those already facing the burdens of poverty, structural racism, and disadvantages in academic advancement. They also have large stakes in using data for equitable environmental governance and decision-making. Making data more findable, available, understandable, and usable can support the inclusion of these groups in the scientific enterprise. A common theme in OEDP's conversations with community partners is an awareness of an abundance of data but uncertainty around where to look (see our Opportunity Brief on "Environmental Data as a Public Good"). Increased access and understanding of environmental data can spark interest in scientific research and lower barriers for scholars from frontline communities to pursue scientific careers.

Access to data collected and maintained by Federal agencies such as the Census Bureau and NASA has historically been restricted. Often there are good reasons for this—in the case of Census data, significant risks to respondent privacy currently outweigh the benefits of providing open access to the data. However, policies that require researchers to pay access fees or travel to data centers effectively restrict data's use to well-resourced scholars and research institutions, especially since centers are often near "top" universities (Tranchero & Nagaraj, 2021).

Lifting or easing these restrictions can expand opportunities for a more diverse group of scholars to access government datasets and contribute scientific knowledge. A 2020 study on NASA's Landsat data, for example, demonstrated that lifting restrictions and reducing the costs of accessing the data led to significant increases in associated, highly cited publications by scientists from "lower-ranked institutions," as well as those earlier in their careers. And if in situ access is deemed necessary for protecting privacy, funding to support the establishment of more data centers would enable scholars with fewer financial resources or those unable to travel to use the data.

Publication metrics, in conjunction with author demographics, for outputs produced using federally funded data can be used to measure changes in who is accessing and using such data. Agencies providing the data might also collect demographic data from users who download their available datasets to assess who is using them.

Federal funding agencies like the National Science Foundation should also strengthen and enforce open data policies within the confines of consent-based protection. While the NSF, which maintains a large environmental and climate research portfolio, encourages data sharing and actively funds the development of data infrastructure, many of its datasets are never uploaded to public repositories. An enforcement mechanism lies in tying future award decisions to prior data sharing for those who have previously received NSF support. A precedent for this lies in NSF's proposal requirement that investigators report on the results of prior NSF awards. The National Institutes of Health's new data sharing policy, which will go into full effect in 2023, can be used as a model for other agencies like the NSF. ***These agencies can further support researchers in understanding and using this data by requiring data uploaders or stewards to include standardized and detailed metadata.***

Q5 & 7. What resources, programs, training, or tools can increase opportunities for community-based organizations to use equitable data to hold government accountable to the American public? In which agencies, programs, regions, or communities are there unmet needs, broken processes, or problems related to participation and accountability that could be remedied through stronger collaborations and transparency around equitable data?

Government-led and funded research as a whole has not holistically represented the experiences of communities facing the worst impacts of environmental degradation and climate change—even when data are collected in a participatory manner, limited funding and avenues for follow-through restrict the usefulness of findings to the communities in closest proximity to the data sources. Furthermore, privatization of the instruments and digital platforms used for collecting or processing data, as well as inefficiencies in Federal data infrastructure, prevents many communities from collecting, accessing, or using data. These barriers threaten to undermine progress in the work of environmental justice, and community and citizen science, as well as erode trust in public institutions, and isolate participating communities, many of whom already bear the brunt of climate change impacts and environmental degradation.

Public agencies should prioritize open data infrastructure that meets the needs of community-based organizations and researchers, as well as government staff. Government and industry datasets could be powerful tools for environmental action at many levels. However, environmental monitoring and compliance data collected by agencies like the EPA are fragmented, stored in different data systems, managed by different entities, and shared in different ways. To ensure broad findability, access, and use of such data, data infrastructure must be designed with multiple uses and stakeholders in mind, and to accommodate and promote open practices.

Programs such as OEDP's Beyond Compliance Network (in partnership with Fair Tech Collective and Intertidal Strategies) aim to modernize environmental data systems and democratize knowledge creation and use by investigating and re-thinking approaches to the management and sharing of environmental compliance data. The obstacles faced in this process include a common reliance on personal relationships to find or understand data, gaps in metadata and data dictionaries, and large variations in data's scale and granularity that make it difficult to integrate (see our recent report for more discussion on these challenges).

Agencies can also look to tools such as NEPAccess and Fair Tech Collective's benzene emissions database as models. The latter consolidates data reported by oil refineries to the EPA to help communities understand their exposure and to support research on benzene's environmental health impacts. Equitable data infrastructure should be measured by how efficiently it handles multi-directional flows of information while (i) serving multiple types of users with widely varying expertise, including concerned constituents and communities, environmental regulators, and private sector actors capable of reducing pollution; (ii) incorporating quantitative and qualitative data from diverse sources and temporalities; and (iii) establishing performance on existing environmental metrics while fostering the development of new metrics that are meaningful, and actionable, for diverse constituencies and geographies.

Public offices and agencies should support the collection and integration of community data in decision-making through funding, signaling of its value, and focusing on the infrastructure necessary to ensure environmental data is a public good. Communities and community-based organizations are creating new data streams using non-standardized sensors and processes. In addition to connecting science with people's lived experiences and empowering them to connect with and explore their environment, these datasets offer hyper-local evidence that is already informing the decisions of individuals and communities. Volunteer water monitors, for instance, have been taking water pollution samples for decades, contributing localized data to help communities, scientists, and governments monitor short- and long-term changes in water quality.

Evolving Federal data infrastructures must prioritize community data to build more equitable approaches to governance that encourage and utilize community input, and strengthen confidence in environmental decisions. Such integration would improve community representation, strengthen data's relevance to communities, and allow for a variety of potential uses by different actors. It would also expand opportunities for community engagement in science and strengthen feelings of civic trust, and efficacy and trust felt by communities often excluded from predominant scientific processes.

Critically, agencies must not stop at supporting the collection of community data and follow through by acting on the information it offers. In recent years, frontline communities have been able to access Federal and state funding to install environmental monitors at nearby polluting facilities. Too often, however, public agencies fail to hold these facilities accountable even when data show they have violated environmental regulations, further eroding trust among already skeptical communities.

Agencies should build and resource community and organizational capacity to participate in planning processes. Many communities and community organizations may be unaware of funding opportunities or lack the resources to access such support. The complexities of navigating agency processes, strategizing, and preparing proposals present barriers to access for less-resourced organizations and communities—often those most impacted by climate change and pollution. Agencies can reduce these barriers by funneling resources to capacity-building programs.

For example, California State Bill 1072 established Regional Climate Collaboratives to serve as local hubs where communities could come together, strategize, develop partnerships, and apply for state funding. It also led to creation of the Partners Advancing Climate Equity (PACE) program to provide training, mentorship, and technical assistance to frontline community leaders. Depending on communities' existing capacity and access to resources, these programs may need to focus on building a range of skills, from digital literacy to proposal writing and budgeting. Where they exist and are useful, open data portals can be leveraged as sources of baseline information and evidence (or lack thereof) to be cited in proposals. Data ombudspersons and intermediaries can support these capacity-building programs by helping organizations find and use data to support their ideas.

Q6. What resources, programs, training, or tools can make equitable data more accessible and useable for members of the public?

To make equitable environmental data accessible and usable for the public, institutions, agencies, and organizations must prioritize and instrumentalize environmental data as a public good. Two ways to do this are to implement data literacy training and localized data governance models.

Data literacy training must be issue-based and place-tailored to effectively lower barriers to data access and interaction. Communities often require access to specific information about particular aspects of their environment to make a case for local governments or grantmaking organizations. Data literacy is foundational for communities to be able to uncover useful data, and for government agencies to be able to integrate evidence into policy making. Programs catered to specific geographies and content areas will be most effective in assisting communities in finding answers to questions and creating evidence for policy making.

Localized and equitable data governance models, including collaborative governance structures, can make data more accessible, usable, and reusable for the public. New technology for data collection, storage, and management does not always need to be built from scratch; investments can be made in critical digital infrastructure and features that will make environmental data usable and useful (Dosemagen & Williams, 2022). Community ownership, direct input routes, and checks and balances can foster stronger community representation in the data. Appropriate models of collaborative governance will consider how new community data fits into current data systems while also being proactively designed to anticipate future needs.

Data collaboratives present a promising opportunity for civil society to conscientiously build and maintain spaces for environmental and climate data that intersect many issues and are shared by different contributors. More and more localities are imagining spaces where governments and communities can share and manage data collaboratively. Open data governance models should be co-created with communities, building intentional space to foster shared metadata curation practices. These processes can bridge gaps in knowledge, and ensure that collaboratives embed community-derived values from the beginning and the bottom-up. Critically, these governance models require sustained support from a team of diverse data stewards, including sociocultural, legal, policy, and technical roles.

October 3, 2022

Office of Science and Technology Policy
Executive Office of the President
Eisenhower Executive Office Building
[redacted]
Washington, DC 20504

Submitted electronically to: [redacted]

Re: Engagement and Accountability RFI

As the director of the *National Commission to Transform Public Health Data Systems*, I appreciate the opportunity to submit comments to the Office of Science and Technology Policy (OSTP), on behalf of the Subcommittee on Equitable Data of the National Science and Technology Council, in response to its request for information on how federal agencies can better support collaboration with other levels of government, civil society, and the research community around the production and use of equitable data. Historic inequities must be considered in our approaches to develop equitable data systems.

Public health data systems take the pulse of our society, providing a snapshot of the strength and vitality of our population. And yet, for too long, that picture has been far from complete—in fact, it's been skewed in ways that have harmed the health of members of many of our diverse communities, especially those of color, those with disabilities, and those who are LGBTQ+. Decades of limited funding, lack of federal and state coordination, and systemic hurdles left a vulnerable public health infrastructure.

After COVID-19 laid bare the gaps in our public health infrastructure, including the disproportionate impact on communities of color, the Robert Wood Johnson Foundation (RWJF) convened a first-of-its-kind independent National Commission to Transform Public Health Data Systems to reimagine how data are collected, shared, and used to identify the investments needed to improve health equity. The 16-member Commission composed of diverse innovators and experts representing multiple sectors—healthcare, community advocacy, government, business, public health, and others—released a set of recommendations in October 2021 for centering both health equity and racial equity. The Commission offered three overarching recommendations for a blueprint for change: center health equity in narrative change, prioritize equitable governance and community engagement, and ensure that public health measurement captures structural racism and other inequities. I encourage you to read the full report of recommendations here.

Highlighted below are recommendations of particular relevance to the questions raised in the request and place-based (i.e., local) grant programs that recently launched in response to the

Commission’s recommendations to build a more equity-centered data infrastructure across the country.

Prioritize and accelerate implementation of the Evidence Act for improved transparency, quality, and availability of data.

In the request for feedback, a reference was made to accessing needed data from federal agencies and departments. We believe that more actors should have access to these data and not just researchers at R1 institutions that can afford to pay for access through the Federal Statistical Data Service. Thus, we encourage equity to be considered in the implementation of the Foundations for Evidence-Based Policymaking Act (Public Law No: 115-435). The law requires agency data to be accessible and requires agencies to plan to develop statistical evidence to support policymaking. As implementation activities of this law begin, such as those with the creation of the National Secure Data Service (NSDS), ensuring equitable access is paramount. For example, similar federal data services, such as the Census Federal Statistical Data Research Service, are cost prohibitive for academic researchers not affiliated with well-resourced institutions or colleges and institutions. Costs to access the data need to be reduced or grants should be offered to help researchers at historically Black colleges and universities (HBCUs) and other less-resourced institutions access this critical data and uncover challenges in their communities.

In addition to equity in access, any kind of federal-level data resource should contain the right measures that help actors achieve their equity goals. Currently, the information that can be extracted from administrative files that can be useful for creating measures that can be used to explore how inequities in health and social outcomes can be reduced is far from clear. We encourage you to become more transparent with what is included in administrative data. Transparency is needed so potential data users know what they can access and what they can request. For data queries and data requests (when possible) there also needs to be appropriate capacity at the federal level to respond. Requests for federal data that are not met in a timely manner limit researchers’ ability to have a clear and accurate picture of community conditions and therefore restrict actions to respond and make improvements. Further, data requests should be met with clean data. Many partners in the field have reported having to make multiple requests from governmental agencies before receiving the data they needed. Dedicated funding and staffing on the federal side will ensure improved community collaboration.

Establish and implement a coordinated state and federal investment strategy that includes regular fiscal support of state and local governments’ efforts to accelerate data system modernization.

Federal and state funding for public health has declined over the past decade, and there has been weak support for federal funding specifically for data infrastructure. Grantees and partners in the field often cite ONC's BEACON Communities Initiative as one of the last programs that had a specific focus on building data infrastructure. That program launched in 2012, and since then, it is difficult to find a similar initiative that can sustain what has been built or that can help with the development of new data resources elsewhere. As a result of inconsistent funding, there is wide variability in public health infrastructure, and we believe this has had effects for health equity. While more direct and dedicated funding is needed, there are new funding resources that could be used to improve local data systems such as those available through the American Rescue Plan and the Infrastructure bill. Unfortunately, we have heard that acceptable expenses of grant dollars from these opportunities are not clear. Federal agencies should clarify the acceptable use of funds, making it explicit that support for data infrastructure is allowable and improve outreach so local communities are aware.

In addition, federal agencies could align federal grant reporting requirements that would encourage cross-sector collaboration and assist states and localities as they work to blend funding streams to maximize impact. Currently it is difficult for local agencies to coordinate outcomes, making blending and braiding funding difficult. The Brookings Institution has encouraged cross-sector collaboration that would enable public health departments and other entities to maximize the use of their funds to support data. We encourage you to draw from their resources to learn how federal departments can be supportive.

Collect better data broken down across population groups (race/ethnicity, gender, disability) and geographic levels to offer a more complete picture of health disparities.

Local government, community-based organizations, and others often fail to reach the most vulnerable groups because of a lack of data by race, gender, and other demographics and structural factors that separate people from health and opportunity. Without consistent disaggregated data, the research we draw upon to inform policies masks disparities that require attention from health providers and policymakers at all levels. Data disaggregation is key to ensuring that those who have been historically excluded are visible, and community input is essential to data collection and analysis.

Current Office of Management and Budget (OMB) standards for race and ethnicity data required for federal programs are archaic and inadequate. They do not reflect the complexities of our current national demographics, nor do they identify data needed for both individual care and community health, such as Sexual Orientation and Gender Identity (SOGI). I applaud the recent announcement by the Office of Management and Budget (OMB) to review the Standards for the Classification of Federal Data on Race and Ethnicity and encourage the standards be updated and clarified to include the influence of gender, class, citizenship, and other factors of inequality. The federal government can also play a key role by encouraging a set of data collection standards at state and local levels tied to federal grantmaking.

Oversampling historically underrepresented populations in national surveys, such as those funded by Health and Human Services (HHS), will also provide additional national data that is more representative of our population. And for all efforts, it is critical that we shift the narrative around data to reflect assets rather than deficits. The Health Opportunity and Equity (HOPE) Initiative is an innovative tool with measures that offer a unique look into the effects of 28 indicators that influence health at the state and national level broken down by race, ethnicity, and socioeconomic status. HOPE's measures provide a better understanding of what barriers stand in the way of equity and opportunity for specific groups and how states can tailor strategies for those most in need.

State leaders and advocates can use HOPE to ask, "What are other states doing right on creating equity and opportunity, how did they get there, and what might I do differently in my state?" These data show where babies are more likely to live past their first birthday, where residents can more easily access a doctor, where air quality is healthier, or where young children are more likely to enroll in pre-K.

Ensure public health measures address structural racism and other inequities. Federal leadership is critical for setting up standards to measure health equity.

We can extract broader lessons on how to build a public health data system grounded in equity that links more clearly to the community conditions that shape inequities, and that properly values an individual's lived experience by capturing data by race, ethnicity, income, education, gender, and disability.

There is no national standard to measure health equity or assess performance to achieve health equity. Currently, the public health data system minimally tracks information to guide the dismantling of structural racism and address other inequities that influence health. Despite increasing amounts of public health data being collected, data on the factors that influence health, such as housing instability, food insecurity and education, are not regularly or consistently available to inform decision-making.

Building on the Equitable Data Working Group established by Executive Order, we can create an interagency data council to improve measures to assess equity and racial justice and bring together different agencies to create interoperable social and public health data. A parsimonious set of metrics to analyze the health effects of structural racism would also provide critical benchmarks into root causes of health inequities. Any effort should ensure that community input is represented in data collection, interpretation, and decision-making.

Building a more equity-centered data infrastructure across the country: Emerging local Case Studies

The Commission's recommendations led the Robert Wood Johnson Foundation to invest more than $50 million for a broad range of efforts to fuel progress in building a modernized public health data infrastructure across the country where data are collected, analyzed, and interpreted with an eye toward equity. These on-the-ground case studies will demonstrate how a more equitable public health data infrastructure can help us see trends faster and track what's happening to who and why sooner.

A number of organizations, large and small, will serve as intermediaries dispersing funds to partners and/or subgrantees across the country on initiatives ranging from:

- Advancing state and local policy change to promote data disaggregation;
- Supporting HBCUs in expanding data collection capacity in Gulf Coast communities;
- Supporting researchers in the discovery of evidenced-based, data-driven tools that combat misinformation and disinformation in the public health space;
- Developing methods for interpreting public health data that are inclusive of community input, and more.

There are currently local partnerships in 14 states with more on the way. A full list is available here. Here are a few examples:

- **Actionable Intelligence for Social Policy (AISP)** at the University of Pennsylvania selected its first cohort of community site teams to participate in their Equity in Practice Learning Community to center racial equity in data integration. The sites will build, test, and implement new models for incorporating community voice in key decisions about cross-sector data use, with an emphasis on health equity and racial justice.
- **Modernized Anti-Racist Data Ecosystems (MADE) for Health Justice** is a new grant opportunity, administered by the de Beaumont Foundation, that seeks to accelerate the development of health-focused local data ecosystems that center principles of anti-racism, equity, justice, and community power. Up to five non-profit organizations will be funded to build and facilitate multisector teams tasked with creating local data ecosystems.
- **The CDC Foundation** awarded grants to five local data equity coalitions to use PLACES health data to design innovative solutions that address the social and structural factors that influence local community health outcomes.
- **The Public Health National Center for Innovations (PHNCI)** is convening its 21st century learning community, a group of 18 states working on statewide public health transformation. PHNCI will engage a subset of states in examining and implementing the Commission's recommendations.

- **The Gulf Research Program of the National Academies of Sciences, Engineering, and Medicine** awarded planning grant awards to two historically black universities to investigate how social determinants of health data can transform public health data systems to better address health disparities faced by communities in the Gulf of Mexico region.
- **The Leadership Conference Education Fund** will promote data disaggregation through state and local policy change by creating advocacy infrastructure to encourage policymakers at all levels to disaggregate ethic/racial data beyond existing minimum federal standards.

In addition to the place-based efforts, additional grantees are working to address other systemic challenges that, if addressed, can move us closer to a data infrastructure anchored in equity.

I commend your efforts for seeking input on how the federal government can engage all of our communities to better support the production and use of equitable data. I hope my feedback will help inform your work and build an equity-centered public health data system. Together, we can help create a society where everyone has a just opportunity to live a long and healthy life.

Sincerely,

Gail C. Christopher, D.N.
Director
National Commission to Transform Public Health Data Systems

ARLINGTON
VIRGINIA

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October 3, 2022

NSTC Subcommittee on Equitable Data
Office of Science and Technology Policy
Eisenhower Executive Office Building
[redacted]
Washington, DC 20504

Colleagues:

Since the beginning of the COVID-19 pandemic, Arlington County, Virginia has made deliberate investments in the use of data to ensure equitable access to vital emergency information and to better inform distribution of goods and critical services. That is why we were so excited to see your request for information and why we are delighted to share with you some highlights of our work.

In the spring of 2020, the Virginia Department of Emergency Management (VDEM) and the Commonwealth's Health Equity Working Group initiated the Health Equity Pilot Program. The Health Equity Pilot Program was a state-local partnership which sought to leverage data and increase equitable access to personal protective equipment (PPE) and public health information in underserved and historically disadvantaged communities disproportionately impacted by COVID-19. Data collected by the state identified communities across the Commonwealth most in need and at risk of contracting COVID-19. Communities were identified using indicators from state and federal data sources such as chronic diseases, household income, age, disability status, and other important health factors. Arlington County leveraged our extensive public health data efforts, namely the Destination 2027 report (https://www.arlingtonva.us/Government/Programs/Health/PHA/D2027), which had been published in 2018 to identify critical health disparities in our community, to compliment the state and federal efforts. As a result, we identified pockets of our community at demonstrably higher risk for serious complications from COVID-19. Arlington was one of fifty localities identified across Virginia to participate in the Pilot Program and received 30,000 masks and 20,000 bottles of hand sanitizer to bolster the existing County mitigation and protection efforts against the virus.

That participation marked the beginning of a data driven, highly collaborative approach to strategy and operations surrounding COVID-19 in Arlington County. Arlington County's Department of Public Safety Communications and Emergency Management (DPSCEM) has incorporated the use of additional tools such as:

1. US Census Bureau's Community Resilience Estimate (CRE) for Equity
2. CDC Social Vulnerability Index
3. Arlington's County Census Tract Demographic Dashboard
4. Arlington County's Profile Report
5. Arlington County's Race and Ethnicity Dashboard
6. Arlington County's Multi Family Contacts Dashboard

7. DPSCEM Customer Relationship Management (CRM) Tool – Community Organizations Active in Disaster (COAD) and engagement management

8. FEMA National Risk Index

These tools provide critical data sets that must be considered when addressing the wholistic needs of the community and ensure that limited resources are provided to those who need it most during times of crisis. While the state provided data is important, it has been critical to have a local lens when analyzing the data and providing relativity when influencing decisions.

And while having the data has been important, equally so was the assurance that the process of collection, interpretation and analysis was carried out in an equitable, transparent, and inclusive manner. Remedying the digital divide and ensuring that data has adequate representation of all community members and demographics is critical to maintaining the integrity of data that can inform operational decisions. Trust in governance is a foundational element in a community's resilience and a focus for Arlington County's Community Advancing Resilience and Readiness Together (CARRT) (https://www.arlingtonva.us/Government/Public-Safety/Emergency-Preparedness/CARRT). After seeing immeasurable success when engaging civil organizations and resident-led advocacy groups in response and recovery efforts, Arlington County established CARRT to create a continuous bridge with Arlington residents that allows them to contribute to emergency and crisis preparedness, response and recovery efforts and provide the county with an actionable body to support efforts post incident. While Alington County accomplished a prolific level of participation in the 2020 Census, it took a concerted amount of manpower and investment from the county that many other counties are not able to mimic.

Outside of the best practices of data transparency, data inclusivity, and interoperable platforms, the Federal government needs to provide resources to enable to the collection of reliable and comprehensive data within local jurisdictions. Establishing competitive grants that build and socialize best practices applied by recipients, as well as addressing the digital divide and limiting the bias represented in most data collection methods, are all steps necessary to encourage sustainable data-driven decision-making efforts. Technical assistance programs, incentivization of local and state investment in hiring individuals with the technical expertise to build and maintain the platforms, helping to grown new collection methodologies, and supporting interjurisdictional system infrastructure to enable smaller or less affluent jurisdictions to contribute to the regional and state data sets is necessary to establish a common operating picture for regional and statewide efforts.

Arlington County is pleased to see these considerations of collaboration, inclusion, and support for equitable data, and looks forward to learning more about the results of the Request for Information on Equitable Data Engagement and Accessibility. We would welcome additional opportunities to contribute to this work and look forward to more chances to engage on the matter.

Sincerely yours

[redacted]

Aaron Miller, PhD, MPH
Deputy County Manager, Public Safety and Information Technology

The W.E. Upjohn Institute for Employment Research

Kalamazoo, Michigan

Response to the Office of Science and Technology Policy's Request for Information; Equitable Data Engagement and Accountability

Part 1 – Written Responses

1. What are examples of successful collaborations involving equitable data between the Federal government and (a) Tribal, territorial, local, and State governments, or (b) local communities?

In 2018, The W.E. Upjohn Institute for Employment Research in Kalamazoo, Michigan launched the *Community Data System* in partnership with the City of Kalamazoo and Western Michigan University's Homer Stryker M.D. School of Medicine (WMed). The Upjohn Institute, a non-profit research organization, has successfully collaborated with governments including the City of Kalamazoo, Kalamazoo County, and the State of Michigan to produce a database that allows for research using equitable data. The Community Data System project aims to assist and measure the efforts of the City's *Shared Prosperity Kalamazoo* initiative, which seeks to reduce the burden of intergenerational poverty within our community. These innovative partnerships have allowed for rigorous analysis while protecting the security and privacy of contributed information. Data collected from multiple sources have been integrated into a longitudinal database tracking events in the life course of Kalamazoo residents. With this rich database, researchers can assess the effectiveness of interventions to poverty. The Community Data System has facilitated evaluations of organizations and programs such as Communities in Schools of Kalamazoo, Healthy Babies Healthy Start of Kalamazoo County, and the Kalamazoo Promise.

For the benefit of the reader, an excerpt from a Community Data System project proposal from The Upjohn Institute to the City of Kalamazoo follows in *Part 2 – Material Responses*.

5. What resources, programs, training, or tools can increase opportunities for community-based organizations to use equitable data to hold government accountable to the American public?

The efforts undertaken at The Upjohn Institute to measure interventions to poverty would be greatly aided by easier access to Unemployment Insurance data, or other wage or employment data that can be matched to individuals. As poverty is largely a question of income, access to this crucial information would allow us to dramatically improve the rigor of our analyses. While disaggregation of data by race, ethnicity, gender, student/family free lunch participation are all a standard part of analysis, the true longitudinal analysis of poverty reduction is hampered by the absence of the wage record data. The Upjohn Institute once recently had access to this information for a temporary amount of time through a partnership with the Michigan Department of Talent and Economic Development - Unemployment Insurance Agency, but that access is not ongoing. Access during this short time was very project specific. The absence of this information for a broader use and time has been sorely felt by our team, and we believe that renewed access to this information would greatly enhance our database of equitable data.

The Upjohn Institutes benefits from a fruitful partnership with Kalamazoo Public Schools, which allows the Community Data System to incorporate K-12 educational outcomes. Information on students' time spent out of school, however, is scarce. There is a lack of data infrastructure to track outcomes and efficiencies in out of school time programming during the K-12 period of life. Our equitable data project would benefit from access to resources that would enable data sharing between youth development programs and like-minded non-profit organizations. In fact, further infrastructure to support youth development organizations in their collection, storage and use of their data would not only enhance the Community Data System, but also the youth and families which they serve. Currently, the subpar data infrastructure limits continuous improvement analyses as well as impact evaluation.

Part 2 – Material Responses

1. What are examples of successful collaborations involving equitable data between the Federal government and (a) Tribal, territorial, local, and State governments, or (b) local communities?

Shown below is an excerpt from a project proposal for the Community Data System from the Upjohn Institute to the City of Kalamazoo.

***

In this memo we propose a plan for Upjohn Institute support to the City of Kalamazoo around the creation and maintenance of a community data system and index.

<u>Assumptions</u>

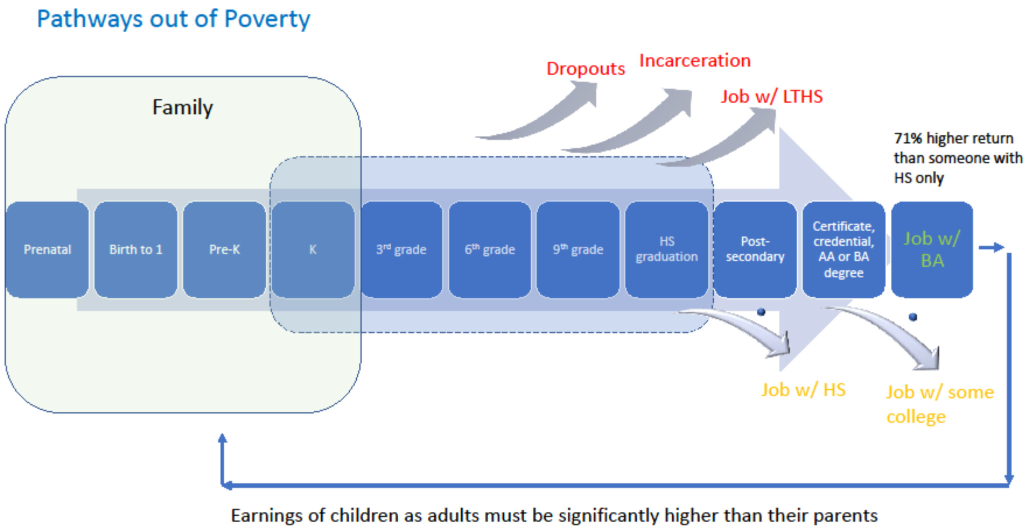
As we have discussed previously, Shared Prosperity Kalamazoo (SPK) will ideally be guided by a combination of community experience (as embodied in the goal teams), local data, and best practices found outside the community. These three sources of input used strategically and in combination with each other can help ensure that SPK is effective in meeting its goals.

A community data system would seek to bring various data sources together to create actionable information for SPK leadership, goal teams, and the city. This data would also be used to set a baseline and track progress as SPK unfolds.

Our proposal is based on the following assumptions:

- Since poverty reduction requires mitigating the barriers to **financial upward mobility**, an effective index monitoring the progress of such an effort needs to track the progress of individuals born into poverty in acquiring the means from birth to adulthood to obtain steady work that pays more than the work of their parents.
- Since the development of human capital through **education** is the primary way in which most individuals improve their chances of finding a career that pays a sufficient wage to provide for themselves and their families, and adequate benefits such as health coverage, an effective index must monitor the success of children/students as they move along the continuum from birth to adulthood.
- Since education beyond high school offers substantially greater returns than merely a high school education, the ability to graduate from high school, enroll in post-secondary education, and **obtain a degree or certificate** is critical in reducing poverty.

The following diagram captures those assumptions, as well as some critical checkpoints along the way:



Constructing a Data System

The first step in developing a community data system and index is to carry out a **comprehensive scan** of the opportunities and challenges facing children as they strive for successful outcomes along the educational continuum. The scan should be as detailed as possible, focusing on the circumstances children and their families encounter in their neighborhoods as well as the resources available to help them progress. These include access to prenatal medical care, post partem new birth care, childcare, parental assistance, health care, behavioral and mental health supports, safe neighborhoods, and supports all along the educational continuum from high-quality pre-K to college access and support. The scan should be tied to individual neighborhoods so that the specific issues and challenges families face can be identified and addressed.

This comprehensive scan would serve as a **benchmark** that documents the starting point of the current community efforts. From the understanding gained from the scan, the city and other resource providers can focus their work where it is most needed to improve the upward mobility of the targeted population.

Since children in poverty face multiple barriers and various organizations in the region exist to address these barriers, information from supporting organizations as to the services they provide and the families/children they serve is also needed. It will be critical to find a **data platform** that allows organizations to contribute information about their services and support of targeted children and families. Ideally, the information provided will identify the children and families being served (with appropriate privacy protections in place) so that it is possible to catalogue and evaluate the effectiveness of these services for those who receive them. We understand that individualized data and tracking may not be available in every case and higher levels of aggregation may be called for. The data platform must also provide various layers of aggregation so that privacy issues can be accommodated. Nonprofit organizations willing to contribute information would enter into data-sharing agreements with the Upjohn Institute, and the institute in turn would commit to protecting data privacy and security while providing objective, unbiased information on progress in achieving the goals of the project.

From a detailed accounting of progress along the continuum, a set of **indexes** will be constructed that document the transition of children at key junctures. These would include:

- Family characteristics (employed, earnings, housing, family structure, stability, etc.)
- Birth outcomes
- Access to medical care
- Access to parental support and assistance
- Access and enrollment in quality childcare
- Transition to K
- Transition to 3rd grade, including reading and other proficiencies as well as physical, mental, and behavioral health
- Transition to middle school, including appropriate academic proficiencies
- Transition to high school, dropout prevention and progress toward graduation
- High school graduation
- Enrollment in postsecondary education (type)
- Progress in postsecondary institution
- Attainment of degrees or certificates
- Preparation for career
- Finding a job (type, earnings, etc.)

While it is important to maintain a level of detail for purposes of targeting resources and evaluating interventions, these data can be rolled up to create a more aggregated index while still capturing transitions rather than cross-sectional outcomes. For example, it is not that useful to know that x% of children in a given area read at grade level unless you know who those children are and what their prior trajectory along the continuum has been. It is more useful to know that x% of children who were at grade level in, say, 1st grade remained at grade level in 3rd grade, while x% fell below grade level, and x% of those below grade level gained proficiency.

Request for Information; Equitable Data Engagement and Accountability

Responses from The Mission Promise Neighborhood and The Mission Economic Development Agency

San Francisco, CA

Submitted by:
Michelle Reiss-Top
Associate Director of Data and Learning
Mission Economic Development Agency
[redacted]

1. What are *examples of successful collaborations* involving equitable data between the Federal government and (a) Tribal, territorial, local, and State governments, or (b) local communities?

Opt out of question #1

2. Among examples of existing Federal collaborations, *what lessons or best practices have been learned from such collaborations* ?

Our Mission Promise Neighborhood initiative has been the recipient of the U.S. Department of Education Promise Neighborhoods grant since 2012. The data requirement for the first 5 years of the grant included the submission of de-identified individual level data across 15 GPRA indicators to be compared with the same data from other Promise Neighborhood grantees from around the country. The resulting combined analysis was not able to tell us anything about our community or the initiative that we couldn't analyze ourselves. The change in data over time was so incremental that it was hard to discuss its meaning with community partners or community members.

But the biggest barrier to interacting with these data was that they were metrics decided upon by someone else. Someone far from our community who could not consider our community alone, but needed to find metrics universal to all communities across the country participating in the initiative. These are metrics that, while we all agree are important, do not address the specific needs of the local community, not ours nor any of the different communities in disparate parts of the country participating in the grant. The data was neither unique to them nor was it decided by them. The key lesson here is that we cannot expect the community to engage with data they do not think is truly impactful.

It is not equity, but rather the traditional white male dominant culture we all contribute to that hands down these metrics to the community with the assumption that academia, data science and government know best about what should be measured in the first place. They do not. This does not mean those universal metrics and general demographics are not important, but they are supporting data that needs to be applied to the root causes each community identifies for itself. When those root causes are identified by the community, more relevant indicators and metrics can quickly come to light.

What we learned more recently is that meaningful data sharing is not when our agency brings data we already have to the people in hopes that they will use it, but instead is when the community shares with us which data they think matters and what is worthy of measuring. Our job is to create ways to have that data discovery conversation with our community so the metrics and indicators they care about can be identified and acted upon.

In order to become partners in the use of data we must become partners in deciding what that data should be in the first place. From these conversations evaluators can learn the language that matters to the community which helps subsequent metrics remain free of jargon, maintains the community as experts in the field of their own lives and which in turn drives engagement and "use" of the data over time.

Examples of community generated indicators from the Mission Promise Neighborhood follow in our response to Question #3.

3. What resources, programs, training, or other tools *can facilitate increased data sharing?*

The Mission Promise Neighborhood used Human-Centered Design to build a Community Report Card unlike any other. We set out to build a community report card that would assess the success or failure of the systems our families access in our Mission District neighborhood and the city of San Francisco. From this we expected to learn how our systems might improve various city services including our own nonprofit programs. Our design team was made up of eight members of the community and five staff members. Our team represented the community we serve, largely extremely low-income, Spanish speaking immigrant families and included youth, parents, mixed legal-status households. Every meeting was conducted entirely in Spanish, their preferred language.

The team designed an interview instrument and learned interview best-practices. They became the researcher instead of the *researched*. From over 40 interviews they coded responses and derived findings all using the Human-Centered Design tools of sharing stories and clustering themes to find insights. They settled on five Key Insights that became our new problem statement. (See attached, *MPN_Follow While Community Leads_ Report Card.pdf*, slide 18).

As domain experts in human services and data and evaluation our expertise would have suggested building something that showed the data we are already accustomed to collecting; health outcomes, education outcomes, graduation rates, financial outcomes. We would have asked how to better set up our families for success in these systems. This amounts to teaching them "how to play the game" while never asking whether the rules of the game are fair or not.

After listening to the community they told us the systems we really needed to address were not domain specific but instead were things like advocating for oneself in one's own language, that documentation status undermines all other improvements to services they have seen so far, and that working to survive and not thrive meant a lack of quality time spent with family. That lack of humanity, the systemic forces that keep them from being there with their children for dinner each night, at school conferences, laughing during leisure time on a day off, this lack of quality time as a parent negatively affects their child's mental health and ability to succeed in school which directly impacts their ability to ever rise out of poverty.

The metrics we really needed to track to show systemic barriers are:

1. The amount of time they can spend with their kids
2. The amount of time at work and number of jobs compared to their income
3. Whether they have job protection
4. Whether they received fair wages
5. Whether labor laws protect them or ignore them

The interviews the team conducted were described as "a conversation with the community". They were revealing and healing. The interviewees were able to share deeper insights because they trusted the person interviewing them and knew they had shared experiences. Because these stories were so impactful to our team and often met with the response "I didn't know that happened to anyone else", the design team determined that to get to the story behind the data we needed qualitative data. Stories must be a key element of the Community Report Card.

The *Community-Designed* Report Card Solution:

- An app that collects reviews of services in the community with standardized questions about language access and documentation status along with open-ended comments about their experience
- Surveys that ask about quality time spent with their family and how work impacts this time
- Youth surveys that allow young adults and teens to share stories of the dilemma between family income and pursuing their education
- All data from these surveys is immediately available to them on the app complete with charts and the ability to read other people's anonymous comments
- Audio file stories to overcome low-literacy rates so they can listen to longer form interviews in their own language and learn they are not alone in their experience
- The app should be used "in community" meaning with other trusted staff or friends around with the app in hand to discuss the survey questions, results and their meaning. The discussion then encourages use of the app and inspires people to contribute to the surveys and story-telling.

See attached Slide deck presentation which includes a link to our Demo app.

We are in Human-Centered Design phase 3 – the Implementation Phase of our solution, piloting it with a small group. While we've been in this phase, this report on the use of HCD with Human Services was published by the Office of Planning, Research & Evaluation (an office of the Administration for Children & Families under the U.S. Department of Health and Human Services) Applying Human-Centered Design to Human Services: Pilot Study Findings, also attached as a PDF.

This report concluded that the application of HCD for Human Services showed great promise and results and all three test groups wished to continue the practice. However, their study ended at the Implementation Phase.

The Mission Promise Neighborhood is energized by our results with the human-centered approach to community data. We will have further examples of success and what we learn from our failures in the Implementation Phase.

We are confident that the Community-led research, with the right support, will produce further findings and data to help us advocate for change based on what our local community says matters. That data will be continuously generated by and contextualized by them.

4. What resources, programs, training, or other tools *can expand opportunities for historically underrepresented scholars and research institutions to access and use equitable data across levels of government* ?

Support and training for Human-Centered Design facilitation will give researchers additional tools for focus groups and other qualitative data collection. The interview style and recruitment of community members as co-researchers can be applied in smaller scale projects or a la carte as a part of a variety of methods.

Aside from HCD –

Our agency saw successful engagement in data analysis from a 9 month-long 2021 NeighborWorks Tableau Fellowship. The intensive training put a powerful and creative analysis tool in the hands of one of our junior Evaluation team members. She has the lived experience of the Mission District community we serve and brought this lens to the data.

She used de-identified demographic and Housing Opportunity Program service data from our internal client database alongside publicly available housing data. While she was not able to share the data tool with the community at large, she shared it with our Direct Service Staff. The ability to interact with the data, visualize it on a map and change it dynamically helped the conversation, staff stories, which in turn gave the data context. This dynamic interaction helped generate new ideas and subversive insight into the systemic problems negatively impacting the way our city funds housing programs.

5. What resources, programs, training, or tools *can increase opportunities for community-based organizations to use equitable data to hold government accountable to the American public* ?

Again Human-Centered Design facilitation training along with funds to offer stipends, technology and technology training to community members who participate on design teams would support equitable data collection and engagement.

But it is not just community members who deserve to be the *humans at the center*.

An often overlooked subset of our community is the Direct Service staff who work with the community most intently. They are overworked and underpaid and often not given the time and space to ruminate on and discuss the data that reflects their work. Navigating healthcare, education, public benefits and job searches with hundreds of clients in a year means they see the patterns of broken systems everyday. They are the most frequent users of the systems. Sharing data with them and hearing their stories behind the data – and challenging the data – is imperative.

Funding and training to use data together with direct service providers across neighborhoods and domains would provide opportunities for breaking out of silos. They have the insight to utilize data to address program and agency issues that are not necessarily evident to a single family or individual pursuing assistance, but patterns that can more easily be seen with the frequent usage only a direct service provider experiences.

6. What resources, programs, training, or tools *can make equitable data more accessible and useable* for members of the public?

As explained in depth in question #3 - the data must be meaningful to them to be engaging and useful. But even our creative digital solution has barriers, namely basic literacy. We also have a multitude of languages in our community, not just English and Spanish, impacted by similar systemic barriers. Audio stories on our Community Report Card app are one way to overcome low literacy levels, but we want everyone to be able to access the quantitative data, too. Add to that low digital-literacy levels and we knew these data needed to be much more than pie charts on a screen. Even the most highly literate of the American public might not read much past 280 characters allowed on a Twitter post or might glaze right over a chart or diagram.

Make data into art. Make it tactile. Make it hands-on and put it in our built environment

Attempts at low-resolution ideas for implementing our app asked, “What if there were no digital technology at all?” We could still collect data and visualize it though wooden beads on a giant abacus, vessels filling up or leaking water based on the data segments each vessel represented. Scenario responsive data visualization would allow the user to change the data based on different inputs. Just like the direct service staff mentioned in Question #4 was more engaged when they could play with the variables on a digital Tableau dashboard, any member of the community is more likely to stop and discuss the data if they can touch it and impact it.

We plan to turn the data generated from our app into visualizations our community can interact with in our agency's office building and community spaces.

7. In which agencies, programs, regions, or communities *are there unmet needs, broken processes, or problems related to participation and accountability* that could be remedied through stronger collaborations and transparency around equitable data?

None of these data related problems will be remedied if the data is not relevant to the public we expect to engage. In order to center someone else, we must first de-center ourselves. That may meen letting go of our preconceived notions of which data matters and what *equitable data* really means. Any agency that is not humbly asking itself whether it is measuring the most meaningful metrics could be made stronger through collaborating with the public it aims to serve.

Supporting small-scale, local, initiatives to deconstruct data is a simple place to start and will produce the most data, successes and failures to learn from. While at the same time, on a federal or state level, build a data "Learning" infrastructure that channels what we learn from local communities into insights for policymakers and encourages government agencies to pilot radically different solutions instead of discouraging them because they are radically different.

RESULTS FOR AMERICA

October 3, 2022

Denice Ross, U.S. Chief Data Scientist
NSTC Subcommittee on Equitable Data
Office of Science and Technology Policy
Eisenhower Executive Office Building
[redacted]
Washington, DC
20504

Re: Engagement and Accountability Notice of Request for Information, Office of Science and Technology Policy (OSTP) – Document Number 2022 - 19007

Dear Ms. Ross,

Growing economic inequality and disparities of opportunity are among the greatest challenges of our modern society, and addressing these systemic obstacles requires transparent, equitable data to spotlight new, innovative solutions that meet equity considerations in program and policy design, implementation, and outcomes. As a national non-profit organization that empowers federal, state, and local leaders to use data and evidence to drive improved equitable outcomes for individuals and communities, Results for America submits the following comments. Our comments are informed by collaborations with the Data Quality Campaign, Blue Meridian Partners, Strive Together, Race Forward, and Harlem Children's Zone.

We welcome the opportunity to further discuss these responses and applaud the Office of Science and Technology Policy for considering how data can increase equity for underserved populations.

1. What are examples of successful collaborations involving equitable data between the federal government and (a) tribal, territorial, local, and state governments, or (b) local communities?

Results for America's *How City-County Collaborations Advance Economic Mobility* and the Institute of Education Sciences Statewide Longitudinal Data Systems (SLDS) effective practices offer important insights into successful, interjurisdictional collaborations in California, Ohio, Georgia, Tennessee, Washington, and Pennsylvania. More specifically, government leaders that used these following practices had the most success to build strong data sets that increased the likelihood of achieving equitable outcomes:

- Pool data among various levels of government to identify challenges and shared metrics to track goals;
- Make pooled data publicly available and enable common search functions across race, salaries or socioeconomic data, education, workforce, and other data;
- Disaggregate data across intersectional categories to draw specific conclusions for various groups disproportionately affected by inequities;
- Adopt formal data-sharing agreements that implement responsible data stewardship;
- Align metrics that build off of existing city, county, state, and federal metrics; and
- Develop a shared data system that centralizes information with one partner or an independent third-party hosting the data.

2. Among examples of existing federal collaborations with (a) tribal, territorial, local, and state governments or (b) local communities involving equitable data, what lessons or best practices have been learned from such collaborations?

RFA's analysis has found that governments that implement the following practices were more likely to have increased collaboration:

- *Define community engagement* - providing a federal definition for "community engagement" could clarify expectations for collaboration across varying government levels. Such clarity could enable tribal, state, and local governments to empower communities to more effectively engage in decision making and deliver equitable outcomes while also ensuring engagement strategies are interoperable with federal data systems. Building on Results for America's April 20, 2022 Recommendation to the U.S. Treasury for language to guide community engagement, the term "community engagement" should include, "1) alignment on key priorities and strategies; and 2) engagement and input from a broad set of community stakeholders (i.e. place-based networks, community-based organizations, service providers, advocacy/grassroots organizations, & businesses)".
- *Invite community stakeholders to the table* - when federal agencies encourage local, state, and tribal governments to seek and incorporate diverse community feedback from constituents, this signals that federal leaders not only seek diverse perspectives, but that community feedback is essential to ensuring data equitably drives national policies and funding. While the federal government has made progress to engage communities, more can be done to prioritize community feedback to advance equity. For example, the U.S. Treasury's State and Local Fiscal Recovery Fund Compliance and Reporting Guidance outlines that tribal, territorial, local and state governments should solicit community engagement strategies to support equity goals. Collaborations can be strengthened through providing training and resources to help governments use an asset-based approach that integrates marginalized or underserved perspectives.
- *Prioritize proximate leaders* - increasing proximate leaders in government can offer critical perspectives for government collaborations. A proximate leader is, "someone who

has a meaningful relationship with groups whose identity, experience, or community are systemically stereotyped, feared, dismissed or marginalized." Building on work from the Actionable Intelligence for Social Policy at the University of Pennsylvania, proximate leaders in varying government levels can move data away from reinforcing inequitable legacies to meaningfully integrating marginalized community voices.

- *Integrate equity into the procurement and budget process* - Varying levels of governments that used data to prioritize equity into procurement and budget opportunities hold promise of meeting needs of underserved groups. With governments facing fiscal challenges, from increased cost of goods, supply chain obstacles, and pandemic response, some best practices infusing equity data and budgets include:
    - Pursuing formal structural changes to advance equity - the cities of Austin and Philadelphia created equity committees to revise budget proposals;
    - Providing training on improving equity through the procurement process - the Colorado Workforce Development Council hosted a training to simplify the process and improve services in vendor selection and public grant making; and
    - Improving vendor experience - By putting equitable outcomes first, the city of Tulsa streamlined the procurement process, building staff capacity and reshaping the experience of vendors, resulting in more requests for proposals submitted by local, women-, and minority-owned businesses.
- *Document best practices* - as tribal, city, and territorial governments have limited staff capacity to capture best practices and develop tools after using equitable data or implementing programs, having state or federal governments capture best practices and draft tools for future efforts can often institutionalize knowledge.

3. What resources, programs, training, or other tools can facilitate increased data sharing between different levels of government (Tribal, territorial, local, state, or federal) related to equitable data?

RFA's analysis has found that the following resources, programs, training, and other tools increase equitable data sharing by:

- *Decreasing data gaps among racial groups*
    - Racial Equity in Government Case Studies, Economic Mobility Catalog, Results for America
    - A Guide to Racial and Ethnic Equity Systems Indicators - Strive Together
- *Funding and integrating multi-sectoral data systems to be interoperable and transferable*
    - Toolkit for Centering Racial Equity Throughout Data Integration - Actionable Intelligence for Social Policy, University of Pennsylvania
    - Why Congress needs to get more serious about K-12 and workforce data - Michele Jolin for District Administration
    - Data for Equity - Data Quality Campaign

- *Promoting Human Capacity to Collect, Analyze, and Share Data*
    - Resources for Promoting Equity, Inclusion, and Cultural Responsiveness in Research and Technical Assistance, MDRC
    - Data-Informed, Equity Driven: Cultivating a Collaborative Data Culture - Social Policy Institute, Washington University in St. Louis
    - Moving Toward Equity Data Tool, American Institutes for Research

5. What resources, programs, training, or tools can increase opportunities for community-based organizations to use equitable data to hold government accountable to the American public?

In 2021 and 2022, Results for America worked with 14 community-based organizations to leverage American Rescue Plan dollars to meet their community goals. Through this work, Results for America documented that organizational capacity to affect policy change and/or public sector practice is significantly affected by the organization's capacity to strategically engage public sector partners. Community-based organizations need strategic capability building (technical assistance) or capacity (talent) to affect policy change and public sector practice. Outside of this, it may be difficult to secure the necessary funding, behavior change, and political will to improve outcomes at scale.

Building off these community partnerships, Results for America in collaboration with the White House co-hosted the Year of Evidence Forum event, "How to Effectively Integrate Stakeholder Engagement in Developing Data-Driven Programs." Over 200 participants joined to learn how to build and implement successful community engagement featuring mayors and board presidents in Oklahoma, California, Washington, and Illinois. An interactive workshop, "Evidence Forum: The Power of Federal Evidence-Based Policy to Improve Local Outcomes" followed the Year of Evidence Forum event using a Framework for Successful Community Engagement and related worksheet.

7. In which agencies, programs, regions, or communities are there unmet needs, broken processes, or problems related to participation and accountability that could be remedied through stronger collaborations and transparency around equitable data?

Results for America's Federal and State Standards of Excellence offer insights where federal agencies and states lead in data policies and where improvements can be implemented. Leading federal agencies and states include the Millennium Challenge Corporation and the U.S. Department of Education, which scored highly among evaluation, research, and data, and Colorado, which provides resources on demographic data collection to statewide teams, respectively.

Equity Plans, developed in response to Executive Order 13985, *Advancing Racial Equity and Support for Underserved Communities Through the Federal Government*, provide further insights to this question. Results for America reviewed the Equity Plans on all nine federal agencies that participate in the Federal Standard of Excellence and notes that agencies lack capacities or facilities to implement equity plan goals, but outline plans to rectify shortcomings that include tracking mechanisms and accountability measures. Most action plans identify the need for either more staff, offices or whole entities dedicated to carrying out their specific equity goals. In this recognition, most plans also identify how their current frameworks lack the capacity to carry out this work.

More broadly, the federal government can play an important role in clarifying guidance around allowable activities that support equitable data integration, interoperability, and modernization efforts as well as cross-agency data sharing. For example, the April 2022 Office of Management and Budget memo, "Advancing Effective Stewardship of Taxpayer Resources and Outcomes in the Implementation of the Infrastructure Investment and Jobs Act" clarifies that grantees can combine program funds to support data-related program objectives. Similarly, the federal government should clarify to state, tribal, territorial, and local governments if and how government grantees can allowably use funding to support equitable data collection and use for annually appropriated programs. Additional collaboration to increase capacity to collect, analyze, and disseminate disaggregated demographic data could help meet unmet needs unique to underrepresented populations. As the Data Quality Campaign notes, without disaggregated data, governments cannot analyze how programming and funding affects various Americans and subgroups based on disability, race, socioeconomic status, sex, sexual orientation, or religion.

Some resources to help governments increase capacity on collecting demographic data to increase equity include:

- So You Want to Collect Demographic Data: Getting Started, D5 Coalition
- Framing Data to Advance Equity, Colorado Department of Public Health Environment
- Racial Equity: Getting to Results, Government Alliance on Race & Equity
- Designing Program Evaluation to Advance Equity, Colorado Department of Public Health and Environment

Sincerely,

Nichole Dunn
Vice President, Federal Policy
[redacted]
www.results4america.org

To Whom this May Concern,

I am submitting this short comment regarding the need to mobilize data for public health and health equity.

To start I will focus on the need to leverage and mobilize electronic health record data for health equity and local, state, and federal levels. I will start by emphasizing that the vast majority of EHR systems are privately owned, with Epic and Oracle making up the biggest market shares. This is a direct result of federal intervention through the meaningful use investments from the Centers for Medicare and Medicaid Services. In a move for data accessibility, Epic has been opening up its data infrastructure to be accessed by researchers wanting to answer health research questions at scale. This initiative, called Epic Cosmos, contains records from more than 162 million patient records and is just starting to be used by researchers to examine the impacts of various care regimes and advance evidence-based care. I will outline briefly why maintaining these open records is vital to the growth of evidence-based medicine as well as how the data sources can be mobilized to advance health equity.

In just the past 3 years since Cosmos launched, it has helped to support vital investigatory work across academia, clinical research, and the federal government. The CDC used Cosmos to study COVID reinfections, and researchers have mobilized the data to study the linkages between COVID and preexisting conditions like diabetes and alcohol use disorder, delays in cancer care, and even firearm injuries. Cosmos allows researchers to query clinical questions in minutes and provides data that is representative of the United States, across race, sexes, age, rural-urban, and types of insurance. Finally, it includes patient-generated data as well as social determinants of health, a marker of health equity. This source of data must remain free to use, especially given the vital questions that can be asked by collaborators such as community organizations and public health departments that do not have the capital of major medical systems. Given the rise of EHRs use as a result of direct federal intervention, these deidentified patient records should be considered a vital asset that can be leveraged by policymakers and federal employees to pursue evidence-based policymaking and funding that supports overall health.

To outline how Cosmos (and open-source, EHR data) can be leveraged for health equity, I will speak about some of my work studying medical technologies that create inequitable outcomes in patient care. To make my point, I will focus on the pulse oximeter, which has been in the news recently because of the racial bias in the tool that negatively impacted patient outcomes during COVID-19. Pulse oximeters (pulse ox) are ubiquitous tools in medical settings, where they help clinicians track the “fifth vital sign”—oxygenation—in patients. These pulse ox readings are then used to inform how clinicians treat everything from asthma to heart failure to COVID-19, with the numerical score being input directly into decision-making algorithms. The racial bias in the tool led to an overestimation of oxygen content, and thus delayed patient care. Studies (on a small scale) show that during the pandemic, Black patients have been 29% less likely to receive supplemental oxygen as part of their COVID-19 treatment, and three times as likely to suffer occult hypoxemia. By mobilizing de-identified EHRs, we could map how this problem affected patients across the nation and the scale of the delay in care in different treatment settings. These findings could then directly inform the FDA about a need to do a post-market evaluation of the technology, and perform adequate safety evaluations to then inform the future use of this technology in patient care. CMS and its accrediting agencies can monitor these technologies and assess whether they should receive government funding and/or be procured in federally-funded hospitals, thus providing incentives for companies to develop more equitable technologies. While my focus was on technology, I can see this regular review and evaluations extending to other medical products like drugs, as well as care practices, that need to be evaluated for bias to create a more equitable standard of care.

Furthermore, there is an enormous need to modernize and standardize data collection in public health, focusing on data sharing capacity between health providers and public health agencies. During the COVID-19 pandemic, many public health agencies were reliant on outdated models of information transfer, such as fax machines, greatly inhibiting the ability to respond to the pandemic. The lack of data infrastructure can be directly connected to funding directed to public health. Public health funding has declined over the last two decades, with the Center for Disease Control and Prevention (CDC) seeing a budget reduction of ⅕ and the Hospital Preparedness Program, the primary source of federal funding for health systems to respond to emergencies, seeing a reduction of nearly ⅔ since FY2002, when adjusted for inflation. While resources have been infused into public health departments through the American Rescue Plan Act, past crises have shown these investments are cut after the emergency period subsides. Federal funding for public health is done in a disease-specific way, limiting investment in resources and infrastructure like surveillance, data collection, and the workforce.

Beyond pandemics, this outdated information technology infrastructure will very likely fail in the face of climate change and emerging climate threats. Climate change presents a diverse array of threats to human health, from immediate climate dangers, such as hot temperatures, rising sea levels, more zoonotic diseases, diseases transmitted from animals to people, or the physical impacts of natural disasters to indirect threats like damages to the social infrastructure of communities, like homes, businesses, and transportation networks (for people and food, water, and resources), and disruptions to personal lives.

Marginalized communities are at a greater risk of the adverse effects of climate change. These differential impacts are already being felt by frontline communities, those that experience the “first and worst” of climate change, especially during the COVID-19 pandemic. Researchers at Harvard University found that higher historic exposure to particulate matter, and air pollutants, were positively associated with higher county-level COVID-19 mortality rates. Vulnerable communities are more likely to live in areas with a higher burden of pollution according to the American Lung Association, contributing to the observed disparities in the overall COVID-19 death toll for Black and Latino Americans. The EPA’s 2021 report on climate and social vulnerability predict these disparities will grow under warming scenarios of 2°C and 4°C, with minority populations experiencing a greater risk of poor health and infrastructural damage compared to non-minority populations. Vulnerable communities are more likely to not have health insurance coverage to care for climate-caused or exacerbated diseases and lack climate adaptations. Interventions to address disparate impacts must address the systemic causes of both climate change and health inequities. Most of our current data infrastructure is not well equipped to monitor these threats and their cumulative impacts.

Big investment is needed to fund infrastructure, especially data infrastructure, to effectively respond to climate change. For example, the CDC’s Climate the Ready States and Cities Initiative can only support 9 states, one city, and one county, despite 40 jurisdictions having applied. The Trust for America’s Health (TFAH) found that a funding increase from $10 million to $110 million would be required to support all states, improve climate surveillance, and offer resources for scientific studies. The TFAH also found that an additional $75 million is needed to extend the CDC's National Environmental Public Health Tracking Program, a program that tracks threats and plans interventions, to every state. Finally, and most seriously for a just transition, the Office of Climate Change and Health Equity remains unfunded a year after being established, leaving it with no permanent staff. FY2023 appropriations authorize $3 million for the office, yet it is unclear whether it will make the final budget resolution. State governments have had to take the lead, with California spending $100 million on community cooling centers and Washington's Department of Health hiring the state's first climate epidemiologist in summer 2022. Federal support, though, will be critical to sustaining this progress. This will be especially true in deploying the necessary affordable multi-modal monitoring technologies needed to increase the capacity to identify emerging climate threats.

October 3, 2022

NSTC Subcommittee on Equitable Data
[redacted]ogy Policy
Washington, DC 20504

SUBJECT: Engagement and Accountability RFI

Dear Denice Ross and OSTP Staff:

Thank you for the opportunity in requesting information regarding data equity and collaboration initiatives. My name's Denny Vang and I am passionate about promoting, advancing, and shaping processes, structures, and outcomes to align more closely with health and racial equity. I am submitting this RFI as an individual submission but have worked (and continue to do so) with partnership of the Hmong Public Health Association and the Minnesota Department of Health as well as other stakeholders that we hope to build partnerships within the future.

I understand that responses to these RFI will not be conducted, but I do hope that there will be greater opportunities and engagement from the federal government in taking initiatives to collaborate with other entities that are conducting this work—through a multitude of channels. Listening to others seems to be the first step in this process—as portrayed by the RFI—but I hope that including these voices, empowering these entities, supporting the advocacy work already being done in these spaces, and maintaining mutual trust can occur. Actions need to be taken and accountability should begin. Listening and then inaction is detrimental to all involved parties.

I have attached a PDF with my responses along with this letter. Thank you again for seeking information from different constituents. I look forward to the next steps.

Sincerely,

Denny Vang

Enclosed: Responses for RFI

Response to Questions:

I. What are examples of successful collaborations between the Federal government and (a) Tribal, territorial, local, and State governments or (b) local communities involving equitable data?

Response: The Hmong Public Health Association (HPHA) with partnership of the Coalition of Asian American Leaders (CAAL) had a released a report during the onset of the pandemic that showed the disproportionate impact of COVID-19 on different Asian ethnic groups which are often times aggregated into the Asian category. This report focused on the Hmong, Karen, and Karenni populations and it clearly shows why the Office of Management and Budget (OMB) race categories, such as Asian, need to be disaggregated. The report can be found here: CAAL-HPHA-Covid-Report-Fin.pdf (caalmn.org). I'm unsure as to how the federal government has followed up with these local advocacy and state partnerships when it comes to successful collaborations from their side. I do know that data equity and disaggregated data within federal briefings has been considered on a larger scale during COVID. Whether this has resulted in greater collaboration and partnerships or some defined metric of success in some way—I do not know.

II. Among examples of existing Federal collaborations with (a) Tribal, territorial, local, and State governments or (b) local communities involving equitable data, what lessons or best practices have been learned from such collaborations?

Response: I know of one collaboration that a good friend and colleague of mine has mentioned which pertains to this question. Him and his team have tried to write reports and conduct policy-based initiatives to consider data disaggregation for Medicare and Medicaid data. Unfortunately, there's been a lot of stop gaps within other federal government entities, in which this work doesn't move forward for several reasons. Agencies don't have time to read the reports and put a hold on the work, different agenda priorities among different entities, and there requires a concerted effort from multiple systems that doesn't always happen. So, with these lessons learned, there could be discussions on strategic system-wide initiatives that could be built or engaged in.

III. What policies, resources, programs, training, or other tools can facilitate increased data sharing between different levels of government (Tribal, territorial, local, State, or Federal) around equitable data?

Response: Currently at the Minnesota Department of Health, there are efforts to begin working on a data cataloging system as well as data demographic standards. The data standards were spearheaded and continue to be co-created and amplified within different communities for their feedback. Additionally, strategic thought has been put into spreading awareness, cross-collaboration with different entities and community partners, and implementation. Both these efforts are in conjunction to better promote data sharing, visibility, useability, and data organization. Most importantly this will aid our data equity efforts for communities and for improving systems that don't support equitable results.

IV. What policies, resources, programs, training, or other tools can expand opportunities for historically underrepresented scholars and research institutions to access and use equitable data across levels of government?

Response: Data equity has been a longstanding issue, and this was greatly felt and seen when the COVID pandemic began. It seems that the pandemic has been a catalyst to improve the systems and consider actionable next steps. Firstly, returns on investment and financial health can be a big driver for different stakeholders and entities. To move the work forward with data equity and collaboration it's important to consider the barriers. Therefore, considerations on doing reports and deeper analysis on how data equity provides financial returns or cost savings in some capacity—could be beneficial. Furthermore, coupling this with what is already known about why this work matters to health and racial equity outcomes is significant. There may need to be a realignment of why the work matters, how to conduct the work, and then what outcomes or expectations are relevant.

Afterwards, providing grants, funding, and policy level changes to help support the underrepresented scholars and research institutions who align with this work can move things along more efficiently. For the Hmong Public Health Association, everyone is a volunteer member and there's no compensation. Everyone is conducting the work because of the passion for equity and for improving the social welfare of communities. There needs to be support on multiple fronts for those already doing this work. Even for MDH, the current role working on data equity is grant funded and will only last for two years. It's a small team and so building out capacity is difficult when there are initial barriers in place.

V. What policies, resources, programs, training, or tools can increase opportunities for community-based organizations to use equitable data to hold government accountable to the American public?

VI. What policies, resources, programs, training, or tools can make equitable data more accessible and useable for members of the public?

Response: I'm grouping questions V and VI together here because my response for this will coincide with that challenges that first need to be addressed. One of the biggest hurdles about data equity is that it mostly affects those that often do not have their voices at the decision table. This may then lead to a structural inequity where the priority of data disaggregation and better data equity with all types of communities is sidelined. Moreover, due to a compounding effect from social, political, and economic determinants of health many people from respective communities that are underserved may not necessarily have the skill sets, the know-how, and the awareness of what the data can be used for—or how they can help support advocacy or change efforts. In a world where, data drives many things, there also needs to be the relationships and people that help move this work forward so that there's meaning and equity. In terms of accountability, those in power can be held accountable when there's a strategic plan that can include a multi-approach of community, stakeholders, researchers, etc. A systems aware change process is needed.

VII. In which agencies, programs, regions, or communities are there unmet needs, broken processes, or problems around participation and accountability that could be remedied through stronger collaborations and transparency around equitable data?

Response: I will state broadly here that: from personal research, current public health efforts in MN, and grassroots advocacy work on data equity—that I have engaged in—there is a lot of unmet need. This unmet need occurs around those of a differing race and ethnicity from the OMB categories, data on disability status, and those of a different sexual orientation and gender identity. Technical data knowledge for data collection, data standardization, and data analytics for these underserved and underrepresented groups is where there's a lot of unmet need. Additionally, the need to build collaborations and sustain partnerships with data equity-focused initiatives and system changes has much room to grow and evolve. There are many sectors within public health, health systems, and research that could benefit. Harnessing this will be mutually beneficial for moving this work forward.

PARTNERS FOR RURAL TRANSFORMATION

Friday, September 30, 2022

Ms. Denice Ross, U.S. Chief Data Scientist
Attn: NSTC Subcommittee on Equitable Data
Office of Science and Technology Policy
[redacted]

Notice of request for information (RFI): Advancing Equity with Community Data Partnerships

Partners for Rural Transformation Comments

Dear NSTC Subcommittee on Equitable Data Members;

Guided by a vision of a nation where persistent poverty no longer exists, six regional Community Development Financial Institutions (CDFIs) located in and serving regions with a high prevalence of persistent poverty came together. The CDFIs—Come Dream | Come Build (cdcb) of Brownsville, Communities Unlimited, Fahe, First Nations Oweesta Corporation, HOPE Credit Union and Enterprise Corporation, and Rural Community Assistance Corporation—formed a coalition, currently called the Partners for Rural Transformation ("The Partners"). With a shared ethos of investing in both people and places and informed by the voices of local people, we seek to unify around opportunities in diverse communities at a time of great division in our nation. A closer look at persistent poverty America reveals how structural exclusion by place and race continues to paint a picture that is steadfastly rural and marred by racial, capital and data inequity. These challenges are exacerbated by a history of disinvestment and data extraction.

Rural America faces systematic, avoidable, and unjust economic, health, and racial disparities. Legacies of forced geographic and cultural displacement, enslavement, financial discrimination, residential segregation, and transitioning economies have left an indelible mark. Despite evidence of persisting rural inequities, there is no coordinated effort to build a comprehensive evidence base to support deep systems change – that is, to generate research that informs the shifts in policies, practices, resources, power, trust, and attitudes necessary to advance equity. Therefore, Partners for Rural Transformation suggest the following steps to achieve data equity:

- Expand Evidence-Based, Policy-Relevant Rural Research: Highlighting rural assets through research and data to shift attention from deficit-based narratives to policy-relevant, solutions-focused outcomes; Federal agencies such as HUD and the U.S. Department of Agriculture could support development and maintenance of new Housing Assistance Council (HAC) tool, Rural Data Central, which helps local community-based organizations and municipalities better strategize, plan, and administer federal resources and programs through combining data from numerous federal agencies that will provide information on social, economic and housing characteristics of communities in the United States;
- Equity Focused Impact Measurement: Capturing the degree of success of new federal and state programs with race and place in mind, and transparent dissemination of results;
- Increase Data Accessibility: Holding educational sessions (webinars, in-person trainings) on datasets available and how to leverage them; adding a "Reliability Index," a classification or typology to Home Mortgage Disclosure Act (HMDA) data that would that would indicate how much lending activity in a particular market is covered by the

data. For example, markets such as the colonias in the U.S.-Mexico border region, where many home purchases involve cash-only transactions that are not covered by HMDA, would be classified as having "limited coverage." Restoring rural codes back to American Housing Survey, conducted by the Census Bureau for the U.S. Department of Housing & Urban Development.

- Developing More Robust Definition(s) of Rural: Leveraging resources by redefining rural America to target rural communities of persistent poverty and communities of color. Consider multiple definitions to ensure equity across race, place and rurality;
- Launch a National Rural Research Network and Agenda: Connecting and amplifying rural researchers by facilitating a national rural research agenda, promoting policy-relevant research, and translating evidence to national audiences; adding metrics to U.S. Department of Labor's National Agricultural Workers Survey (NAWS) such as: detailed information on housing quality or conditions, and farmworkers on temporary H-2A visas who account for a large portion of the farm workforce. NAWS should be revised to collect this information, and federal agencies should support relevant private efforts
- Strengthen Investment Capacity and Strategy: Supporting asset-based policymaking, investments, and impacts through capacity building and tools to strengthen how decisions are made, outcomes are tracked, and equity is advance

Rural America is much more than the sum of its deficiencies. These communities possess unique strengths and potential—in human and natural capital, in social and physical infrastructure, in cultural resources. To affect change and increase equity requires evidence-based policymaking that invests in these strengths, centers rural voices, and focuses on solutions and not just problems. The moment is now. With rural issues gaining attention as part of the national equity agenda and historic and bipartisan federal investments in rural communities through the American Rescue Plan Act, Inflation Reduction Act, and the Infrastructure Investment and Jobs Act, many are seeking new data and evidence-based strategies to advance equity and strengthen investments to create thriving and equitable rural futures.

In Partnership,

[redacted]

PARTNERS FOR RURAL TRANSFORMATION

cdcb come dream. come build.
COMMUNITIES Unlimited
Hope credit union enterprise corporation
fahe Strength in Numbers
OWEESTA
RCAC

beyond lucid
Technologies & Consulting

From the Desk of
Jonathon S. Feit, MBA, MA
Co-Founder & Chief Executive

2 October 2022
Ms. Denice Ross, U.S. Chief Data Scientist
Stacy Murphy,Operations Manager
Office of Science & Technology Policy
Executive Office of the President of the United States
Via Electronic Mail to [redacted]

Re: Engagement and Accountability RFI

Dear Ms. Ross and Ms. Murphy:

I hope this letter finds you well. Within the Fire & Emergency Medical Services industry (also known as "Mobile Medicine"), I occupy several roles, including as:

- Entrepreneur (CEO of a *prehospital* health records system and health information exchange);
- Technologist (presenting often for trade and academia on matters of finance and education);
- Journalist (for the *Journal of Emergency Medical Services* and *EMS World Magazine*); and
- Association member (representing the Data Committee for the California Fire Chiefs Association, EMS Section, Northern Branch—including as its delegate to the California Health Data Exchange Framework Stakeholder Committee).

Prior to my present role, I served in the White House Office of Management & Budget, where I liaised frequently with OSTP. I mention this to provide some context for my comments: i.e., that I empathize with—and appreciate—OSTP's desire to ask about whether its ongoing efforts to collect, aggregate, and analyze data are sufficiently equitable and *useful*. I have compiled the questions from the RFI below (truncated):

A. *Successful collaborations involving equitable data between the Federal government and (a) Tribal, territorial, local, and State governments, or (b) local communities?*

B. *What lessons or best practices have been learned from such collaborations?*

C. *Resources, programs, training, or other tools can facilitate increased data sharing between different levels of government related to equitable data?*

D. *Resources, programs, training, or other tools can expand opportunities for historically underrepresented scholars and research institutions to access and use equitable data?*

E. *Resources, programs, training, or tools can increase opportunities for community-based organizations to use equitable data to hold government accountable?*

F. *Resources, programs, training, or tools can make equitable data more accessible useable for members of the public?*

G. *Unmet needs, broken processes, or problems related to participation and accountability that could be remedied through stronger collaborations and transparency?*

In light of recent natural disasters (e.g., Hurricane Ian), statistics regarding roadway injuries and deaths (i.e., more deaths than in several decades, according to the National Highway Traffic Safety Administration), and the continuing stepwise implementation of changes pertaining to healthcare data in light of the 21st Century CURES Act, I would like to make two points about the value of including Mobile Medical agencies and their data in the Government's consideration of equity initiatives:

1. It has been well-documented that ambulances use and related services—including the emerging discipline called "Community Paramedicine" or "Mobile Integrated Health," which finds a federal analogue in the Center for Medicare & Medicaid Innovation's "Emergency Triage, Treat and Transport" (ET3) program—skews toward the poor, underserved, and disenfranchised. In other words, as I have often said and published, **"Mobile Medicine IS Safety Net Medicine.**"

2. However, to the extent that there remains a widespread lack of clarity regarding the status of Mobile Medicine (Fire & EMS) under federal law, and therefore a lack of clarity about the extent to which mandates such as Meaningful Use and the 21 Century CURES Act—*and incentives associated with the implementation of such mandates*—apply to Mobile Medical agencies, an extraordinary amount of data associated with out-of-hospital care, from chronic disease to overdose intervention, is unseen by the Government and is unavailable for access, use, aggregation, or incorporation. The regulation of emergency medical services is "artificially" split, to dramatic downstream effect. The following (federal only) agencies are among the many that regulate pieces of Mobile Medicine.

    a. National Highway Traffic Safety Administration, Office of Emergency Medical Services

    b. Federal Emergency Management Agency, U.S. Fire Administration

    c. Health & Human Services, Administration for Strategic Preparedness and Response

    d. Executive Office of the President, Office of National Drug Control Policy (ONDCP)

    Each of these has specific requirements in terms of data. They often do not talk to one another. They frequently contradict one another, both at the data level and at the mandate of use level (i.e., more focus on chronic care management and "whole person care" alongside a greater focus on car crashes). Perhaps most poignantly, the lack of cohesive data has left the industry underfunded to the point where Fire & EMS agencies, across the United States, are being forced to cut services.

3. In addition to these, many state, local, and even multi-jurisdictional authorities impose upon Mobile Medicine: For example, the California Emergency Medical Services Authority sits within the state department of Health & Human Services, while the California Department of Forestry and Fire Protection sits within the California Natural Resources Agency. But when dealing within major wildfires, EMS agencies go into fire zones, and fire services provide emergency medical services.

4. The crossover between these agencies—but the separate nature of their regulatory authorities—has led to a range of political, operational, and financial conflicts that are in part the fault of competing data requirements—and as such, could be remedied through a clearer policy related to data collection and use. Unfortunately, over time, rather than being remedied they have festered into mistrust that has contributed to the arrested development of health information exchange in California. Some jurisdictions have even turned down millions of dollars in grants that would have benefited underserved communities, due to a lack of trust between the local fire and EMS agencies.

5. One poignant and tragic example of information that has been lost amid conflicting government mandates pertains to the national drug crises relative to opioids, opiates, amphetamines, and crack.

6. *At present, we are aware of no state that enjoys interoperability between the Prescription Drug Monitoring Program (PDMP) and the emergency medical service data and/or fire data repository.* This has impacted the political sphere in many ways, including around the discussion of safe injection sites: When asked about the utility of safe injection sites to address substance use disorders in his community, the chief of an ambulance service in a community that struggles with a high rate of addiction and overdose, responded that the answer depends on the nature on the substances being used. If the community has an injectable problem, a safe injection site can help. If most overdoses in the area involve pills, smoking, or snorting, then safe injection sites "could give people another way to get high." A more nuanced approach to the crisis demands deference to data so that each proposed solution fits its need and alleviates the root cause vs. papering over it (the latter is a common and ineffectual approach that has earned a bevy of illustrative nicknames, like "lipstick on a pig" or "Band-Aid on a bullet wound"). However, no such data are available: without access to prehospital data, so if the patient is resuscitated but refuses transport to a hospital, the PDMP never sees the overdose or its suspected cause, so policymakers referring to the PDMP for guidance are using data that are flawed by definition, perhaps to an extreme degree.

7. A second problem is that the data themselves are insufficient with respect to substance use—a factor that prevents equitable use of data that emerge from its collection in the field. The National EMS Information System has been honest about restrictions in its data use agreements that prevent the provision of granular detail about the location and nature of overdose clusters, even if doing so could enable community engagement and prevent death and injury from "hot batches." The restrictions are may be borne out of a concern for patient safety and privacy, but those could be attended in other ways. State regulators are instead compelled to use separate databases, but data coming out of these systems is only as good as data going in. As this author wrote in a publicly distributed 2019 white paper titled, "*Naloxone (Narcan) as a Poor Proxy for Overdose: Toward a National Standard for Capture of Drug-Related Data by EMS Agencies Across the U.S.A.,"* NEMSIS data are insufficient to determine causation because medications are rarely administered on their own by a Mobile Medical (Fire & EMS) professional, and because Mobile Medical professionals generally lack access to contextual information (like the patient's medical history) that are important to assess when determining whether an overdose was the cause of injury or a contributing factor (e.g., if an opioid exacerbated an underlying condition, or if the patient took more than prescribed).

8. Related directly to social equity, new Government-led frameworks for the data use and sharing—e.g., the Trusted Exchange Framework and Common Agreement (TEFCA)—are only just starting to include use cases associated with the "Unknown Patient," also known as

a John or Jane Doe. But Unknown Patients may be unknown for a range of reasons in a Mobile Medical environment: language barrier; injury that causes the individual to be unable to communicate; disability; age (e.g., a child or elderly patient); effect of substance or medication. ***To require that patient must attest to a past data lookup is inherently inequitable, because he or she may be unable to do so.***

9. The relatively meager participation of Mobile Medical (Fire & EMS) agencies in recent major, data-driven funding initiatives with the potential to positively impact Mobile Medicine—e.g., ET3 and the Safe Streets for All (SS4A) Program—should be considered instructive. They highlight dissonance between what the Government *thinks* is easy and inviting of participation vs. concerns harbored by Mobile Medical agencies about the downstream costs of using federal funds even when the outcomes may be worthwhile. The Government has an opportunity to be clearer, for example, about the real burdens associated with accepting a grant, such an influx of paperwork or risk of an audit—both of which can be expensive in terms of time, external counsel, and delayed payments.

Finally: We simply wish to make a statement asking that the Government do a better job of ensuring that the case studies it highlights are fair, true and accurate. We are personally aware of several instances in which federal publications highlighted innovations that never in fact came to pass, or were significantly scaled down—a moral hazard made possible by publishing case studies before data were available to prove their veracity and impact. By contrast, despite admirable activities by agencies such as the GSA Schedule 70 to create “fast-lanes” for entrepreneurs to engage with Government and provide data showing success, it can be challenging to break through the noise (especially at the local level, e.g., liaising with local or state elected officials). This friction is ironic because the federal government—especially the Biden administration—has made plain its intention to support innovation in data-driven areas like healthcare.

Labyrinthine regulations like the intersecting agencies noted above (just with respect to Mobile Medicine, let alone transportation, housing, food, and the many other aspects of life that contribute to equity) make it harder for innovators to attract support, because time is everyone’s most precious commodity—but the fewer hands that are available, the more every minute counts.

Perhaps the Government could conceive of a virtual (or physical?) space for innovators to submit case studies, including their associated data, to a growing repository of success stories from which others can learn—the better to bridge “islands of success” that occur frequently in smaller American companies and communities, where the resources to promote all that is wonderful and working are scarcer, but success at having found a path can encourage others who are seeking a path? Thank you for your consideration—I am happy to answer any questions or concerns.

[redacted]

Jonathon S. Feit, MBA, MA
Co-Founder & Chief Executive
[redacted]

NNAAC
NATIONAL NETWORK FOR
ARAB AMERICAN COMMUNITIES

www.nnaac.org

October 3, 2022

Office of Science and Technology Policy
Attn: Public Comments

Re: Request for Information; Equitable Data Engagement and Accountability Engagement and Accountability RFI

Dear Ms. Ross,

On behalf of the National Network for Arab American Communities (NNAAC), a consortium of 30 community-based organizations across 13 states, I am pleased to submit this comment regarding the Vision for Equitable Data (VED).

"Equitable data are those that allow for rigorous assessment of the extent to which government programs and policies yield consistently fair, just, and impartial treatment of *all* individuals. Equitable data illuminate opportunities for targeted actions that will result in demonstrably improved outcomes for underserved communities [emphasis mine]," begins the VED report. The first component listed in the VED document is disaggregation of data. Though there have been steps at local and state levels—including in health care and education—to remedy the federal government's lack of data disaggregation, the MENA community is functionally erased in federal data collection. The group, listed as White on the US Census and across federal data collection forms, is not represented in federally conducted or supported data collection and research activities, as well as federal programs intended to address underserved communities.

Without a MENA category, we are significantly limited in our ability to assess the needs in our communities and provide relief. It is worth briefly considering the source of this exclusion. The Office of Management and Budget (OMB) coordinates the federal statistical system, which comprises a set of principal statistical agencies which either conduct or support data collection activities across all levels of government, civil society, and the research community. The OMB coordinates statistical activity through a set of Statistical Policy Directives. Statistical Policy Directive Number 15 (SPD No. 15) concerns the minimum standards for data collection on racial and ethnic groups for all institutions across government, civil society, and the research community. According to the latest guidance, data on MENA Americans is aggregated into and disarticulated by the White reference category. SPD No. 15 disarticulates the MENA community. To the extent that federal agencies rely upon data collected through the standards set forth in SPD No.15 to design programs for underserved communities, MENA Americans are limited in their access to such programs. Without data to indicate the needs of MENA Americans, o , agency officials are ill-equipped to incorporate an understanding of MENA communities into the design of federal programs that alleviate culture or linguistic barriers to access of appropriate, high-quality, effective, and appropriate health care services. The same is true of MENA community access to programs targeted at specific risk behaviors or chronic health conditions, which tend to implicate individuals with similar cultural backgrounds and migratory histories. In these ways, MENA exclusion is felt in the statutory guidelines for federal programs, which determine availability of and eligibility for federally conducted and supported programs.

Through the data conducted through the American Community Survey, the Census Bureau produces data that provides a significantly representative account of the quality of life and well-being indicators for MENA Americans. MENA Americans face higher levels of poverty, are significantly more likely to have limited English proficiency, are less likely to have a high school degree, and are almost four times as likely to not have insurance than non-Arab Whites.[1] Further, private research suggests MENA residents face lower life expectancies and higher rates of cancer, hypertension, diabetes, and mental health disorders than non-Arab Whites.[2]

To alleviate these problems and truly move toward health equity, MENA Americans must become part of the data collection efforts. Congress imposes no limit on the authority of agencies to collect information on additional groups not articulated in SPD No.15, where doing so makes for better policy. In fact, the *Foundations for Evidence-Based Policymaking Act* authorizes the Department of Health and Human Services (HHS) Data Council to submit on an annual basis a list of the "data the [HHS] intends to collect, use, or acquire to facilitate the use of evidence in policymaking."

As it is established in the request for information posting, "[e]quitable data can illuminate opportunities for targeted actions that will result in demonstrably improved outcomes for underserved communities." Having no data, research, or statutory recognition as either an underserved community or racial and ethnic minority group, MENA Americans are excluded from available pathways to improved well-being and quality of life. NNAAC submits these comments as potential ways for the Office of Science and Technology Policy, to collaborate on inclusion of the MENA community.

Within the RFI is a series of questions. Here, I will respond to inquiries three, four, and five.

3. What resources, programs, training, or other tools can facilitate increased data sharing between different levels of government related to equitable data?

A good example of successful data sharing is with the Center for Disease Control's Environmental Justice Index. This tool has information on how the data is collected and analyzed, as well as an interactive map that shows specific information per Census tract. Public health departments rely heavily on this information to address environmental health issues. If this information cannot identify MENA populations, then the MENA populations served through the NNAAC network suffer from a limited access to representation in federally conducted or supported programs intended to address environmental justice concerns. The same holds true for other programs and initiatives which rely upon demographic data that does not disaggregate Additionally, the Department of Housing and Urban Development's Public Housing Dashboard and Low-Income Housing Tax Credit Dataset provide in-depth and intuitive information on demographic information. To provide meaningful and accessible information to the public, we must fully establish demographic categories—including data on the MENA group—and be able to reconcile these categories with Census information.

4. What resources, programs, training, or other tools can expand opportunities for historically underrepresented scholars and research institutions to access and use equitable data across levels of government?

Currently, there is no government-sponsored research or data on the MENA community at the federal level. Although states, such as Illinois and California, have taken steps toward equitable collection, truly meaningful data would require a top-down approach. The Arab Community Center for Economic and Social Services (ACCESS), the nation's largest Arab American nonprofit, hosts a body of private research. This research capacity, however, has its limitations. First, it is often outdated. A large portion of the research was conducted 10 to 20 years ago, creating a gap in current knowledge and trends. Second, much of this research took place in hyper-specific areas: we do not have any data on MENA residents nationally. Finally, much of this information is simply on Arab Americans instead of MENA Americans. Though Arab Americans make up the majority of MENA residents, it is not a one-to-one comparison. To truly address a community in virtue of their cultural and linguistic affinities, which corresponds with inclusion within the federal programs' authorizing statutes, data on MENA Americans must be aggregated, analyzed, and visualized in federally conducted or supported data collection activities national data and research. Opportunities for research communities and civil society organizations to utilize federal grants and data products in areas where enclaves of MENA communities reside would allow for more sustainable and scalable approach to MENA inclusion under the current OMB standards.

5. What resources, programs, training, or tools can increase opportunities for community-based organizations to use equitable data to hold government accountable to the American public?

Opportunities include supporting platforms and collaborative partnerships that allow the public to easily find meaningful data about the well-being of their communities and the services that are available to them. The Census Bureau's Community Resilience Estimates is a good example of this. To improve accountability and credibility with the American people, the government must provide tools that enable communities to not only visualize data but also track the government's progress toward equitable outcome. Section five of President Biden's "Executive Order On Advancing Racial Equity and Support for Underserved Communities Through the Federal Government" focuses on equity assessment, but there is no approach to providing any data to the public that can demonstrate the government's progress in increasing equity.

For questions, contact Adam Beddawi at [redacted]

Respectfully submitted,

Adam Beddawi
Federal Policy Manager

Center for the Study of Social Policy
Ideas into Action

June 13, 2018

Ms. Kathleen McHugh, Director
Policy Division
Administration for Children and Families
[redacted] Department of Health and Human Services
SW
Washington, DC 20024

RE: Proposed rulemaking for Adoption and Foster Care Analysis and Reporting System (AFCARS) data elements, 45 CFR 1355 (Mar. 15, 2018) [RIN 0970-AC72]

Submitted via email t [redacted]

The Center for the Study of Social Policy (CSSP) is a national nonprofit organization recognized for its leadership in reforming public systems. We work directly with state and local child welfare systems providing technical assistance on policy and practice strategies impacting families with young children, adolescents, transition age youth and expectant and parenting youth in foster care, youth facing homelessness, and youth who identify as lesbian, gay, bisexual, transgender or questioning (LGBTQ). We also serve as a federal court-appointed monitor in several states engaged in system improvement while under a class action Settlement Agreement. All of our work is devoted to ensuring that all children and youth served by public systems including the child welfare system achieve positive outcomes and can maximize their potential.

CSSP welcomes the opportunity to provide comments on the Advance Notice of Public Rulemaking (ANPRM) regarding the proposal to streamline data collection through the Adoption and Foster Care Analysis and Reporting System (AFCARS). CSSP previously provided comment on the NPRM for the 2016 Final Rule (81 FR 90524), the Supplemental Notice of Proposed Rulemaking (SNPRM) for AFCARS data elements related to the Indian Child Welfare Act of 1978 (ICWA) (81 FR20283), and the most recent NPRM regarding the proposed delay for compliance and effective date for the AFCARS 2016 Final Rule (83 FR 11450).

CSSP strongly opposes reducing the data elements in AFCARS as proposed in the current ANPRM. In order to use data to effectively drive policy, program, and resource development, allocation, and implementation – the states and the federal government need accurate and relevant data that are aligned with current best practice in child welfare. The 2016 Final Rule was a positive step toward collecting currently unavailable data. Without such data, federal, state and local leaders are unable to assess and evaluate the impact of their work and investments. There is broad state and local support to expand the AFCARS data elements. The AFCARS 2016 Final Rule was adopted following an extensive and thorough comment process and many states, including California, Minnesota, and the District of Columbia, have already started to collect these new data elements.

As described in more detail below, the benefit of adding these data elements far outweigh any associated costs and data collection burdens; they are each critically important to improving child welfare systems' ability to better support and promote the safety, permanency, and well-being of the children they serve.

Alignment with Federal Laws and Reporting Requirements
AFCARS data are used by HHS and state governments in multiple ways including assessing agency compliance with Title IV-E; preparing reports to Congress and state legislatures; budgeting based on trends in child welfare populations; identifying areas for technical assistance; and justifying policy changes and legislative proposals. The 2016 Final Rule was the first update to AFCARS since 1993, when AFCARS was first implemented. Since that time, several key pieces of federal child welfare legislation have passed, including the *Fostering Connections to Success and Increasing Adoptions Act (PL 110-351, 2008)* and the *Preventing Sex Trafficking and Strengthening Families Act (PL 113-183, 2014),* both of which require the Children's Bureau to collect and report on critical data elements that are currently not included in AFCARS. The required data elements included in these statutes are important for policy and program development aimed at promoting overall well-being outcomes for children and youth in foster care. Specifically, these statutes require states to implement new programs and policies for improving education outcomes for children and youth in care and promoting well-being for children and youth who have been or are at risk of experiencing commercial sexual exploitation (CSEC).

Most recently with the *Family First Prevention Services Act (Family First)*, which was passed as part of the *Bipartisan Budget Act (PL 116-123, 2018)*, it is even more important for states and the federal government to have accurate and relevant data about the children and youth currently in care and potential foster and adoptive parents. These data are central to states' abilities to identify and implement services to prevent the removal and placement of children in foster care as well as reduce reliance on congregate care in favor of placing children in family-like settings whenever possible.

The production of relevant and accurate data is foundational to ensuring that desired policy changes are in fact reaching the intended beneficiaries and objectives of new laws. These data can support better decision-making which can lead to improved outcomes (including expedited permanency for children and youth) which can ultimately lead to more effective and in some cases lower federal and state expenditures on high cost and ineffective placements and supports.

Benefits of the Expanded 2016 Final Rule Data Elements
AFCARS is an essential tool for collecting national and state data to inform policy development, identify gaps in services, and highlight populations that are experiencing disparate outcomes. These data need to identify the distinct reasons for entry into foster care and child demographic information – including sexual orientation, gender identity, race, tribal affiliation, and whether youth are pregnant or parenting. Being able to disaggregate overall population data will permit us to better understand barriers to achieving positive well-being and permanency outcomes for youth in foster care.

Particularly in light of the recently passed *Family First* legislation*,* child welfare systems must have data to inform the development and implementation of evidence-based prevention services, reduce the reliance on congregate care, and improve recruitment and retention of foster parents. Without understanding the reasons for entry into care – for example, how many children enter foster care due to parent child conflict related to the child's sexual orientation or gender identity– child welfare systems will not be able to design prevention services to meet the needs of these candidates of foster care. Furthermore, if child welfare systems are unable to disaggregate well-being and permanency outcomes including the reason for entry into care, placement type, length of stay in foster care, permanency goal, or receipt of health care, states' ability to make smart, data-driven investments that reduce the costs associated with placement in foster care while maximizing opportunities to promote the well-being of children and families will be hindered.

[redacted]

Support for Including Expanded Demographic Data on Key Population Characteristics

Youth who are Pregnant or Parenting

Given the high percentage of youth in foster care who are pregnant or already parents, it is vital that states and the federal government collect data on a youth's parenting status. The pregnancy rate for youth in foster care is higher than their peers who are not in foster care and youth in foster care who are pregnant or parenting face unique challenges. For youth in foster care who are pregnant or parenting, the government has a responsibility to promote their healthy development and well-being and that of their children. *Family First* provides that youth in foster care who are pregnant or parenting and their children are newly eligible for prevention services financed through Title IV-E. Removing this data element from AFCARS now will hinder a state's ability to have the needed data to drive practice, policy and resource decisions regarding pregnant and parenting youth – in terms of meeting current needs as they transition from the child welfare system and preventing future child welfare system involvement for their children. The burden and cost of collecting this data element is minimal in comparison to the potential cost savings from reducing future placements in foster care, decreasing time to permanency, and ensuring needed medical and mental health care for these youth and their children.

Children and Youth Who Identify as LGBTQ

Research indicates that LGBTQ youth are involved with child welfare systems at high rates and that these youth experience poorer health, safety, and well-being outcomes compared to their cisgender, heterosexual peers. One study in Los Angeles County found that LGBTQ youth were over represented in foster care at a rate of 1.5 to 2 times, often due to being rejected by their families, and that approximately one-fifth of youth in foster care identify along the LGBTQ spectrum.

We know from the places that do collect this data that LGBTQ youth in foster care are subjected to higher numbers of placement changes, lower rates of permanency, and are more likely to be placed in congregate care settings. We need these data from all states in order to develop foster care recruitment, retention and support strategies and evidence-based interventions to meet these youth's unique needs. *Family First* requirements for Title IV-E reimbursement for the placement of children in family foster homes and reducing reliance on congregate care facilities further heightens the need for these data for both planning and implementation.

Need to Collect Data related to the Indian Child Welfare Act (ICWA)

The 2016 Final Rule included the addition of critical data elements related to American Indian/Alaska Native (AI/AN) children, who are subject to the *Indian Child Welfare Act (ICWA) of 1978 (PL 95-608, 1978)*. These data elements, as reported in a 2005 report from the Government Accountability Office are not currently collected at a national level. It has been almost four decades since ICWA enactment and there remain substantial gaps in data, practice, and policy that need attention in order to reduce AI/AN disproportionality and improve tribal, state, and federal responses to child abuse and neglect. AI/AN children are overrepresented within state foster care systems nationally and in some states are overrepresented in care at a rate as high as 10 times their population rate.

The 2016 Final Rule includes the first federal data elements that can provide detailed information on ICWA implementation, allowing tribes, states and federal agencies to develop a greater understanding of the trends in out-of-home placement and barriers to permanency for AI/AN children. Improved policy development, technical assistance, training and resource allocation can and should stem from having access to these data. Removing or reducing any of these data elements in AFCARS will only continue to hinder, rather than support, child welfare's ability to respond to the well-being and permanency needs of AI/AN children.

[redacted]

Promoting Education and Healthy Development for Youth in Foster Care
The 2016 Final Rule included the addition of data elements related to the receipt of health care services and educational status of children placed in foster care. These data are aligned with the *Fostering Connections to Success and Increasing Adoptions Act's (PL 110-351, 2008)* emphasis on meeting the health and well-being of children and youth in foster care. Available research shows that children and youth in foster care have significant health care needs and graduate from high school at lower rates compared to their peers who are not in foster care. Child welfare systems are required to ensure the health and well-being of children and youth in foster care as well as promote their success in school. Having timely and accurate information on a state and national level about children's health and educational status is a basic responsibility of a child welfare system and should be monitored on a regular basis by child welfare workers. Any potential cost and burden of collecting these data within AFCARS is far overshadowed by the absolute necessity of having this data available to both states and the federal government for basic accountability as well as policy and investment decisions. Further, being able to disaggregate health and education data by demographic indicators will help policymakers and administrators allocate dollars to targeted populations with specialized needs.

Ensuring Permanency for Youth in Foster Care
Every child and youth in foster care deserves to be raised in a permanent family. However, as current AFCARS data show, on September 30, 2016, 117,794 children were waiting to be adopted from foster care. States need additional data to understand existing gaps in recruitment strategies and supports to adoptive parents. The 2016 Final Rule included demographic information for adoptive parents. This information, which adoptive parents have the option to share, can provide insights about who chooses to become adoptive parents and can help inform recruitment strategies to better attract potential adoptive parents for the many waiting children and youth.

Alignment with a Comprehensive Child Welfare Information System (CCWIS)
AFCARS implementation depends significantly on the ability of state agencies to implement a comprehensive child welfare information system. As we noted in our response to the CCWIS NPRM (81 FR 35449), the upcoming changes in AFCARS should be aligned with the redesign of CCWIS. Many state are well into their planning to implement a new CCWIS; a delay in the effective date of the 2016 Final Rule will cause confusion for states and prevent them from adequately building their systems to collect these important data. Lessons from previous system updates have shown that it is much more difficult to retrofit a system to collect information than to include essential data elements in the system at the time that it is being built. Any attempt to remove important data elements from AFCARS now will create regulatory uncertainty and undermine the implementation of an effective CCWIS – and possibly lead to additional future costs to states who may need to retrofit their systems later on.

Supporting Reliable Data Collection
The data elements included in the 2016 Final Rule are not only important to driving policy and financial investments at a system-level but are also central to daily case planning activities for each and every child involved with child welfare. Without collecting information on reasons for entry into care; demographic data including information related to tribal affiliation, sexual orientation, and gender identity; receipt of health care; and educational status, frontline child welfare workers will continue to be at a disadvantage and face barriers in fulfilling their job responsibilities to promote children's safety, permanency, and well-being. Collecting these data routinely and as part of a state's administrative data should be, and in many places has become, standard practice. Having these data available through the national AFCARS data base is an important accountability tool for child welfare system performance and for ensuring individual, child, and family outcomes consistent with federal law.

[redacted]

Conclusion
Reliable and complete state and national data are needed to guide decision-making and financial investments for achieving better child and family well-being outcomes, including shorter stays in foster care. By updating AFCARS through the 2016 Final Rule, HHS had taken a significant step toward correcting extensive gaps in federal child welfare data collection and analysis. Any attempt to remove data elements from the 2016 Final Rule will be detrimental and inhibit states' abilities to effectively promote permanency and well-being outcomes – directly undermining their legal responsibility to children, youth and families, decreasing the ability of the federal government and the states to use data to promote improved outcomes and ultimately increasing the financial burden to the federal government, states, and the public of ineffective child welfare programs and systems. Rather than reducing data collection, we strongly encourage HHS to move ahead with the 2016 Final Rule and additionally support state agencies with direct technical assistance as they work to implement changes in their data collection.

We look forward to working with HHS in the future on how to best use the data available in AFCARS to promote accountability and impro [redacted] ou have any questions, please don't hesitate to contact me

Sincerely,

[redacted]

Megan Martin
Vice President, Director of Public Policy
Center for the Study of Social Policy

[redacted]

Center for the Study of Social Policy | Ideas into Action

July 20, 2018

Ms. Naomi Goldstein
Deputy Assistant Secretary for Planning, Research, and Evaluation
Administration for Children and Families
[redacted]Department of Health and Human Services
C 20416

Re: Decisions Related to the Development of a Clearinghouse of Evidence-Based Practices in Accordance with the Family First Prevention Services Act of 2018 (*83 FR 29122*)

Submitted via email t [redacted]

The Center for the Study of Social Policy (CSSP) is a national nonprofit organization recognized for its leadership in reforming public systems. We work directly with state and local child welfare systems providing technical assistance on policy and practice strategies impacting families with young children, adolescents, transition age youth and expectant and parenting youth in foster care, youth facing homelessness, and youth who identify as lesbian, gay, bisexual, transgender or questioning (LGBTQ). We also serve as a federal court-appointed monitor in several states engaged in system improvement while under a class action Settlement Agreement. All of our work is devoted to ensuring that all children and youth served by public systems including the child welfare system achieve positive outcomes and can maximize their potential.

CSSP welcomes the opportunity to provide comment on the initial criteria and potential candidate programs and services for review in a Clearinghouse of evidence-based practices in accordance with the Family First Prevention Services Act (FFPSA) of 2018. FFPSA marks a significant policy shift and finally brings child welfare financing into alignment with what research tells us is best for children and families – keeping children in their homes whenever safe and possible. By allowing states to claim federal Title IV-E reimbursement for prevention programs and services to support eligible children, youth and their families, there is a significant opportunity for child welfare systems to reimagine their work and implement a new vision for moving forward in service of children and families.

As described in more detail below, in order for children, youth and families to benefit from prevention services there must be a range of programs to meet their unique needs. Programs in the Clearinghouse must include a wide selection that allow states to implement programs that support comprehensive service delivery within diverse settings and communities. This will be a challenge as it has been well documented that each evidence-based program is intended to serve a specific population, and consequently, there is no single evidence-based program that exists that would be able to meet the needs of every unique family.

[redacted]

By including a broad range of programs in the Clearinghouse, states will have the flexibility to identify and implement a continuum of programs that meet the needs of each family that comes to the attention of child welfare. Specifically, this will give state child welfare systems the opportunity to implement programs that meet the needs of those children and families who disproportionately come to the attention of child welfare, and once involved with child welfare often experience disparate outcomes including children and families of color and those who identify as LGBTQ, are immigrants, speak a language other than English, or face the most significant barriers to thriving.

Our comments below include responses to 1) *Program or Service Prioritization Criteria;* 2) *Study Eligibility Criteria;* 3) *Study Prioritization Criteria;* 4) *Study Rating Criteria;* and 5) *Recommendations of Potential Programs and Services for Review.*

Program or Service Prioritization Criteria

- Target Population of Interest: As HHS prioritizes their review of studies of programs that target children and families involved in child welfare systems, CSSP encourages the agency to include studies pertaining to children and families and pregnant or parenting youth where the child, youth, or family may have been involved with mental or behavioral health services, substance use services, juvenile justice, or family preservation services as we know there is significant cross-over between these systems. HHS should also review programs where the goals of the intervention focus on improving well-being for the child and family related to substance use, mental health, domestic violence, and family preservation.

  Furthermore, it is important that the review is inclusive of studies with caregivers who are not the biological parent but are serving in a parenting capacity. It is also important to recognize that there has not been extensive research on interventions with ethnic minorities in child welfare including American Indian/Alaska Native (AI/AN) children and families. Therefore, in order to ensure programs are included in the Clearinghouse that meet the needs of diverse children and families, it is important to look outside of traditional public systems and at those that have been effective within tribal communities and systems.

- Target Outcomes: CSSP encourages HHS to review programs where the outcomes may be considered proximal outcomes to the target outcomes outlined in FFPSA: prevent child abuse and neglect, reduce the likelihood of foster care, and improve outcomes for pregnant and parenting youth and their children. Many evidence-based programs have not been designed or evaluated through a child welfare lens so the goals of the intervention and results from the study may speak, for example, to improvement in parent-child communication, reduction of family conflict, improvement in mental health, increased engagement in services, or increased access to services. These outcomes are important in child welfare and to ensuring child safety and well-being. We know that when parents have increased access to necessary services they are better able to meet their own needs and the needs of their children and when this happens, children are less likely to come into foster care. For many adolescents, parent-child conflict is often documented as the reason for removal and placement in care. This is particularly true for LGBTQ youth, who are overrepresented in child welfare at a rate of 1.5 to 2 times. LGBTQ youth often enter foster care as a result of family rejection, which is coded by systems as "parent-child conflict." Interventions that work with families to reduce conflict, and in the case of LGBTQ youth move families from being rejecting to more affirming, as well address other key proximal outcomes including increased engagement and access to services should be prioritized as HHS reviews programs and services to include in the Clearinghouse.

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- Trauma-informed: The intent of the "trauma-informed" language in FFPSA was to ensure that in the delivery of services to families providers recognize that families involved with child welfare have often experienced trauma prior to coming into contact with the child welfare system and apply this lens to their work. The intent was never to exclude programs, like Cognitive Behavioral Therapy, in favor of Trauma-Focused Cognitive Behavioral Therapy (TF-CBT) even though only TF-CBT is a trauma-informed, evidence-based program. To make this intent clear, HHS should provide guidance to states that services should be delivered in a way that recognizes the past experiences of families and the impact those experiences have had on their lives. Further, it is important to note that from a cultural perspective, "trauma-informed" language can imply that a family is operating from a deficit. Hence, HHS should include in its guidance to states that providers may operate services and programs within an organization that promotes healing in addition, or instead of, being trauma informed.

- Delivery Setting for In-Home Parent Skill-Based Programs or Services: CSSP would encourage HHS to recognize that often parent skill-based programs are delivered through organizations within the community. While a component of the program may include visits to the parent's home, often these types of programs consist of group classes that allow for parents to learn from one another as well as the instructor. In addition, there are often health-based programs that are delivered within a medical setting rather than in the parent's home. CSSP encourages HHS to allow for flexibility within the definition of "in-home" to include "parent skill-based programs or services" within the community.

  For pregnant and parenting youth in foster care, CSSP also encourages HHS to provide states with flexibility to define "in-home" programs or services. Recognizing that these youth under FFPSA may reside in specific settings for pregnant and parenting youth, independent living settings, or other non-family foster homes, the delivery of services for these youth should be reimbursable whether they occur in their home or in the community.

Study Eligibility Criteria

- Impact Study: FFPSA specifically does not require that services and programs included in the Clearinghouse are included in government reports and peer reviewed journals and it is unclear why HHS is applying this criteria. By limiting eligibility in this way, HHS is negating investments that Foundations and other private partners have made in evaluations since many programs may not have been submitted in a government report or peer reviewed journal but were included in a report to a Foundation or private partner. When the other criteria established in FFPSA have been met, HHS should consider studies beyond those published in government reports and peer reviewed journals to include white papers, Foundation reports, and academic dissertations.

  Qualitative research has contributed significantly to knowledge about effective practices in many areas including health care and well-being and often is the most reliable methodology for collecting data and evaluating the effectiveness of an intervention. HHS's decision to only include studies that assess effectiveness using quantitative methods also ignores the extensive work on establishing validity in evaluations that have been conducted using qualitative methods. Furthermore by limiting its review to only quantitative studies, HHS is ignoring the challenges associated with conducting these types of evaluations in communities of color and within smaller communities as stated in OPRE Report #2017-76, Evidence and Equity: Challenges for Research Design. HHS should include studies that have used rigorous qualitative and quantitative methodologies to assess outcomes as not doing so will be harmful to children and families moving forward.

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- Conducted in U.S., U.K., Canada, New Zealand, or Australia: CSSP strongly disagrees with the decision to limit eligibility to studies conducted in these countries as it ignores extensive, rigorous research that has been conducted across the world. Many countries, including the Netherlands and countries in Scandinavia, have invested financial resources into developing and evaluating services and programs to support child and family well-being. By ignoring these investments, HHS is creating a dynamic where services and programs that may significantly help families cannot be implemented. This restriction puts state child welfare systems at a disadvantage and creates an unnecessary barrier for families to access a needed service. Further, over 20 percent of the children currently placed in child welfare identify as Hispanic and many of the families who come to the attention of child welfare do not speak English as a first language. It is critical that in an effort to identify programs that meet the needs of these children and families HHS recognizes the importance of services and programs that were developed in non-English speaking countries and that incorporate the languages and cultures of diverse children and families.

- Study Published in English: In addition to the comments noted above regarding eligibility restriction based on where a study was conducted, CSSP does not understand the decision to limit eligibility to studies published in English. Studies published in Spanish, French, Dutch, etc. are no less valid than those published in English. Further, this creates unnecessary confusion if a study is, for example, conducted in the U.S. and published in another language like Spanish. By implementing this restriction, HHS is dramatically reducing access to the possible interventions that have been shown to prevent child abuse and neglect.

Study Prioritization Criteria
CSSP recognizes and acknowledges the short time period HHS has to review services and programs and publish the Clearinghouse – this is not a small task to be completed by October 2018. As such, CSSP strongly encourages HHS to implement an ongoing process of review for services and programs that are not able to be reviewed by October 2018.

- Implementation Period: Not all interventions are limited to a 12-month period and this should not preclude a program or service from being included in the Clearinghouse. For example, there are mental health interventions, programs to support children and families where the child has a significant developmental or intellectual delay, and services to support pregnant and parenting youth in foster care that may be longer than 12-months. While we recognize a state may not be reimbursed beyond 12-months, these programs should still be included in the Clearinghouse to give the states the option of receiving reimbursement for the first 12-months and then using state dollars to pay for the remaining time period.

- Sample of Interest: In addition to our comments above related to the *Target Population of Interest,* CSSP encourages HHS to review other catalogues of evidence-based practices including SAMHSA's Evidence-Based Practices Resources, Treatments that Work from The National Child Traumatic Stress Network, Office of Juvenile Justice and Delinquency Prevention's Model Programs Guide, the California Evidence-Based Clearinghouse for Child Welfare, the HHS Teen Pregnancy Prevent Evidence Review, and the What Works Network in the United Kingdom.

Study Rating Criteria
- Favorable Effects: CSSP recognizes HHS's desire to include programs and services that have been assessed to have a favorable impact for children and families. However using a two-tailed hypothesis test and a specified alpha level of $p < .05$ will exclude effective programs and services from the Clearinghouse. First, the goal of programs and services that promote safety and well-being is to shift outcomes in one direction, which would suggest that a one-tailed test would be

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more appropriate than a two-tailed test. Second, and more importantly, it is significantly harder for an evaluation with a small sample size to show a small p-level even if there are notable and important benefits of the intervention. Simply based on the sample size, it is much less likely that a program would meet the criteria set forth here by HHS. This is problematic for multiple reasons including that innovation often first occurs with small groups and that smaller samples are often involved in studies on smaller populations, including AI/AN families and LGBTQ youth. Further, often researchers are unable to conduct randomized controlled trials or rigorous quasi-experimental designs for small, but high priority, populations like AI/AN for pragmatic, cultural, and ethical reasons. By utilizing the proposed definition of "meaningful favorable effect," HHS would be reducing a state child welfare system's ability to effectively implement prevention programs that meet the needs of a diverse population of children and families while also increasing the burden associated with innovation and building a greater evidence-base.

Recommendations of Potential Programs and Services for Review

Pregnant and Parenting Youth

For youth in foster care who are pregnant or parenting, the government has a responsibility to promote their and their children's healthy development and well-being. It is critical that the Clearinghouse include a wide range of services and programs to meet the needs of pregnant and parenting mothers and fathers in foster care. Given the high percentage of youth in foster care who are pregnant or already parents, it is vital that states are able to serve these youth and their unique needs as both parents and adolescents. There should be programs that serve both male and female parents in foster care, regardless of whether or not they have sole physical custody of their child. By strengthening youth's knowledge of their own development and that of their child and providing family-centered, strength-based interventions to support their well-being, these youth will be equipped with additional skills and resources to thrive as young adults and parents beyond their time in foster care.

CSSP would specifically recommend that HHS include evidence-based programs that serve pregnant and parenting youth and incorporate a developmentally informed lens with particular attention to the science on adolescent brain development. These programs include:

- *Adolescent Parenting Program* is centered on supporting young parents in building a strong, stable, and positive social network and includes a peer education and support component. Research supports that having a strong social network is a protective factor against child abuse and neglect and predictive of child and family well-being.
- *Adolescent Community Reinforcement Approach* targets adolescents who have substance abuse and co-occurring mental health diagnoses through cognitive and behavioral interventions. The model emphasizes rapid linkage to community services for continuity of care and replace prevention and recovery support.
- *The Young Parenthood Program* uses a developmental framework to focus on building healthy co-parenting relationships among pregnant and parenting youth. This program is also unique in that it engages fathers to build their own capacity as parents prior to the birth of their child.
- *Parenting Together Project* targets first time parents and focuses on the development of fathers' knowledge, skills, and commitment to the fatherhood role. The programs goals are to increase mothers' support and expectations for the fathers' involvement and to foster a positive co-parenting relationship.
- *Healthy Families America* has an enrollment policy that allows for parents and their children to enroll prenatally or within three months of the child's birth, which is important for serving pregnant and parenting youth in foster care who often do not disclose their pregnancy early on. This program provides services to all family members through the child's fifth birthday and

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includes a focus on engaging father, healthy bonding and attachment, and building nurturing relationships.

While the examples above and Attachment A include a select programs that should be included in the Clearinghouse, it is critical to note there have been limited resources devoted to evaluating programs for pregnant and parenting youth in foster care, particularly young fathers. As states build evidence around effectiveness through implementation and continuous quality improvement processes, HHS should allow for states to claim Title IV-E reimbursement when states identify adaptations to evidence-based programs that will increase positive outcomes for young parents and their children.

Substance Abuse, Mental Health, and In-home Parent Skill-Based Programs and Services

As has previously been mentioned, the majority of evidence-based programs have not been tested on diverse families nor do they incorporate the cultural and ethnic strengths of minority communities. However, there are some programs that have demonstrated positive outcomes for children and families of color and/or are grounded in a cultural framework. These programs include:

- *SafeCare* is an in-home parent training program that targets risk factors for child neglect and abuse and has been adapted for Latinx families as well as has been tested with American Indian families.
- *Minority Youth and Family Initiative for African American Children* and *Minority Youth and Family Initiative for American Indian/Alaskan Native Children* programs utilize culturally competent practice to support parents in their home and through peer supports, including parent partners, to reduce the likelihood of children entering foster care.
- *CICC's Effective Black Parenting Program* is a skill-building parenting program created and specifically tested with African American parents to improve parenting capacity through culturally relevant strategies to reduce child abuse and neglect.
- *Iowa Parent Partner Approach* is based on peer mentorship where parents who have been previously involved with the child welfare system and have successfully achieved reunification are trained and supported to mentor parents who are currently involved with child welfare. The program promotes skill-based parenting as well as support parents in addressing substance use and mental health concerns as applicable. The approach has been shown to reduce incidents of repeat maltreatment for children when they return home.

American Indian/Alaska Native

FFPSA specifically states that "the requirements shall, to the greatest extent practicable, be consistent with the requirements applicable to states under section 471(e) and shall permit the provision of the services and programs in the form of services and programs that are adapted to the culture and context of tribal communities served." The Clearinghouse should include programs that have been adapted to the cultural context of tribal communities, regardless of whether or not the program meets the suggested definition for favorable impact ($p<.05$) or has been published in a government report or peer reviewed journal. HHS should also provide clear direction to tribal communities and states serving tribal communities that cultural adaptations of evidence-based programs included in the Clearinghouse are eligible for Title IV-E reimbursement.

Cause No Harm

FFPSA clearly states that programs should not be included in the Clearinghouse or reimbursed with Title IV-E dollars if they have been shown to cause harm. While we recognize that many programs that cause harm will be excluded from the Clearinghouse due to unfavorable effects and not meeting the criteria set forth in FFPSA, HHS should explicitly exclude conversion therapy for LGBTQ youth and individuals as a promising practice as it has been shown to cause incredible amounts of harm to the health and well-

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being of these children and youth.[1] In order to prevent states from including conversion therapy in their Title IV-E state plan, HHS must explicitly exclude conversion therapy from range of prevention services that will be reimbursable.

Kinship Navigator Programs

We would also like to note that there has been little investment in evaluating kinship navigator programs and it is critical that states are reminded that these programs are not subject to the same eligibility criteria, effective dates, or reimbursement structure as the prevention services for candidates of foster care and pregnant and parenting youth in foster care. These programs are important to improving the well-being of children and families involved with child welfare and it is critical that there is no confusion among states about their ability to draw down Title IV-E dollars in October 2018 without updating their state plan or restructuring their continuum of care.

Building Evidence from Innovation and Adaptation

Historically, there has not been a significant investment in building the evidence-base to serve children and families involved with child welfare systems. Additionally, much of the research supporting well-supported evidence-based programs has not been done with low income families, families involved with child welfare, families of color including AI/AN families, LGBTQ youth, or immigrant families. There is now an opportunity to continue to build this evidence-base as states implement selected programs, collect more data, and engage in continuous quality improvement processes. FFPSA specifically states that "The Secretary shall directly or through grants, contracts, or interagency agreements, evaluate research or practices specified in clauses (iii), (iv), and (v), respectively of section 471(e)(4)(C), and programs that meet the requirements described in section 427(a)(1), including culturally specific, location- or population-based adaptions of the practices to identify and establish a public clearinghouse of the practices that satisfy each category described by such clauses."

As there is no "one size fits all" evidence-based program, it is critical that HHS prioritizes disciplined adaptation and in doing so building the evidence-base for innovative programs and services that will meet the diverse needs of children and families involved with child welfare. One mechanism for HHS to support innovation and continue building an evidence-base is to support states in implementing continuous quality improvement processes and allowing for states to adjust evidence-based prevention programs based on findings from these processes without risking the loss of Title IV-E reimbursement. Implementing programs in the field is complex, especially when programs and practices are implemented in culturally diverse communities. Specifically as Anthony Bryke, President of the Carnegie Foundation notes, through using a robust continuous quality improvement process, like Improvement Science, systems can focus more on the results for children and families not just fidelity to a specific evidence-based program.

Moving into the future, as more is learned and the evidence-base for prevention programs is built, CSSP encourages HHS to explore the possibility of allowing states to implement a tailored "modular approach" to better meet the needs of children and families. Dr. Bruce Chorpita at UCLA has shown that by distilling common elements from a range of evidence-based treatment programs and using those elements to implement a tailored service, systems can more effectively respond to the needs of a larger percentage of children and families than using one specific evidence-based program.

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[1] Mallory, C., Brown, T. N., & Conron, K. J. (2018, January). Conversion Therapy and LGBT Youth. Retrieved from https://williamsinstitute.law.ucla.edu/wp-content/uploads/Conversion-Therapy-LGBT-Youth-Jan-2018.pdf; American Psychological Association. (n.d.). Resolution on Appropriate Affirmative Responses to Sexual Orientation Distress and Change Efforts. (2009, August 5). Retrieved from http://www.apa.org/about/policy/sexual-orientation.pdf

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Conclusion
CSSP recognizes the huge task HHS has to review programs and publish the Clearinghouse by October 2018. This work is foundational for child welfare system reform moving forward. It is important that HHS includes a wide range of services and programs that serve diverse populations while also recognizing where gaps in research exist and where cultural adaptations are necessary to ensure quality and equity. As states begin to implement evidence-based prevention services and programs, it will also be important that they are able to be nimble in tracking and adjusting as they go – adapting current programs and implementing new ones as they learn about what programs best meet the needs of the children, youth, and families within their communities.

This is a very important time in child welfare reform and we look forward to working with HHS in the future to support states in implementing the prevention service [redacted] other aspects of FFPSA. [redacted] please don't hesitate to contact me a [redacted]

Sincerely,

[redacted]

Megan Martin
Vice President, Director of Public Policy
Center for the Study of Social Policy

ATTACHMENT A

Additional program recommendations for inclusion in the Clearinghouse:

Program	Service Category	Program Goals and Outcomes
Nurturing Parent Program	- Skill-based parent program	- Prevent child abuse and neglect - Increase caregiver's knowledge of age-appropriate development - Increase use of positive parenting and discipline strategies
Triple P – Positive Parenting Program	- Skill-based parent program	- Prevent child abuse and neglect - Increase caregivers' use of positive parenting strategies in managing their children's behavior
The Incredible Years	- Skill-based parent program	- Improve caregiver-child interactions and attachment, - Improve caregiver functioning and less harsh, more nurturing parenting, - Increase caregiver social support and problem solving
Supporting Fathers Involvement	- Skill-based parent program	- Prevent child abuse and neglect - Increase father involvement
Systematic Training For Effective Parenting (STEP)	- Skill-based parent program	- Reduce caregiver-child conflict
Combined Parent-Child Cognitive Behavioral Therapy (CPC-CBT)	- Skill-based parent program - Mental health	- Improvement in mental health stability and coping skills - Increase caregiver capacity to support child's mental health
Nurse Family Partnership	- Skill-based parent program *(specifically for pregnant youth in foster care)*	- Improve child health, development, and safety by promoting competent caregiving - Prevent child abuse and neglect
Parent Child Interaction Therapy (PCIT)	- Mental health - Skill-based parent program	- Improve caregiver-child relationships - Improve child's mental health through the caregiver's support
Child Parent Psychotherapy (CPP)	- Mental Health - Skill-based parent program	- Improve mental health for young children who have experience trauma - Support and strengthen the caregiver-child relationship
Attachment, Self-Regulation, and Competency	- Mental Health - Skill-based parent program	- Improve caregiver functioning - Improve child's mental health
All Babies Cry (ABC)	- Skill-based parent program	- Increase knowledge of parenting and child development - Prevent child abuse and neglect
Child First	- Mental Health - Skill-based parent program	- Improve caregiver's mental health - Reduce involvement with child protective services - Prevent child abuse and neglect

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Circle of Security	• Skill-based parent program	• Increase secure attachment between the child and caregiver • Reduce risk of child abuse and neglect
Family Connections	• Skill-based parent program	• Reduce the risk of child abuse and neglect
Seeking Safety	• Mental Health • Substance Abuse	• Reduce trauma and/or substance abuse symptoms • Increase caregiver's overall mental health
The Seven Challenges	• Mental Health • Substance Abuse	• Decrease caregiver's drug use • Improve caregiver's mental health
Steps to Success	• Skill-based parent program	• Reduce risk of child abuse and neglect • Increase parenting capacity through home visiting, counseling, and future pregnancy prevention • Increase father engagement

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Response to OSTP Engagement and Accountability RFI
Building Disaster Resilience through Community Knowledge and Information Integration: The Case of Puerto Rico

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October 3, 2022
Dr. Alondra Nelson
The White House Office of Science and Technology Policy
Eisenhower Executive Office Building
[redacted] Washington, DC 20504

Re: Center for American Progress Written Comment on RFI for Equitable Data Engagement and Accountability
Submitted via email to [redacted]

Dear Dr. Alondra Nelson,

The Center for American Progress (CAP) is pleased to share written feedback with the Office of Science and Technology Policy (OSTP) on its Request for Information on Equitable Data Engagement and Accountability. CAP is heartened to see the work of the Equitable Data Working Group, OSTP, and the Subcommittee on Equitable Data of the National Science and Technology Council as it pursues measures to support the advancement of racial equity through the production and use of data, and commends engagement with other levels of government, civil society, and the research community on ways to collaborate to achieve this goal.

CAP is an independent, nonpartisan policy institute that is dedicated to improving the lives of all Americans through bold, progressive ideas, as well as strong leadership and concerted action. One of CAP's key priorities is to advance racial equity and justice through developing and advancing policies that root out deeply entrenched systemic racism to ensure everyone has the opportunity to thrive. To understand, develop, and advance these policies, access to data disaggregated by race, sexual orientation and gender identity, disability status, and other data elements that characterize the experiences of historically underserved groups is crucial to ensuring inclusive involvement and policies that will positively impact those that are most vulnerable.

We believe the federal government has immense opportunity and responsibility to ensure federal agencies collect, report, and use data that allows for engagement from the public, analysis by researchers and organizations of all backgrounds, and holds the government accountable for its policies, programs, and decisions. The federal government also has a responsibility to work with state and local governments to provide best practices, develop data-sharing agreements, and expand capacity and access to analyze equitable data.

We see the potential for OSTP to lead federal agencies and better support collaboration with other levels of government, civil society, and the research community around the production and use of equitable data in the following ways:

I. Identify, learn from, and leverage successful collaborations between the Federal

government and (a) Tribal, territorial, local, and State governments or (b) local communities involving equitable data:

Successful collaborations between the Federal government and other governments and local communities involving equitable data that should be learned from include:

- Collaboration between the Centers for Disease Control and Prevention (CDC) and state and territorial partners to conduct the Behavioral Risk Factor Surveillance System (BRFSS) questionnaire, which collects data about U.S. residents regarding their health-related risk behaviors, chronic health conditions, and use of preventive services. The BRFSS survey is conducted through joint federal-state partnerships and is the largest continuously conducted health survey system in the world, providing invaluable data at a scale that allows for disaggregation based on key demographic variables that facilitates intersectional analyses. We encourage the CDC to work with state coordinators to add questions on sexual orientation, gender identity, and variations in sex characteristics, including intersex traits (SOGISC) to the standardized demographic core questionnaire, which would enhance consistency and improve data validity and the ability to make national-level inferences from the dataset.
- Collaboration between the Census Bureau and others through the Census's State Data Center (SDC) Program, which is a longstanding effort to work more closely with users, relying on a network of designated agencies, libraries, state and local government, and higher learning institutions.
- Collaboration between the Census Bureau and an NGO through the Bureau's Population Reference Bureau's American Community Survey Data Users Group. In addition to general data users, many Census Bureau and state/local staff are a part of the network to crowdsource answers on data access and sources as well as a direct line of communication with many of the Bureau's experts.

Successful collaborations between the Federal government and other governments and local communities involving equitable data provide important lessons and best practices, including:

- Disaggregation based on key demographic variables provides in depth information to further understand the quality of life and lived experiences of diverse groups. Collecting and reporting these disaggregated data, including identification beyond broad race categories, will provide researchers and policymakers with the tools to better understand the experiences of marginalized groups including LGBTQ+ people, people with disabilities, and people of color. These data are crucial to inform evidence-based decision-making and equity-centered policy and to eliminate structural barriers and discrimination.
- Due to the fragmentation of numerous data sources, demographic information across systems is often incomplete, not standardized, and not comparable, preventing identification of disparities and hampering reforms to target them. To support equity-centered data collection, it is essential to invest in improving data collection and disaggregation by a core set of standardized socioeconomic and demographic

characteristics, including race, ethnicity, and sexual orientation, gender identity, and variations in sex characteristics, including intersex traits (SOGISC).

- Cross collaboration between sectors, levels of government, agencies, and the public provide multiple perspectives for analyzing and addressing a question and a problem.

II. Facilitate increased data sharing between different levels of government around equitable data:

Increased data sharing between different levels of government around equitable data is critical to expanding access and engagement with the data to make better informed and evidence-based decisions. Some examples of policies, resources, programs, training, and other tools that can facilitate increased data sharing between different levels of government include:

- Increased resources for state governments to analyze workforce training and job quality data in partnership with federal agencies and local communities to assess who is benefitting from training and programs and who is excluded from these programs.
- Disaggregated program-level outcome data collected at the state level in partnership with the Department of Labor of Workforce Innovation and Opportunity Act (WIOA) participants disaggregated by race, gender, disability, LGBTQI+ status, veteran status, and other demographic factors. Current WIOA outcomes show that WIOA outcomes mirror occupational segregation in the labor market, and workers of color are more likely to enter lower-paying occupations than white workers. However, the lack of disaggregated program-level data makes it difficult to ascertain which interventions are more or less contributory to these outcomes.
- Policies that provide direct authority to the CDC to require states to submit standardized public health data reporting in order to lead timely, coordinated, and appropriate response to health threats and emergencies. Without access to data, the CDC is hampered in its ability to identify threats and provide information to inform decision making. The authority to require reporting of essential data should not be tied to the temporary declaration of a public health emergency. Currently, health care providers and systems can choose which data to share with local and state health departments, and states and localities can decide what information is collected and voluntarily shared with the CDC. The variation in approaches leads to inconsistent data received by CDC. During the COVID-19 response, data on race and ethnicity were sometimes found to be missing, inconsistent, or inaccurate.
- Policies that mandate reporting by laboratory, vaccine, hospital, nursing home, and long-term care facilities of key information on age, gender, race, ethnicity, sexual orientation, and gender identity to state and local health departments. The COVID pandemic and the monkeypox response have highlighted the need for consistent, representative, and complete data to detect, track, and respond to outbreaks, identify vulnerable populations, and target responses.
- Programs and training that build and retain the public health workforce and data related skillsets are needed so that public health officials can develop data tools, work

processes, and interfaces necessary for public health work. Currently, informatics specialists represent only about one percent of the public health workforce, which limits the system's capacity to comprehensively collect and report demographic data and facilitate interventions equitably.

III. Expand opportunities for historically underrepresented scholars and research institutions to access and use equitable data across levels of government:

The access to and use of equitable data is critical for expanding skill sets, advancing equity, and supporting historically underrepresented communities. The federal government should expand opportunities for scholars and research institutions to access and use equitable data across levels of government, including by:

- Developing and expanding formal partnerships between Minority Serving Institutions (MSIs), Historically Black Colleges and Universities (HBCUs), and state data centers.
- Working with specific programs and institutions that focus on research focused on underrepresented communities, such as Women and Gender Studies, African-American Studies, Native American Studies, and others.
- Developing strategic partnerships with professional associations, affinity groups, and research publications that cater to underrepresented scholars and authors.

IV. Increase accessibility of equitable data for community-based organizations and the public and provide opportunities to use equitable data to hold the government accountable to the American public:

Opportunities to increase accessibility of equitable data for community-based organizations and the public to hold the government more accountable include:

- Federal agencies should do more to make public use files available, make disaggregated data the norm while protecting privacy, and publish easily accessible reports and data tables stratified by race, ethnicity, sexual orientation, gender identity, and other key demogaphic variables. Doing so will be particularly useful for organizations that do not have capacity to engage in original quantitative analysis but rely on data to support and inform their work. For example, when the Census Bureau added sexual orientation and gender identity questions to its Household Pulse Survey, it developed materials explaining the wording of the questions and how they code LGBT populations, released interactive data visualizations of the survey results, and published tables with LGBT cross-tabs.
- The White House and federal agencies should develop tools, resources, and public facing data that the public and community-based organizations can use to hold the government accountable to the recently released Agency Equity Action Plans. Each agency listed specific goals and targets on how they plan to advance racial equity,

remove barriers to access government programs and services, and mechanisms to increase accountability. By creating public dashboards using equitable data, federal agencies can better be held accountable towards meeting their equity action plan goals. The public, community-based organizations, and others can also use public facing dashboards to pursue programs, contracting opportunities, and ensure compliance with civil rights laws and anti-discrimination protections through monitoring of these measures, which will help to inform policy and advocacy strategies to aid federal agencies better advance racial equity.

- The Office of Management and Budget should devise a process for collecting and disaggregating data to track beneficiaries of federal spending and programs, identify who is benefiting from federal resources, and determine where the greatest equity needs exist. This would be an effective way of coordinating its many responsibilities under EO 13985.
- Orientation guides should be developed for data.gov. The website provides extensive and important information, but it can often be somewhat unapproachable for users, especially those new to data and analysis work and those with broad questions looking for specific information to address those questions. Resources that cover information on the data included in the site, the location of different datasets, the frequency at which they are updated, and where to start would increase accessibility. Promoting and streamlining the website would also make it accessible to a broader audience.
- The federal government should seek to develop additional usable tools with equitable data, modeling the success of the beta launch of the Council of Environmental Quality's (CEQ) Climate and Economic Justice Screening Tool (CEJST) to help identify disadvantaged communities for the historic Justice40 Initiative. Through a collaborative effort and with input from the White House Environmental Justice Advisory Council, environmental justice experts, stakeholders and community-based organizations, the CEQ utilized datasets from across the federal government to identify communities overburdened by pollution, economically disadvantaged and most in need of federal funding to improve public health and community infrastructure and create jobs and economic opportunities at a Census Tract level.
- CEQ should release an updated version of the CEJST to incorporate feedback from frontline communities and environmental justice and climate experts to more accurately identify communities of color and rural communities that are disadvantaged to ensure these communities can access federal Justice40 resources and benefits. The Biden Administration should also invest in expanding and improving data collection to continually improve the CEJST's indicators and accuracy. For example, improving the availability of data on electricity shut offs, projections of census tract exposure to climate change hazards, among other data would improve the accuracy of the CEJST. Similar tools for public health, such as the Environmental Justice Index and the Social Vulnerability Index, poverty, housing, and other initiatives would greatly expand accessibility and use by members of the public.
- The Office of Management and Budget (OMB) and CEQ should develop a Justice40 and Environmental Justice Scorecard, as directed in Executive Order 14008 on Tackling Climate Change. The Scorecard should be accessible to communities and environmental

justice and climate experts data on the federal investment benefits and funding amounts delivered to disadvantaged communities by federal agencies to hold the administration accountable on meeting its goal to deliver at least 40 percent of federal climate and infrastructure investment benefits to disadvantaged communities. Through these scorecards, members of the public and representatives from disadvantaged communities would be able to better see what is delivered where and offer guidance on how to most effectively meet the Justice40 goals.

- Federal agencies should provide greater access to staff who can dedicate time to support state and local government staff, researchers, and the public to learn how to use data and to field specific data questions. Their contact information should be made more readily accessible and intuitively found. Additional prioritization of community engagement would be aided by designating agency staff to data sources that accompany the source pages, potentially including contact information on the page itself.
- The Bureau of Labor Statistics (BLS) should provide simplified data visualizations that are more accessible to the general public and those without a statistical background. While the Bureau has made progress in displaying and presenting BLS data through a variety of demographic lenses, many of these visualizations target statistical researchers or economists rather than the general public. Furthermore, BLS should provide sufficiently greater guidance and technical assistance to state-level economic research departments as to how they display labor market and unemployment data, given state-level data platforms vary significantly in terms of their accessibility and usefulness. While some states provide substantive equity analyses on their data, others meet only the bare minimum required by BLS.
- Federal agencies should support cities and state governments by providing guidance on best practices for tracking compliance with commitments through the Infrastructure Investment and Jobs Act (IIJA), CHIPS and Science Act of 2022, and the Inflation Reduction Act, which include numerous new competitive grants and incentive programs with opportunities to expand jobs for historically marginalized populations. This includes compliance measures to ensure jobs created through these programs are high quality and accessible to women, workers of color, LGBTQ+ people, and disabled workers. Agencies such as the Department of Labor and other awarding agencies should engage their own tracking of competitive grants that are aimed at achieving these goals and guide state and local governments on how to increase data tracking and accountability to ensure equity in the labor market.

V. Use collaborations and transparency around equitable data to remedy unmet needs, broken process, and problems around participation and accountability:

Opportunities to use and expand collaborations and increase transparency around equitable data that involve remedying unmet needs, broken process, and participation and accountability problems include:

- Federal agencies should recognize where data collection efforts fail to enable critical analysis of equity in agency actions and enforcement. Agencies who fail to collect data about the equity impacts of their work miss opportunities to understand the results of their actions and deprive the public of those opportunities for analysis, collaboration, and participation that are necessary for public accountability. Foundationally, advancing racial equity and support for underserved communities must include regular data collection and sharing about agency actions and enforcement of their missions relative to those communities.

- Federal agencies should work in partnership with organizations representing and serving populations of diverse race, ethnicity, national origin, immigration status, sex, sexual orientation, gender identity, age, or disability status in order to support effective awareness initiatives, as well as public and community education campaigns. Examples include the Queer the Census (National LGBTQ Task Force) and Census Counts (LCCHR).
- The Census Bureau should make adjustments to the American Community Survey (ACS) to make it more representative of the population as a whole and restore the trust of the public. Since the survey is regularly reported, comprehensive, and very accessible to many community organizations, and local and state institutions, it is critical that it be accurate and accessible, particularly as it is used to disburse state and local funds, make policy decisions, advance equity, and increase accountability. Some opportunities to do so include:
  - Make improvements to data collection practices to remedy known undercounts of difficult to reach groups, and to restore trust from those communities in the Census and government's role in supporting and representing them.
  - Restore researchers, governments, and data users' trust in the Census by undoing damage and underfunding from previous administrations and from lapses in data from 2020 due to the COVID-19 pandemic, which as a result was deemed experimental in 2020.
  - Add SOGISC questions to the ACS. The absence of SOGISC measures on the decennial census or ACS mean that there is no "gold standard" against which data collections can perform weighting adjustments or assess data quality and nonresponse bias for LGBTQI+ populations. Adding SOGISC measures to the ACS is crucial to ensure the needs and experiences of LGBTQI+ communities are reflected in the government policies, programs, and funding investments that derive from ACS data and to advance equity. We strongly encourage the administration to revitalize efforts to add these measures.
- Federal agencies should prioritize building social trust with diverse communities and stakeholders to increase participation in relevant surveys and data-gathering processes. This will require working with community-based organizations and partners and will require an increased focus on transparency for how the data will be used. As part of these efforts, agencies should consider promotional campaigns. In particular, to encourage public response to questions about sexual orientation and gender identity to improve sample sizes and population coverage, federal agencies should also provide public materials that address frequently asked questions about the use of the data; nondiscrimination protections; privacy, security, and confidentiality standards; restrictions on data sharing and other topics.

- The Department of Treasury's Office of Tax Policy should develop accessible mechanisms to include race and ethnicity in its tax data. Since there are particular challenges with tax data owing largely to the tax code's strong confidentiality rules and the fact that the IRS does not collect information about race or ethnicity on tax forms, many scholars have emphasized there are gaps in our understanding of the economic impacts of tax policies and proposals by race and ethnicity. We are encouraged that Treasury's Office of Tax Policy is pursuing multiple approaches to address these challenges including by imputing race, ethnicity, gender, and other demographic characteristics into tax analysis and validating and refining those imputations using non-tax data sources.

Conclusion:

Advancing equitable data engagement and accountability measures are critical to advancing equity through the whole of the federal government as well as through state and local policy, community-based initiatives, and collaborations with the public and private sectors. Our recommendations listed in this comment are designed to help achieve the goals of the historic executive order to advance equity and create a more just, inclusive, and equitable society. By leveraging leading practices and developing additional tools, resources, collaborations, and policies, more access to equitable data will advance crucial policy initiatives that center historically marginalized populations.

CAP is grateful to the White House Office of Science and Technology Policy for the opportunity to share feedback on equitable data engagement and accountability, and we are eager to continue serving as a thought partner on how best to support collaboration around the production and use of equitable data as well as the advancement of racial equity throughout the federal government.

Signed,

The Center for American Progress

CAP

Response to OSTP Engagement and Accountability RFI
Building Disaster Resilience through Community Knowledge and Information Integration: The Case of Puerto Rico

Contributors: *Yiyuan Jasmine Qin, re+connect; Sally Everson, Foundation for Puerto Rico; Daniel P. Aldrich, Northeastern University; Robert Soden, University of Toronto; Sophia Story, 3 Sided Cube*

Date: *October 3, 2022*

1. Introduction

In the wake of Hurricane Fiona and on the fifth anniversary of Hurricane Maria, Puerto Rican communities are again facing widespread destruction, flooding and landslides, and disruptions in water and electricity for millions across the archipelago (Taylor, 2022). In September 2017, category 5 Hurricanes Irma and Maria made landfall in Puerto Rico, causing catastrophic damages to homes and critical infrastructure with devastating, long-term effects on people's health and safety (Segarra, 2017). Before people could recover from complex sequelae triggered by hurricanes, Puerto Rico suffered a swarm of earthquakes in 2020 prior to the arrival of the global pandemic (Ayala et al., 2020).

Due to climate change, places like Puerto Rico will face more frequent and more destructive disasters. The need to better prepare the archipelago for future disasters is immense and urgent. In particular, these back-to-back disasters highlight the current information, coordination, and accountability gaps between local communities and agencies in the allocation and distribution of disaster relief resources and services across the multitude of individuals and organizations (Qin, 2020). Disaster research and accounts from the field show that citizens and community-based organizations (CBOs) demonstrate adaptability, innovativeness, and responsiveness in the face of crisis, where strong social networks and structures are the driving forces for recovery after disasters (Aldrich & Meyer, 2015; Liboiron, 2015; Whittaker et al., 2015). However, individuals and groups working outside of the official disaster management system have been largely undervalued through formal institutional structures and arrangements (Drabek & McEntire, 2003; Harrald, 2006; Quarantelli, 1985). Truly engaging and empowering citizens and CBOs will require the disaster management community to transform its thinking, planning, and practice to value the time, skill, knowledge, and resources from individuals and communities (Gaillard et al., 2019; Wachtendorf et al., 2017). The introduction of civic technology objects (e.g. information systems) in combination with participatory processes to promote cross-border collaboration has been found to be helpful in overcoming various challenges.

In our response to the RFI, we offer insights, tools, and processes drawn from our years of on-the-ground research and engagement with key stakeholders in Puerto Rico in light of the urgent need to advance equity with community participation and data integration for building a more resilient future. In particular, we hope to shed light on pathways to: 1) facilitate increased data sharing between different levels of government; 2) increase opportunities for community-based organizations to use equitable data to hold government accountable to the American public; 5) highlight unmet needs, broken processes, or problems related to participation and accountability that could be remedied through stronger collaborations and transparency around equitable data.

2. Resilience and Disasters: The Role of Social Capital

Community level resilience — the collective ability of a neighborhood or geographically defined area to deal with stressors and recover following shocks, with the understanding that the resilience of individuals and organizations within the community are integral components of resilience at different scales (Aldrich & Meyer, 2015). Based on studies in disaster resilience, capacities are often broadly grouped as socioeconomic, ecological, institutional, infrastructure, and social capital (Cutter et al., 2010; Kendra et al., 2018). Among these factors, social capital has been at the forefront of thinking about resilience. Social capital is broadly defined as the social networks and relations that can have positive consequences for the individual and the community based on social cohesion, trust, and reciprocity (Portes 1998; Meyer 2018). It refers to the ideas of unity, togetherness, a sense of shared identity and community, cooperation, and community action (Dekens, 2007). Social support networks can function as the most crucial means of adjustment for the most vulnerable groups. In general, social capital (the phrase social networks is used interchangeably) provides information, knowledge, and access to network members; strengthens trustworthiness across the network; and builds new norms about compliance and participation among network members (Aldrich 2012). These mechanisms of social capital have been witnessed to allow communities to recover from disasters faster with citizens and organizations responding to helping others in times of crisis (Whittaker et al., 2015). With growing evidence and improved measurement, many disaster researchers have pointed to social capital as a vital, perhaps even decisive attribute of social systems that influence a community's ability to respond and recover from disasters (Nakagawa and Shaw 2004; Aldrich 2019; Cutter, Ash, and Emrich 2014; Adger 2003). However, practitioners have underutilized social cohesion and social networks in disaster planning and management (Aldrich, 2012).

3. Community Knowledge and Information Integration & Disaster Management

Information and knowledge management is foundational to achieving effective disaster response and recovery. Preparedness and effectiveness of disaster management rely on the process of acquiring, analyzing, and sharing quality data to support decision-making around logistics, supplies, and cooperation among relief agencies, which face complex operational challenges. In response to large-scale disasters, decision-makers often face tremendous time pressure and uncertainty to allocate scarce resources, which could lead to severe, sweeping consequences (Jiang et al., 2012). Emergency operations can be further impeded by damaged communication, energy, and transportation infrastructure in the wake of disasters. The disaster management community needs a large variety of information in this time and mission critical process to perform different tasks at different phases around decision making and situational awareness, including generating early warnings, planning for response and recovery activities, evaluation of disaster severity, and distribution of relief actions and supplies (Zhang et al., 2002). Information needs also vary across different stakeholders. For example, disaster relief workers need information about the dispatch of supplies; agency officers demand access to disaster situations, and availability of staff and resources; philanthropic entities require assessments of victims' needs. In most disaster operations, the need to gather, analyze, and share timely, comprehensive, and reliable information is paramount.

Even though there has been a considerable increase in disaster-related research and scientific activities, as well as advances in technology (e.g. satellite coverage and surveillance technology), disaster damage and loss is still on an upward trend (Dekens, 2007; White et al., 2001). There are clearly gaps and barriers between the complex interaction of knowledge production, sharing, and implementation. Studies have found that poor information and knowledge management in disaster management can lead to disaster propagation and higher levels of casualties (Jiang et al., 2012). Given the diverse and distributed nature of information and knowledge across different entities, the challenges around disaster information and knowledge management are multifold and complex, particularly around sharing and coordination (Bharosa et al., 2010; Spiekermann et al., 2015; White et al., 2001; Zhang et al., 2002).

Often stored away and difficult to access, knowledge is most commonly lost or fragmented due to inadequate coordination, partnership, communication, and sharing (Spiekermann et al., 2015). Research around disaster information and knowledge management show that the lack of knowledge is not the key challenge, but rather the problems lie with risk interpretation and understanding, mentalities across scales, power structure, personal attitudes, values, and other constraints across individual, community, and agency levels (Bharosa et al., 2010; McConnell & Drennan, 2006; Spiekermann et al., 2015). Spiekermann et al. (2015) identified three types of barriers to the fragmentation of knowledge, including functional barriers related to resource issues (divergent objectives, needs, scope, priorities, and lack of cooperation); structural barriers related to institutional settings and standards; and social barriers related to factors such as trust, values, understanding, and communication.

Due to many of these barriers, a key component of the disaster knowledge space — local knowledge and practices in disaster risk reduction — has not been adequately incorporated into the official channels of disaster management (Corburn, 2003; Dekens, 2007; Liboiron, 2015; Mercer et al., 2010; Milliken & Linton, 2015). While the importance of local knowledge — "what the residents know about natural hazard risks and what they believe and do about them in a given situation" — has been recognized and advocated in relation to disaster risk reduction, particularly for the most vulnerable populations, the practical application has been limited and marginalized (Dekens, 2007; Mercer et al., 2010). Some key factors that prevent the inclusion of local knowledge are ideological (e.g. the conventional or scientific knowledge is "superior"), institutional (e.g. it's difficult to use local knowledge because of their "invisibility," complexity, diversity, and changeability), and political (e.g. disasters are issues around national defense and security). The oppression of local knowledge is a reflection of the structural marginalization, exploitation, powerlessness, violence, and denial of the people who bear the knowledge, which often are the root causes of their vulnerability to disasters (Dekens, 2007; Liboiron, 2015; Mercer et al., 2010).

Participatory approaches to disaster management acknowledge local knowledge and people as the primary actors, providing an entry point for promoting local people's participation with "higher-level" institutions that already have a comparative advantage. In the context of complex, changing, and growing hazards, understanding, accounting for, and respecting local knowledge can help agencies improve their disaster management planning, as well as project performance, acceptance, ownership, and sustainability (Dekens, 2007). Therefore, although there are many challenges to the documentation and use of local knowledge in disaster management, working with communities to integrate their knowledge system on an equal and respectful basis has the potential to serve as an effective tool for building overall disaster resilience (Dekens, 2007; Mercer et al., 2010; Spiekermann et al., 2015).

To bridge these functional, structural, and social barriers across the heterogeneous actors in disaster information and knowledge sharing and coordination, the concept and role of boundary objects and activity theory have shown promise as theoretical foundations in cross-border collaboration in disaster management (Bharosa et al., 2012; Carlile, 2002; Engeström, 2000). The introduction of socio-technical objects (e.g. information systems) in combination with processes to promote cross-border collaboration (e.g. inclusive governance and communication mechanisms that involve all stakeholders) has been found to be helpful in overcoming various challenges.

4. Disaster Management Challenges in Puerto Rico

Located in the northeast Caribbean Sea and home to 3 million people, Puerto Rico faces a range of natural hazards including hurricanes, earthquakes, tsunamis, landslides, subsidence, and flooding (Palm & Hodgson, 1993). In September 2017, category 5 Hurricanes Irma and Maria caused complete disruption of power, damaged telecommunication towers, roads, bridges, water treatment and distribution systems, as well as the structural integrity of most healthcare (Resilient Puerto Rico Advisory Commission, 2018). On average, households went 84 days without electricity, 68 days without water, and 41 days without cellular telephone coverage (Hinojosa & Meléndez, 2018; Kishore et al., 2018). Hurricane Maria caused over $90 billion in damage, approximately 3,000 to 5,000 deaths, and an exodus of more than 150,000 people in the two months after (Chinoy, 2018; Kishore et al., 2018; Segarra, 2017). Before people could recover from complex sequelae triggered by hurricanes, Puerto Rico suffered a swarm of earthquakes in 2020 prior to the arrival of the global pandemic (Ayala et al., 2020). Even though it's going to take weeks for the public to understand the full impact of Hurricane Fiona that struck Puerto Rico in September 2022, early numbers showed devastating impacts on the archipelago, including huge amounts of rainfall, threats to human lives and safety, as well as widespread disruptions to electricity and water services and potential long-term socioeconomic setbacks (Diaz, 2022).

Disproportionately affecting the most vulnerable, these recent shocks have exposed Puerto Rico's stark inequalities. Studies have found that age, poverty, and remoteness along with its associated service disruptions, particularly delayed or prevented access to medical care, were among the most critical factors attributed to the excess deaths and other associated challenges post-Maria (Qin, 2020). On the archipelago, these vulnerability factors often compounded one another, making poor elderly Puerto Ricans in remote areas one of the most vulnerable groups (COR3 & Government of Puerto Rico, 2018; Resilient Puerto Rico Advisory Commission, 2018). Furthermore, with an economic crisis spanning more than a decade, colonial legacy, and other structural, demographic, health, social, and infrastructure stresses, Puerto Rico is in a particularly vulnerable position when confronted with natural hazards like hurricanes (Klein, 2018; Sullivan, 2018). Due to climate change, places like Puerto Rico will face more frequent and more destructive disasters. The need to better prepare the archipelago for future disasters is immense and urgent. In particular, these back-to-back disasters highlight the current information, coordination, and accountability gaps between local communities and agencies in the allocation and distribution of disaster relief resources and services across the multitude of individuals and organizations (Qin, 2020).

5. Understanding Community Information & Knowledge for Disaster Resilience in Puerto Rico

Over the past years, our team of researchers, designers, and technologists have led collaborative design and research efforts to identify and analyze the current challenges and opportunities in improving disaster management in Puerto Rico. We use a set of premises as guidance for our research: 1) Effective information and knowledge management is foundational to achieving disaster response and recovery goals; 2) Local knowledge is a key component of disaster information and knowledge management, but it is not consistently integrated into formal response mechanisms, due to functional, structural, and social barriers; 3) Social connectedness is vital for community resilience to build capacity for adapting and coping with the shocks from disasters; and 4) Leveraging existing strength and innovation enhances collaboration across individuals, CBOs, and agencies to achieve disaster resilience goals.

In response to the need for a more inclusive and effective information and technology system to close the last-mile disaster relief gap in Puerto Rico (Qin, 2020). The team has been collaborating with key stakeholders in Puerto Rico to co-develop solutions to mobilize, inform, and coordinate collective action across residents, community groups, and agencies to direct the right responses to the right places at the right time. With support from the Natural Hazards Center and the National Science Foundation, through interviews, focus groups and collaborative design workshops, and other ethnographic research methods such as cultural probes, the team worked with community residents, CBOs and their leadership teams, and different agencies across governmental and non-governmental entities across Puerto Rico (Chauhan et al., 2022; NSF, 2020; Sury et al., 2021).

Through these collaborative efforts to understand and improve disaster response for communities in Puerto Rico, we have identified major gaps in effectively leveraging the strengths, resources, and best practices of communities and residents in response to disasters. Our interviews and workshops with CBOs using cultural probes revealed communities' essential but overlooked and undernourished capacity to provide shelter-related services during a crisis (Chauhan et al., 2022; Sury et al., 2021). They expressed their desire to be integrated into formal government emergency shelter planning and response efforts and identified their role as a critical link to the needs of their communities regardless of an inherent distrust based on previous disaster experiences. As expected, some CBOs have been assuming responsibility and defining their roles to support community emergency planning since the 2019/2020 earthquakes and Hurricane Maria. These findings suggest the role of these organizations as central actors in a community's resilience to disasters, and that they have a desire to gain capacity, education, and resources to reach the most vulnerable people in a community. While our participants were not emergency managers or experts in shelter planning, they have experienced disasters before and have important knowledge about their communities' needs and were therefore able to provide useful feedback to the shelter planning process.

Currently, for emergent CBOs, either newly formed or pivoting their services in response to the hurricane, as they grow, most take a trial-and-error approach in their first efforts. Most organizational leaders, many of whom had little prior experience running organizations, had reported challenges as they learned how to mobilize community members, navigate levels of political bureaucracy, manage funding partnerships, and the plethora of many challenges of running a nonprofit. Studies have found varying degrees of capacities, knowledge, and experience with disaster management, as well as access to funding and resources across community groups on the archipelago (Sledge & Thomas, 2019). For these emergent groups, coordination and service delivery challenges have been prevalent in response to Maria, which was particularly hampered by effective information management within the community and outside entities. Without a reliable information system to coordinate efforts across the entities, people reported: “an enormous duplication of efforts, wasting money and resources” (Sledge & Thomas, 2019).

Recognizing the need to improve disaster information management, many CBOs in Puerto Rico initiated projects to map their community's needs and resources in detail, in order to deliver help to the right places and better plan for future disasters after Hurricane Maria hit the archipelago. Many leaders and volunteers of these CBOs led independent efforts to collect and manage various information about residents, including socioeconomic status, medical conditions, as well as needs for supplies such as food and water. For example, for over six months, the four presidents of a CBO, ACUTAS in Toa Baja, went to hundreds of households to collect information about their socioeconomic status, medical conditions, as well as needs for supplies such as food and water. They then transcribed paper surveys to notations on a large printed Google satellite basemap. For small towns in Puerto Rico like the one where ACUTAS is located, the information on Google Maps is either outdated, incorrect, or nonexistent. In Puerto Rico, the lack of a consistent mailing address system makes the project even more complex using a universal basemap like Google. House by house, they wrote down house numbers, used colored dots to indicate the presence of particular demographic groups (e.g. children, elderly, and bedridden), and corrected the wrong street and landmark names. Given the changing nature of community information, with only four people managing the information system, it became an impossible task to keep updating the paper map. Similar efforts to map community information were reported by CBOs from across Puerto Rico, tapping into the power of community knowledge and social networks. All of these community mapping efforts were initiated and managed by CBOs as part of their disaster resilience-building efforts, presenting opportunities to bridge the disaster information gap for citizens and communities. However, as a result of the time and resource intensive nature of these initiatives, many small, resource and staff strapped CBOs cannot keep up with the requirements to maintain community information up-to-date. Additionally, due to the lack of appropriate and accessible digital tools, spotty internet access, and unpredictable weather, such information is often collected in analog formats (e.g. paper surveys) and recorded on hand-drawn maps, which makes it more difficult to share, preserve, and manage the information collected (Qin, 2020). While these emergent community mapping efforts present opportunities to tap into valuable community knowledge and social networks, they still have not been effectively integrated into the formalized disaster management systems.

6. Our Collaborative Design

Building on these past research efforts and findings, the team, together with key stakeholders in Puerto Rico, has created preliminary designs for a civic technology initiative, re+connect, in response to the challenges faced by communities and agencies ready for further testing. Through a mobile (individuals) and a web (organizations) application, re+connect leverages human networks, data, and machine intelligence to inform and coordinate collective action to direct the right responses to the right places at the right time through four phases: 1) Crowdsource: In disaster-prone communities, residents join the mobile app as Community Ambassadors to crowdsource information on individual needs & capacities for themselves and others who do not have access to a smartphone. 2) Match: Based on crowdsourced community information supported by ethical machine learning/artificial intelligence, organizations match with other trusted allies to share and/or receive relief resources to help communities in need. Community leaders can also connect with interested, qualified Community Ambassadors to join their local mission. 3) Coordinate: Different organizations can coordinate and streamline resource and service delivery to communities and individuals by completing key actions step by step while keeping all important logistics and contact information in one place. 4) Track: Organization users can gather impact reports, data, and stories from all partners to track and demonstrate where relief resources have made a difference with customizable graphics and reporting options. Our demo video (link in reference) outlines the software design that will be used in our continued collaborative work (re+collective, 2022).

7. Humanitarian Ethics, Data, and Technology Governance

Humanitarian settings are unique contexts where circumstances change rapidly, safety is paramount, and challenges are shifting constantly. For these specific reasons, innovation has traditionally been difficult to implement and harness. To develop innovation that responds to the needs of humanitarian work, project teams must be aware of the unique aspects of the target context to fully be successful, and not enhance the risk exposure to self and others. Global actors and stakeholders in the humanitarian sector have developed ethics and principles that govern humanitarian endeavors to bind a standard set of behaviors and protections. With regard to humanitarian technology, in particular, it is critical that the development and deployment of any proposed technology is carefully evaluated on the basis of its fit into the current humanitarian landscape, and its alignment with the aforementioned guiding principles to mitigate unintended consequences. The data and technology governance strategy underlying our work prioritizes taking a collaborative approach to designing an innovation program alongside local stakeholders in Puerto Rico. In close consultation and collaboration with experts from adjacent academic and industry domains, humanitarian practitioners, and community members, we have been working with our civic partners in co-creating and iterating protocols to orient product development processes and the technology and data generated to promote human rights and ethics-based outcomes.

8. Conclusion

Confronted with more frequent and more destructive disasters, places like Puerto Rico present immense and urgent needs to overcome the deep-rooted political, power, cultural, and institutional barriers to integrating community knowledge and information in disaster management, without causing more harm to the already vulnerable populations. We believe our collaborative design approach could help yield sustainable, scalable, and transferable impacts in community participation and data integration for building a more resilient future in Puerto Rico and beyond through the following pathways:

1) Integrating local knowledge to make disaster management more human-centered and effective. A key component of the disaster knowledge space – local knowledge and practices in disaster risk reduction – has not been adequately incorporated into the official channels of disaster management. The inclusion of resident and community information and knowledge will help improve overall disaster management planning, as well as project performance, acceptance, ownership, and sustainability.

2) Enhancing collaboration as a path to building resilience and reducing risk. As disasters grow in scale and severity, governments at all levels are already grappling with the limitations of their resources and capacities. Building resilience at the individual and community level has become increasingly vital. It's vital to bridge the current collaboration gaps so that residents, communities, and agencies can collectively understand and assess the needs and determine the best ways to leverage their assets, capacities, and interests, leading to greater resilience and risk reduction.

3) Strengthening social bonds as the core of building resilience and survival mechanisms. Accounts from around the world have shown that social connectedness is one of the most important factors in whether and how fast a community can recover from disasters as organized communities are more likely to access essential resources and information. Initiatives should strengthen social connections among individuals and between organizations through the participatory design and research process as well as the product to mobilize, inform, and coordinate collective action in the face of crises.

4) Sharing valuable lessons for building disaster resilience and risk reduction in other contexts. As we enter the age of disasters, it's important for researchers and practitioners from interdisciplinary fields to share valuable research insights and lessons learned to inspire and help communities and agencies facing similar challenges enhance resilience and reduce risk in other contexts.

Advancing Equity with Community Data Partnerships: Response to OSTP RFI
87 FR 54269, October 3rd 2022

From: Greg Bloom, Open Referral Initiative
Subject: Promoting open access and interoperability to information about the accessibility of human services

Thank you for the opportunity to comment on 'equitable data' and its potential to improve accountability of government in our society. In response, I'm pleased to provide this summary of recent progress toward the standardization of 'resource directory data' – i.e. information about the location and accessibility of health, human, and social services available to people in need.

While resource directory data may not have been what the authors of this request for information had in mind when they described "equitable data," it is essential public information that is critical for any perspective on the effectiveness of federal funding to meet the needs of disadvantaged Americans. In other words, before we can improve the ability to use data about the *results* of government-funded human services, we need to address the fact that Americans don't have equitable access to information about what government-funded human services exist in the first place.

Below is a description of the challenges pertaining to accessibility of resource directory data, recent developments in the standardization thereof, and potential roles that federal agencies can play in promoting accessibility and reliability of information about services available to people in need.

The Problem: a landscape of fragmented silos

Information about the accessibility of health, human, and social services is constantly in flux. Shifts in funding, staff turnover, and other factors regularly change which services are available to whom, where and how they can be accessed. Nonprofit and government agencies are often under-resourced and overwhelmed, and it is often not a high priority for them to widely promote detailed information about their own services to the public.

There are many 'referral services' — such as call centers, resource directories, and web applications — that manually aggregate and maintain this information themselves, usually soliciting it through recurring outreach to service providers. The resulting service information landscape is redundant, fragmented, and siloed. As a result of this costly and ineffective status quo:

- **People in need** have difficulty discovering and accessing services that can help them live better lives.
- **Service providers** struggle to connect clients with other services that can help meet complex needs.
- **Decision-makers** are unable to gauge the effectiveness of programs at improving community health.
- **Innovators** are stymied by lack of access to data that could power valuable tools for any of the above.

The Opportunity: interoperability through standardization

Many have tried and failed to build 'one stop shop' solutions (i.e. 'centralized community resource clearinghouses') — and new efforts still emerge all the time. The scale of labor required to maintain this information is often too great for any one organization to accomplish itself. So these well-intentioned efforts end up causing more fragmentation and confusion.

However, if the many different kinds of information systems that connect people to services could all recognize a common data format, then **resource directory data could be published canonically, as standardized open data, to be simultaneously accessed and used in many ways by many systems**.

Our Progress: development of an industry standard for data exchange

In 2014, the Open Referral Initiative (https://openreferral.org) formed out of a series of dialogues among the Alliance of Information and Referral Systems, Google.org, Code for America, and a variety of resource referral software vendors in the fields of health, human, and social services.

Open Referral's objective was to establish a data exchange format that would enable interoperability among service directory information systems used by conventional call centers and emerging web apps, as well as search engines like Google, Yelp, etc.

The result of our efforts is the Human Services Data Specification (HSDS) and API protocols (HSDA), which are documented at https://docs.openreferral.org.

In November 2018, the Alliance of Information and Referral Systems (http://airs.org) formally endorsed HSDS as industry standars for resource data exchange. (Read more about this endorsement here: https://openreferral.org/airs-recommends-open-referral-for-resource-database-interoperability/)

HSDS is currently used by market leaders for both resource-referral call-center software (such as iCarol: https://openreferral.org/icarol-deploys-open-referral-in-new-resource-api/) as well as health-centered care-coordination software (such as Healthify: https://openreferral.org/how-healthify-uses-open-referral-standards-to-strengthen-care-coordination/). The United Way Worldwide's National 211 data platform is using these protocols to publish directory data (https://openreferral.org/united-way-worldwides-national-211-data-platform-bringing-people-and-services-together/) as are many state and local 211 providers and other information-and-referral providers.

These protocols are also under adoption by a range of local governments (such as New York City: https://openreferral.org/nyc-government-publishing-open-data-for-municipally-contracted-service-providers/) and philanthropic funders (such as the Florida Bar Foundation: https://openreferral.org/the-florida-legal-resource-directory-project/).

Open Referral's protocols for resource data exchange have also been recognized by the US Data Federation, under the General Services Administration (https://federation.data.gov/) and supported by HHS agencies such as the Administration for Community Living and Administration for Children and Families.

The Role for Government in promoting open standards and interoperability

We encourage federal agencies to leverage HSDS and associated API protocols as default, non-proprietary methods for the publication of resource data about the health, human, and social services available to people in need. There are several roles that government agencies might play in this regard.

First of all, government agencies can directly publish standardized open data about those services that are provided within their own remit. Some government agencies provide services directly. Many agencies also fund services through grants and contracts. In any such case, up-to-date machine-readable non-proprietary data should be made available to the public. By using this industry standard as a default format for publishing data about government services and publicly-funded services, the government can simultaneously promote interoperability and innovation — as well as transparency and accountability — across the fields of health, human, and social services.

Some federal agencies also produce directories of assorted services within their domains. Sometimes such resource directories are made available in PDFs or searchable websites. By ensuring that each such service directory is also available in a standardized, machine-readable format — ideally through a standardized API — government agencies can ensure their investment into such information products can yield even broader value, as such information can be interoperably accessed for reuse by an ecosystem of third-party intermediaries.

Government agencies also provide funding for the development of community-based infrastructure for care coordination. Through procurement policy, such funding could entail contractual requirements that any resource information that is aggregated and exchanged through related activities should be made available in a non-proprietary, machine-readable, industry-standard format.

The benefits of human service directory data standardization

Any of the above actions could enable cost savings, enhanced data quality, and improved service discovery and deliverability — across the many domains of health, human, and social services.

By making open, standardized resource directory data freely available as information infrastructure for use by referral providers, technology developers, and researchers and analysts, the government can greatly improve our collective capacities for innovation — from institutions like the HHS IDEA Lab to community-based hackathons across the country.

When standardized resource data is published in a predictably structured way on the web, it will also be easier for this information to be indexed and delivered to users directly by web engines like Google, Facebook, Yelp, etc.

Furthermore, this evolutionary step forward can enable new capacities for feedback collection and quality improvement across the field. Today, agencies often only collect data at periodic intervals — if at all — about the accessibility of services that they fund; however, service accessibility is constantly changing. By enabling standardized open access to canonical resource data across any given information channel, we can subsequently enable agencies to receive real-time feedback — about the accuracy of the data, and also about the quality of services — from those channels. These feedback loops can enable a much more accurate view of the service landscape over time.

Perhaps most importantly, these developments can make it easier to assess — and improve — the effectiveness of public investments in the health and well-being of children, families, and communities. As the industries of resource referral and care coordination shift from competitive silos to the aligned use of canonical data through open infrastructure, it will become possible for researchers and policy-makers to analyze data about communities' needs — and programs' effectiveness in meeting those needs — at a scale that was not previously possible. By enabling interoperable aggregation and analysis of 'usage data' such as search queries, and referral logs, we can generate insights into questions about which kinds of people are in need of which kinds of services — where the gaps are, and how service delivery might be made more efficient.

Moving forward

Leadership from the Open Referral Initiative is available to provide advice, consulting, and even implementation of new methods to publish standardized resource directory data. Open Referral can also support the development of demand-side 'use cases' to demonstrate value propositions through testing and evaluation, from across the thousands of organizations represented by members of our network. Thank you for your service.

Greg Bloom
Open Referral
[redacted]

COMMUNITY CATALYST

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October 3, 2022

NSTC Subcommittee on Equitable Data
Office of Science and Technology Policy (OSTP)
[redacted]e Building
NW
Washington, DC 20504

Re: Notice of Request for Information (RFI) [87 FR 54269]

Community Catalyst is a leading non-profit national health advocacy organization dedicated to advancing a movement for health equity and justice. We partner with local, state, and national advocates to leverage and build power so all people can influence decisions that affect their health. Health systems will not be accountable to people without a fully engaged and organized community voice. That's why we work every day to ensure people's interests are represented wherever important decisions about health and health care are made: in communities, state houses, and on Capitol Hill. We share your goals of making the healthcare system work for those not currently well-served, especially people of color, individuals with low incomes, older adults, and those with chronic conditions or disabilities.

We respectfully submit the following responses to some of the questions put forth in the Request for Information on improving equitable data engagement and accountability [87 FR 54269]. We deeply appreciate the Biden-Harris Administration (the Administration)'s commitment to advancing equity and racial justice. We commend the Administration for its interest in and willingness to receive input on how federal agencies can best demonstrate their commitment to and effectively implement Executive Order 13985,[1] which directs the federal government to "pursue a comprehensive approach to advancing equity for all, including people of color and others who have been historically underserved, marginalized and adversely affected by persistent poverty and inequality."

General comments on equitable data

For decades, the United States' broken data system, which was built on unconnected, aggregated, and time-lagged information, has played a central role in deepening health inequity and economic injustice for historically excluded communities – such as those who are low-income, older adults, persons with disabilities, LGBTQI+, communities of color (Black, Native American, Indigenous, Hispanic, Latino/a/e/X, Arab/Arab American, Southeast Asian, Asian,

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[1] The White House. Executive Order on Advancing Racial Equity and Support for Underserved Communities Through the Federal Government. Executive Order 13985. January 20, 2021. https://www.whitehouse.gov/briefing-oom/presidential-actions/2021/01/20/executive-order-advancing-racial-equity-and-support-for-underserved-communities-through-the-federal-government/ Accessed September 29, 2022.

Asian Pacific Islander, Native Hawaiian, Desi and/or immigrant communities). As shown from the brutal toll of the COVID-19 pandemic, inconsistent and flawed nationwide data[2] undercut efforts to collect accurate and timely information to improve access to vaccines, testing and life-saving treatments for those communities. If it is one thing limited data on COVID-19 revealed is that structural racism is real, and it has profound impacts on diverse communities. The Administration must leverage its agencies to improve the measurement of structural racism and its impact on health policies.[3]

We applaud the OSTP to take the first critical step to use equitable data—meaning robust disaggregated data by demographic information (e.g. race, ethnicity, gender, sexual orientation, language spoken, etc.) geographic information (e.g. rural/urban) and other variables that allows for rigorous assessment of the root causes that impact health outcomes of historically excluded populations. While data collection alone is not enough to address racial health disparities, it is important in highlighting and targeting specific disparities and in tailoring programs that best address communities' health needs and drive policy changes.

As part of data equity, it is important to collect and stratify it in ways that is useful for all communities. This includes disaggregating data. Particularly, we urge the OSTP to include the following disaggregated data to the list of demographic information: race, ethnicity, language, disability, age, sex, sexual orientation, gender identity, pregnancy status, and sex characteristics. The Department of Health and Human Services (HHS) has already established or acknowledged recommended practices for engaging in demographic data collection in each of these demographic categories.[4] The OSTP should adopt those existing data collection practices and engage in additional research where necessary—specifically disaggregated data on gender identity and sexual orientation. With any demographic data collection requirement, the OSTP must be sure to provide appropriate training and technical assistance resources to programs and grantees.

Additionally, the OSTP must ensure that data collected is maintained safely and securely by the appropriate entities. Strict standards must be adopted to make clear that data cannot be used for negative actions such as immigration or law enforcement, redlining or targeting of specific groups, criminalization of persons seeking reproductive health and gender affirming care. While requests for data should be required, individuals' responses must be voluntary and should be self-reported to ensure accuracy. It is critical to train relevant staff on the collection of demographic data, including how to explain why data is being collected. These protections will help to ensure that data collected can be best utilized to prevent discrimination and disparities in

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[2] Abraham (Adi) Wyner. "Why the U.S. Needs Better COVID Data Collection." Knowledge at Wharton. February 8, 2022. https://knowledge.wharton.upenn.edu/article/why-the-u-s-needs-better-covid-data-collection/ Accessed September 29, 2022.

[3] Rachel R. Hardeman, Patricia A. Homan, Tongtan Chantarat, Brigette A. Davis, and Tyson H. Brown. Improving The Measurement Of Structural Racism To Achieve Antiracist Health Policy. Health Affairs; Vol. 41, No. 2: Racism & Health. https://doi.org/10.1377/hlthaff.2021.01489. Accessed October 1, 2022.

[4] Office of The Assistant Secretary for Planning and Evaluation. U.S Department Of Health And Human Services Implementation Guidance On Data Collection Standards For Race, Ethnicity, Sex, Primary Language, And Disability Status. October 30, 2011.https://aspe.hhs.gov/sites/default/files/private/pdf/76331/index.pdf. Accessed October 1, 2022.

healthcare access and quality, which have shown to lead to increases in morbidity and mortality.

We are pleased that the OSTP encourages diverse collaboration across levels of government (i.e., federal, tribal, territorial, local and state), researchers and research institutions, and local communities involving in producing, accessing and using equitable data. However, we stress that to achieve race equity and health justice, collecting data and disaggregating it must be coupled with interpreting and analyzing the data collected. Additionally, it is imperative that process orchestration builds feedback loops and patient and community and lived experience into consideration.

What are examples of successful collaborations between the Federal government and (a) Tribal, territorial, local, and State governments or (b) local communities involving equitable data? Among examples of existing Federal collaborations involving equitable data, what lessons or best practices have been learned from such collaborations?

An example of a promising collaboration model - The Accountable Health Communities (AHC) model offers a promising model of collaborations between the Center for Medicare and Medicaid Innovation (CMMI) and clinical delivery sites, community service providers, state Medicaid agencies, and other community stakeholders to address social determinants of health.[5] Launched in 2017, the AHC model was to test whether connecting Medicare and Medicaid beneficiaries to community resources can improve health outcomes and reduce health care costs. As of Winter 2021, 29 of 32 AHC funded entities known as bridge organizations remained in the AHC. These entities were diverse in terms of types of organizations, including county governments, hospitals, universities, community-based organizations, health payers, and health departments. They covered 328 counties in 21 states, including 7 of the 10 largest US cities and rural areas in Colorado, Kentucky, New Mexico, Oklahoma, Oregon, Virginia, and West Virginia.

As community engagement is a fundamental component of the AHC model, AHC bridge organizations promoted clinical-community collaboration. For example, using hospitals, clinics, doctors' offices, and other clinical settings as entry points, AHC bridge organizations and clinical partners screened Medicare and Medicaid beneficiaries for unmet health-related social needs (HRSNs), such as food insecurity, housing instability, transportation problems, utility difficulties, and interpersonal violence; and referred them to community services. With community feedback, HRSNs screening may also include across supplemental domains include family and social supports, education, employment and financial strain, mental health, disabilities, and health behaviors.

By the time the AHC ended, over 35 percent of patients screened reported at least one health related social needs and were eligible for referral to community services. The AHC also provided at least monthly outreach from navigators to assist beneficiaries who had multiple health related social needs but faced barriers accessing community services. This approach was proven to be

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[5] Kate Abowd Johnson Natalia Barolin Christine Ogbue Katherine Verlander. "Lessons From Five Years Of The CMS Accountable Health Communities Model." Health Affairs Forefront, August 8, 2022. https://www.healthaffairs.org/content/forefront/lessons-five-years-cms-accountable-health-communities-model. Accessed September 30, 2022.

effective. As of today, although the AHC model has ended, participating communities are using infrastructure built during the model to scale and spread the tested interventions.

Lessons learned: The AHC model offers several valuable lessons.[6] Those include, but are not limited to:

- *Requiring the inclusion of Disparities Impact Statements in AHC model applications* - A notable factor contributing to the success of the AHC model to achieve health equity goals is that from the start, CMMI signaled to the field that health equity is a priority for CMS by requiring AHC model applicants to incorporate Disparities Impact Statements (DISs) with annual updates into the AHC model test as a data-driven approach for identifying and addressing health disparities within minority and underserved communities.

- *Requiring use of the standardized AHC Screening Tool to ensure model integrity and consistency with screening*. An area for improvement would be to add screening for medical debt in addition to screening for financial strain given that medical debt is a growing concern for as many as 100 million adults – 41 percent of all adults in the United States.[7]

- *Providing regular technical assistance to build capacities for AHC funded entities* throughout the process from implementation to monitoring and evaluation of their DIS strategies and action plans to ensure effectiveness.

- *Using screening data to monitor performance and drive quality improvement effort*. Successful navigation is challenging. However, many AHC bridge organizations were able to identify strategies to improve effectiveness. For instance, when St. Joseph's Hospital Health System began implementation of the AHC model, many sites struggled to effectively engage existing registration staff in taking on additional screening responsibilities for the AHC model. To address these challenges, both the project management team and local leaders at the sites developed and disseminated data monitoring reports and used them to foster engagement and accountability among staff, which in turn has led to a noticeable increase in the average number of completed screenings. For more information on the best practices offered by St. Joseph's project's best practices management team: Using Data for Quality Improvement: A Case Study from St. Joseph's Hospital Health System.

The AHC model is a great start to address HRSNs. However, we must go beyond equitable data to provide equitable funding for community-based organizations to build or strengthen skills for interoperable data. We encourage the OSTP to provide technical assistance to better facilitate how data can be triangulated (e.g., Census data, HHS data, local community health needs assessments data, HRSN screening data, SIPP data, etc.).

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[6] Wilson, Brandon G.; Jones, Emily. Lessons on Increasing Racial and Health Equity from Accountable Health Communities. Journal for Healthcare Quality. September/October 2022 – Volume 44- Issue 5 – p 276-285. https://journals.lww.com/jhqonline/Fulltext/2022/10000/Lessons_on_Increasing_Racial_and_Health_Equity.4.aspx Accessed September 30, 2022.

[7] Lunna Lopes, Audrey Kearney, Alex Montero, Liz Hamel, and Mollyann Brodie. Health Care Debt In The U.S.: The Broad Consequences Of Medical And Dental Bills. *Kaiser Family Foundation: Health Care Debt Survey*. June 16, 2022. https://www.kff.org/report-section/kff-health-care-debt-survey-main-findings/

What policies, resources, programs, training, or other tools can facilitate increased data sharing between different levels of government (Tribal, territorial, local, State, or Federal) around equitable data?

Government policymaking and processes need to directly involve the individuals and communities who will be most impacted by the policy or process, both in the identification of the problems that the policy/process is intended to solve, as well as the development of solutions to address the problem. However, due to lack of knowledge, skills, resources or willingness, sometimes policymakers, healthcare providers, health systems, public payers and insurers do not always meaningfully engage with individuals and communities, which can then lead to barriers and burdens in accessing health care.

Recommendations: Under a federal requirement (Section 501(r)(3)), nonprofit hospitals are required to provide community benefits in order to maintain their tax-exempt status. To help guide their investments, they must conduct a community health needs assessment (CHNA) every three years and develop an implementation strategy that responds to identified needs. However, there is little regulation on the extent to which community members must be involved in this process. Furthermore, while hospitals may identify health disparities in their communities, surprisingly few devote resources to address them. The Administration could do more to strengthen community engagement requirements within CHNAs for nonprofit hospitals.

For more information, see the following resources:

- Hospital Community Benefit Dashboard – Advancing Health Equity and Community Engagement
- Building Local Capacity To Engage Hospitals Through Community Benefit: Lessons And Learnings From Three Communities
- Building authentic community-hospital partnerships and fostering community engagement: A conversation with A Vision of Change-University Hospitals in Cleveland Ohio and the Cultural Wellness Center-Allina Health in Minneapolis, Minnesota.

One driver of health inequities is medical debt, which is unevenly distributed across people of different races and ethnicities – Black people and people of Hispanic origin are more likely to have medical debt than white, non-Hispanic people. Because medical debt is a financial barrier to care, disparities in medical debt can lead to disparities in health care access and outcomes.[8] We believe that collecting data about hospital practices that are associated with the accumulation of medical debt will help advance equity by allowing hospitals to identify where their policies are and are not being properly applied, whether there might be bias in how the policies are applied, and how they can improve their service to patients by limiting their exposure to medical debt. Therefore, we recommend adding a requirement in CHNAs to (1) include screening for medical debt and (2) develop an action plan to address the issue – those actions include, but are not limited to:

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[8] Consumer Financial Protection Bureau. Medical Debt Burden in the United States. February 2022. https://files.consumerfinance.gov/f/documents/cfpb_medical-debt-burden-in-the-united-states_report_2022-03.pdf. Accessed October 2, 2022.

- Proactively screening all patients for eligibility for financial assistance, regardless of their immigration status.
- Extending financial assistance programs to underinsured as well as uninsured patients
- limiting fees to no more than the Medicare or Medicaid rate for patients who are uninsured or underinsured, and for any portion of a bill that is self-pay.
- Eliminating collection actions that impoverish such patients, including liens on homes (which often is a family's only asset), wage garnishments, and body attachments or civil actions that lead to arrest or incarceration.

In which agencies, programs, regions, or communities are there unmet needs, broken processes, or problems around participation and accountability that could be remedied through stronger collaborations and transparency around equitable data?

Collect and analyze disaggregated data on patients' experiences of being refused reproductive care or gender-affirming care, or experiencing dangerous delays in treatment of pregnancy emergencies - The Consumer Assessment of Healthcare Providers and Systems (CAHPS) survey is intended to capture patients' experiences with health plans, providers and health care facilities. The reports that come from these surveys are important because they are used to create strategies to improve patients' experiences with care. However, the CAHPS and HCPHS surveys currently do not capture patients' experience with hospitals' refusals to provide prompt, medically-appropriate treatment of pregnancy emergencies, such as ectopic pregnancies and miscarriages, because of hospital religious/ethical policies or administrators' concerns about potentially violating state abortion bans. Moreover, the surveys do not ask about health facility refusals to provide reproductive health services, such as administered wanted contraception or post-partum tubal ligations, or gender-affirming care. This presents a major gap in current data with a dire need for data to understand how provider's religious or ethical directives impact those already most marginalized by the health care system.

Recommendations: Patients in many areas of the country are experiencing great difficulty in obtaining needed reproductive and pregnancy emergency care in this post-Roe era. At least 13 states have implemented abortion bans,[9] and four of the 10 largest private health systems in the country operate under religious directives that ban the provision of contraception, sterilization and abortion, while compromising the provision of pregnancy emergency care.[10] Research shows that the average patient travels approximately 50 miles one way to access legal, safe abortion services.[11, 12] Providers refusing needed reproductive, sexual and LGBTQI+ competent care is an

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[9] Center for Reproductive Rights. After Roe Fell: Abortion Laws By State. https://reproductiverights.org/maps/abortion-laws-by-state/ Accessed October 1, 2022.

[10] Bigger and Bigger: The Growth of Large Catholic Health Systems," Community Catalyst, 2020, https://www.communitycatalyst.org/news/press-releases/new-report-finds-rapid-growth-of-catholic-health-systems

[11] Liza Fuentes. Distance Traveled to Obtain Clinical Abortion Care in the United States and Reasons for Clinic Choice. Journal of Women's Health 28(12). July 2019. https://www.liebertpub.com/doi/10.1089/jwh.2018.7496. Accessed October 3, 2022

[12] See, for example, the case of Evan Minton, a transgender man denied gender-affirming surgery by Dignity Health, part of the CommonSpirit Health System, the largest Catholic system in the nation and the second largest private health system. His case is summarized in an amicus brief filed in support of Minton's legal challenge here: https://www.nclrights.org/our-work/cases/minton-v-dignity-health/

alarming health equity concern that disproportionately impacts already marginalized groups such as women and LGBTQI+ people of color. Given that national data sources like the CAHPS do not currently collect data on patient's experiences of being refused reproductive or gender-affirming care, we urge the federal government to devise ways of beginning to collect such data using methods like Community Based Participatory Research or Participatory Action Research, including assembling an advisory group to help envision such research and ensure patients' voices are incorporated. We are aware that a maternity care version of the CAHPS survey is under development, and suggest including questions concerning whether desired services (such post-partum tubal ligations) were provided as requested during the patient's hospital stay, or whether patients experienced any delays in the provision of needed pregnancy emergency care. We were also intrigued to learn about a new question being tested for inclusion in Medicare enrollee CAHPS surveys asking whether the patient has experienced perceived "unfair treatment" from providers related to the patient's health condition, disability, age, culture or religion, language or accent, race or ethnicity, sex (female or male), gender or gender identity, sexual orientation or income. This survey was described during a presentation at the September 2022 ARHQ Virtual Research Meeting on "Assessing Patient Experience for Insights into Enhancing Equity in Healthcare."[13] We believe this question has some promise in beginning to explore discrimination in the provision of reproductive and gender-affirming care, and should be evaluated for use with population cohorts of reproductive health age, potentially with follow up questions to ask more specifics about the unfair treatment. One potential follow up question could address health facilities' religious directives and ethical policies as a source of unfair treatment. We need to be able to disaggregate the sources of unfair treatment and discrimination, in order to address the root causes.

We also suggest expanding the Minority Research Grant Program (MRGP) [14] to include research on this area. We believe that MRGP should go beyond National Institutes of Health (NIH), Centers for Disease Control and Prevention (CDC), and Centers for Medicare and Medicaid Services (CMS) funded research at academic institutions, by extending to entities that facilitate community-based research (e.g., community-based organizations, health advocacy organizations, and the health justice movement). Furthermore, MRGP should include fellowships for historically underrepresented scholars and minority serving community-based organizations and research institutions to access data across the federal government.

What policies, resources, programs, training, or tools can make equitable data more accessible and useable for members of the public?

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[13] Presentation by Joy Binion of CMS at the Virtual Research Meeting," MA and PDP New Item Testing: Perceived Unfair Treatment, September 22, 2022. https://www.ahrq.gov/cahps/news-and-events/research-meetings/assessing-patient-experience.html

[14] The CMS Office of Minority Health administers the Minority Research Grant Program (MRGP), to support researchers at minority-serving institutions (MSIs) who are investigating or addressing health care disparities affecting racial and ethnic minorities, including lesbian, gay, bisexual, transgender, and queer (LGBTQ+) persons; persons with disabilities; persons who live in rural areas; and persons otherwise adversely affected by persistent poverty or inequality. https://www.cms.gov/About-CMS/Agency-Information/OMH/equity-initiatives/advancing-health-equity/minority-research-grant-program

The Administration should lead efforts to facilitate more access to their data, more ease of use for claims files, quicker turnaround for Medicaid data, remove the fee associated with ResDAC data or waive the fee for minority serving researchers and community-based organizations. We recommend that federal agencies can put out an RFI or RFP for tech developers to develop a user-friendly platform that allows for better integration and interoperability of community-based organizations and healthcare data addressing social determinants of health (SDOHs).

Additionally, we recommend providing policies and support systems to expand the utilization of Z-codes to document SDOHs, which will allow for a richer analysis of disparities and health equity. The benefit of using Z codes to address SDOHs and improve outcomes is explained clearly in the Centers for Medicare and Medicaid Services (CMS)'s document "Using Z Codes: The Social Determinants of Health (SDOH); Data Journey to Better Outcomes." We recommend the OSTP work with CMS to expand Z-codes to provide higher reimbursements, expand providers who can bill for SDOH, or allow billing under general physician supervision. We also recommend that a new code be created that would allow medical debt to be analyzed directly for its influence on outcomes as a SDOH.

We welcome an opportunity to partner with the OSTP on all of the above-mentioned recommendations.

Respectfully submitted,

[redacted]

Dr. Brandon G. Wilson, DrPH, MHA
Director of the Center for Consumer Engagement in Health Innovation
Community Catalyst

THE GEORGE
WASHINGTON
UNIVERSITY
WASHINGTON, DC

Jeremy Bearer-Friend
Associate Professor of Law
[redacted]
[redacted]

October 3, 2022

NSTC Subcommittee on Equitable Data
Office of Science and Technology Policy
Eisenhower Executive Office Building
[redacted]
Washington, DC 20504

Submitted electronically to [redacted]

Re: Equitable Data Engagement and Accountability RFI

My name is Jeremy Bearer-Friend and I am an Associate Professor of Law at George Washington University Law School.[1] My published research on the omission of race and ethnicity from federal tax data and its implications for federal tax administration has been cited by the U.S. Treasury Department, in testimony before Senate Finance Committee, the House Ways & Means Committee, and in numerous academic journals. I write to you now in response to the Office of Science and Technology Policy's (the "**OSTP**") Request for Information Regarding Equitable Data (the "**RFI**").[2]

My comments pertain to RFI question seven: "*In which agencies, programs, regions, or communities are there unmet needs, broken processes, or problems related to participation and accountability that could be remedied through stronger collaborations and transparency around equitable data*?"[3]

The Internal Revenue Service (the "IRS") has unmet needs, broken processes, and problems related to participation and accountability. Specifically, the IRS does not provide the public with aggregate statistics about the racial equity implications of its enforcement activities, such as the proportion of Hispanic taxpayers denied innocent spousal relief relative to white taxpayers.[4] The IRS also does not share the internal measures it uses for evaluating the racial equity implications of its tax enforcement activities—from the policy choices about enforcement priorities to the discretionary actions of individual examiners.

Instead, the IRS has repeatedly taken the position that because the IRS does not ask taxpayers to identify their race or ethnicity on submitted tax returns, IRS enforcement actions are not affected by taxpayers' race or ethnicity. This claim, which I call "colorblind tax enforcement," has been made by

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[1] I do not speak on behalf of George Washington University; my title is included for identification purposes only. The purpose of this letter is to make available to governmental bodies, officials, and employees the results of my nonpartisan research on racial equity in tax data collection and tax enforcement.

[2] Notice of Request for Information, *Equitable Data Engagement & Accountability,* 87 Fed. Reg. 54,269 (Sept. 2, 2022).

[3] *Id.*

[4] While information included on tax returns is subject to additional privacy protections under 26 U.S.C. §6103, publishing aggregate statistics about tax collection is a longstanding practice at the IRS. *See* Jeremy Bearer-Friend, *Should the IRS Know Your Race? The Challenge of Colorblind Tax Data*, 73 Tax. L. Rev. 1, 47 (2019).

multiple IRS Commissioners serving in multiple administrations (both Democratic and Republican). This claim has been made to members of Congress and to members of the press.

In my research, I refute the IRS position that racial bias cannot occur under current IRS practices.[5] I do so by identifying the conditions under which race and ethnicity could determine tax enforcement outcomes under three separate models of racial bias: racial animus, implicit bias, and transmitted bias. I then demonstrate how such conditions can be present across seven distinct tax enforcement settings regardless of whether the IRS asks about race or ethnicity. The IRS enforcement settings analyzed include summonses, civil penalty assessments, collection due process hearings, innocent spouse relief, and Department of Justice referrals. In short, current data practices are insufficient to protect against racial bias in tax enforcement and may in fact enable ongoing bias by preventing prudent interventions.

Ultimately, the ongoing practice of omitting race and ethnicity from IRS data publications interferes with our ability to achieve just results in tax policy by obscuring the disparate racial outcomes of tax policy and stalling efforts to remedy that disparate impact. These data policies also undermine democratic accountability of tax policy by preventing the public from knowing the impact of IRS tax enforcement.

As an outsider to the IRS, OSTP could make decisive impact on this issue. OSTP will also be building on the preliminary advances of the Equitable Data Working Group, including a pilot inquiry on distribution of Economic Impact Payments and ongoing work developing an imputation model.[6]

Best,

Prof. J. Bearer-Friend
Associate Professor of Law
GW Law School
[redacted]

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[5] Jeremy Bearer-Friend, *Colorblind Tax Enforcement*, 97 NYU L. REV. 1 (2022).

[6] *See* Wally Adeyemo & Lily Batchelder, *Advancing Equity Analysis in Tax Policy (*Dec. 14, 2021), available at: https://home.treasury.gov/news/featured-stories/advancing-equity-analysis-in-tax-policy. The signature publications of the Treasury Department, however, including the Green Book and the Tax Expenditure Budget, still do not include race and ethnicity in their published analysis.

DREXEL UNIVERSITY
Nowak Metro Finance Lab
Lindy Institute for Urban Innovation

September 29, 2022

Attn: NSTC Subcommittee on Equitable Data
Office of Science and Technology Policy
Eisenhower Executive Office Building
[redacted]
Washington, DC 20504

Re: Request for Information; Equitable Data Engagement and Accountability

To whom it may concern:

The Nowak Metro Finance Lab at Drexel University is responding to your request for information about how federal agencies can increase the availability and use of "equitable data" in collaboration with other levels of government, civil society, and the research community. Founded in 2018 by Bruce Katz and Jeremy Nowak, the Nowak Lab helps cities identify and implement innovative strategies to leverage public assets and fund public infrastructure for public benefit, with a focus on supporting inclusive and equitable growth. Over the past four years, we have used and transformed federal data for a range of projects:

- The Small Business Equity Toolkit, developed in collaboration with the Mastercard Center for Inclusive Growth, used Annual Business Survey and Non-employer Statistics Data to track and rank Small-, Black-, Latino-, and Women-owned businesses in US Metro Areas
- Our Supply San Antonio project relied on information about federal contracting data from USAspending.gov
- Our Investment Playbooks in Erie, Buffalo, El Paso, and other US cities rely on data from the US Census County and Zip Code Business Patterns Data
- Our 2020 Report, *Big Ideas for Small Business,* relied on extensive analysis of the Federal Reserve Small Business Credit Survey

In conducting these projects, and many others, we have often been confronted with the limits of federal data as it is currently collected and disseminated. In response to your request for information, we will build off of our experiences and the experiences of our partners in these projects to highlight how we hope the federal government can move forward through its Open Government Partnership National Action Plan and its other data-focused reforms moving forward.

What resources, programs, training, or other tools can facilitate *increased data sharing between different levels of government related to equitable data*?

Data Standardization Related to Procurement

Government procurement at the federal, state, and local levels are largely incompatible. Federal data provides every contractor with a DUNS number, and tracks whether a business is Black-, Hispanic-, Asian-, or Woman-owned, among other categories. The Department of Transportation keeps track of firms that are Disadvantaged Business Enterprises, while the SBA keeps track of small businesses, which uses a different definition than the DOT DBE to determine eligibility.

In order to define a business's main industry, many entities use North American Industry Classification System (NAICS) codes. Yet some state and local governments procure based on National Institute of Government Purchasing (NIGP) Commodity Codes. What's more, we have found that some entities — notably, utilities — utilize in-house commodity codes to track businesses that are completely distinct from NAICS and NIGP codes.

Some government entities track *prime* or *Tier 1* minority- and small-business spending, while others track *subprime* and *Tier 2* or *Tier 3* spending. Many hospitals purchase through Group Purchasing Organizations, further obscuring where their money is ultimately going. Some government entities assign each vendor a unique vendor ID, while others have no clear way to track what businesses are receiving their contracts and purchases.

In short, there is almost no standard regarding how governments and public entities track their procurement and contracting spending. There are differences regarding industry classification, size definitions, and appropriate scope of procurement tracking. A federal program to help *level up* governments on procurement tracking would be a huge service to the field.

In which agencies, programs, regions, or communities and there *unmet needs, broken processes, or problems related to participation and accountability that could be remedied through stronger collaborations and transparency around equitable data*?

Business Ownership Data from the US Census

The US Census Annual Business Survey (ABS) and Nonemployer Statistics by Demographics (NES-D), and the Survey of Business Owners (SBO) beforehand, are our only national sources of data about the ownership status of employer and non-employer businesses, broken down by the race, ethnicity, gender, and veteran status of owners. Yet the ABS and NES-D are of seriously degraded quality compared to the SBO, making it nearly impossible to accurately track the creation of businesses in the US.

With a smaller sample size than the SBO, the ABS and the NES-D are significantly less useful for tracking the creation and scaling of Black- and Latino-owned businesses, even when the nation has turned its attention to the serious racial and ethnic disparities in business ownership. For instance, the 2018 ABS did not contain information on the number of Black-owned businesses in four states, and the 2019 ABS did not contain information on the number of Black-owned businesses in seven states. Similarly, five states in the 2019 ABS did not contain information on the number of Hispanic-owned businesses. These problems are accentuated at the metro, county, and place levels. For instance: a majority of MSAs do not have data about the number of Hispanic-owned businesses from the 2019 ABS.

Additionally, the SBO previously supported data about specific industries (i.e., the SBO broke data out by six-digit NAICS codes), while the ABS and NES-D generally only provide high-level industry information (i.e. two-digit NAICS codes).

We ask that the US Census Bureau identify steps to address the data quality issues of the ABS and NES-D, in order to provide more accurate, timely, data on business ownership data by race- ethnicity, gender- of the owners, size of the business, and industry of the business, at smaller geographies than are currently available.

US Government Spending

In 2021, the SBA released, for the first time, federal government purchasing information disaggregated by race and ethnicity. We applaud the Biden Administration in taking this first step. However, the federal government is not a single buyer, it is a conglomerate of agencies, departments, and subagencies, each with their own buying needs and processes. While some of this data can be analyzed through USASpending.gov, it behooves the federal government to disaggregate data on federal spending by race and ethnicity by:

- Spending category
- Agency
- Business Size

Data Tracking Among Institutions that Receive Federal Funding

The Federal Government provides billions of dollars to state and local governments, universities, and hospitals every year. As required by federal law and regulations, those institutions track how they spend their federal dollars, and comply with a complex set of procurement procedures for prioritizing Disadvantaged Business Enterprises and Small Businesses. However, these institutions also spend trillions of dollars from other sources, and that spending goes largely untracked.

We call on the federal government to design a reporting schema for institutions that receive federal funding to better track how they spend their procurement dollars. States such as Illinois require institutions of higher education and utilities to track procurement spending with regards to Black-, Hispanic-, Asian-, Native-American, and Woman-owned businesses. The federal government could follow suit, directing institutions that receive federal funding to track their procurement spending and make it publicly available for greater transparency around the Procurement Economy.

We thank OSTP and the NSTC Subcommittee on Equitable Data for the opportunity to share our experiences with the use of federal data sources and suggestions for how the federal government can increase the availability and use of federal data towards equitable goals. The federal government must demonstrate to other levels of government the ideals of data transparency, and, where necessary, must provide incentives and requirements to level-up their data systems towards greater availability of data for equitable goals. We welcome the opportunity for further updates and conversations at progress is made on the Open Government Partnership National Action Plan.

[redacted]

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Distinguished Fellow
Lindy Institute for Urban Innovation
Director, Nowak Metro Finance Lab

[redacted]

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Research Fellow
Nowak Metro Finance Lab
Drexel University

MEMORANDUM

Attn: National Science and Technology Council Subcommittee on Equitable Data, Office of Science and Technology Policy

From: Dr. Dariush Mozaffarian, Friedman School of Nutrition Science and Policy at Tufts University

Re: Response to the Request for Information; Equitable Data Engagement and Accountability

I am pleased to submit this letter in response to the RFI issued in 87 FR 54269, which invites input on how Federal agencies can better support collaboration with other levels of government, civil society, and the research community around the production and use of equitable data. Our input highlights several areas that address this topic within a recent comprehensive report that was developed to inform the 2022 White House Conference on Hunger, Nutrition, and Health.

The Friedman School of Nutrition Science and Policy at Tufts University was a convener of a Task Force on Hunger, Nutrition, and Health, a diverse, non-partisan group of 26 esteemed subject matter experts and leaders co-chaired by Chef José Andrés, Ambassador Ertharin Cousin, Senator Bill Frist, Secretary Dan Glickman, and Dean Dariush Mozaffarian. The Task Force's goals were to bring together and engage multiple stakeholders with a range of perspectives to develop a consensus report of policy recommendations to inform the Conference. The final report, *Ambitious, Actionable Recommendations to End Hunger, Advance Nutrition, and Improve Health in the United States: A Report of the Task Force on Hunger, Nutrition, and Health,*[1] was publicly released on August 23, 2022. It contains 30 high-priority policy recommendations, undergirded by more than 200 specific actions for the federal agencies, Congress, and other stakeholders, to end hunger, advance nutrition, and reduce diet-related conditions in the United States.

Highlighted below are the policy recommendations and corresponding actions in the report that are most relevant to the topic of this RFI (note: multiple actions correspond to the first policy recommendation presented below). It is commendable that the Federal Equitable Data Working Group is developing a strategy for increasing data available for measuring equity and representing the diversity of the American people. Thank you for the opportunity to support OSTP's information-gathering about encouraging collaborations between the Federal government and multi-sector stakeholders.

Policy Recommendations and Associated Actions from the Report of the Task Force on Hunger, Nutrition, and Health that Relate to Equitable Data Engagement and Accountability

- Policy Recommendation: Utilize research and data sharing to improve nutrition policies.

Action: USDA should disaggregate all federal nutrition program participation data by key demographic categories, including race, ethnicity, and gender.

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[1] Task Force on Hunger, Nutrition, and Health. *Ambitious, Actionable Recommendations to End Hunger, Advance Nutrition, and Improve Health in the United States*. Chicago Council on Global Affairs, Food Systems for the Future, the Gerald J. and Dorothy R. Friedman School of Nutrition Science and Policy at Tufts University, and World Central Kitchen. August 2022. Available at https://informingwhc.org/2022-task-force-report/.

Comment: This recommendation and action call for key demographic data to be collected and disaggregated for participants in federal nutrition programs, such as the Supplemental Nutrition Assistance Program (SNAP) and the Special Supplemental Nutrition Program for Women, Infants, and Children (WIC). These data would allow for assessment of disparities in program reach, engagement, and outcomes, among other insights.

Action: Congress should provide additional resources for, and CDC and USDA should prioritize, nutrition monitoring including regular data collection and reporting on nutrition behaviors, environments, and policies, including drivers of and strategies to address health disparities. This should include dedicated regular funding for efforts such as but not limited to the National Health and Nutrition Examination Survey, the National Household Food Acquisition and Purchase Survey, the Behavioral Risk Factor Surveillance System, and the USDA National Nutrient Database for Standard Reference; and new collection instruments on environments and policies.

Comment: This action calls for regular data collection and reporting on nutrition behaviors, environments, and policies, including drivers of and strategies to address health disparities. To sufficiently inform sources of and potential solutions to health disparities, such data must be stratified by demographic, geographic, and/or other key information. An example of an outcome of this recommendation could be that appropriate amounts and types of data are collected to allow assessment of disparities in dietary intake behaviors, food environments, etc.

Action: CMS should make data publicly available on the utilization of Medicare Part C coverage of Food is Medicine programs under the Special Supplemental Benefits for the Chronically Ill. Utilization data should include the amount spent on Food is Medicine treatments, the type of treatments, the geographic reach, and the quantity of patients served. These data could facilitate research on payors' experiences in implementation, identification of barriers to expansion of these benefits, and patient experience.

Comment: Inclusion of data on the geographic reach of uptake of Medicare Part C coverage of Food is Medicine programs could enable assessment of any geographic disparities in regions served.

- Policy Recommendation: Increase nutrition security by promoting dietary patterns that align with the latest Dietary Guidelines for Americans (DGA) through federal nutrition programs.

Action: Congress should require that USDA regularly collect, analyze, and report purchasing data from all federal nutrition programs to measure alignment with, and progress toward, improvements in dietary quality and food security for participants in these programs. Data sets should be at the aggregate level, and be made available for public use with all participant and store level identifiers removed. Results should be interpreted in the context of other research on barriers to choosing foods that align with the DGA and trends in dietary intake patterns of federal nutrition program participants compared with the broader U.S. population.

Comment: This action calls for regular collection, analysis, and reporting of purchasing data from federal nutrition programs, such as SNAP and WIC. Although the action states that participant and store level identifiers should be removed (i.e., due to privacy and other concerns), demographic data could and should still be included in such activities and could enable assessment of disparities that may exist.

- Policy Recommendation: Increase leadership, coordination, and investment in nutrition research at the National Institutes of Health (NIH).

Action: NIH and other funders should require or incentivize researchers to include the perspectives of public, community, and patient stakeholders at all stages in the research process, including defining research questions, collecting quantitative or qualitative data, interpreting findings, and communicating and disseminating results.

Comment: This action aligns with Section 8 of the Executive Order on Advancing Racial Equity and Support for Underserved Communities Through the Federal Government—E.O. 13985 ("Engagement with Members of Underserved Communities"), as it appeals for engaging community member and/or patient stakeholders in all stages of the research process. Such engagement is important for ensuring that a community's needs and interests are adequately reflected in the research and that the overall experience is fulfilling and positive, which can help promote continued future collaboration. By engaging with those whom a research study or intervention is intended to benefit, researchers can assess their perspectives, values, preferences, priorities, lived experiences, and views of treatment acceptability and feasibility. These inputs can also inform dissemination and implementation strategies so that they are more likely to be taken up by the intended beneficiaries.

- Policy Recommendation: Catalyze private sector and philanthropic research funding to stimulate high-integrity, transparent investment in unbiased research that can help address the nation's priorities for hunger, nutrition, and health.

Action: Funders should push for researchers to incorporate perspectives of individuals impacted by the program or policy under study at all stages in the research processes, including defining research questions, collecting qualitative or quantitative data, interpreting findings, and communicating and disseminating results.

Comment: This action is similar to the action listed immediately above that is directed to NIH, except it is directed to private sector and philanthropic research funders. The Federal government could consider current or future opportunities to incentivize these funders to engage relevant community and/or patient stakeholders in all stages of the research process.

- Policy Recommendation: Fund and implement a comprehensive strategy to build a national ecosystem of evidence-based, mission-oriented business innovation to reduce hunger, improve nutrition, reduce diet-related chronic conditions, and increase health equity.

Action: The White House should task relevant federal agencies with incentivizing and convening investors and capital markets around standardized ESG reporting by businesses across the food sector, with a focus on consumer and workforce food security, nutrition, health, racial equity, and health equity; as well as fair wages and working conditions. This should involve development of impact-oriented metrics, transparent data systems for tracking and reporting, and independent adjudication. Key metrics could encompass: (1) product healthfulness, (2) product distribution and equity (affordability and accessibility), (3) marketing policies and spending, and (4) nutrition-related governance.

Comment: This action calls for development and tracking of metrics that could be used to drive equitable outcomes.

Thank you for your leadership and commitment to equitable data engagement and accountability. Should you or any of your colleagues have any questions or wish to discuss anything contained in this RFI response, the Friedman School is happy to serve as a resource.

Sincerely,

[redacted]

Dariush Mozaffarian, MD, DrPH
Special Advisor to the Provost, *Dean for Policy*,
Friedman School of Nutrition Science & Policy
Tufts University

To: Office of Science and Technology Policy
From: Race Forward
Re: RFI on Equitable Data Engagement and Accountability
Date: October 3, 2022

Race Forward is a 501(c)3 nonprofit organization that builds leadership among people of color through multi-racial coalition building, conferences, capacity building and training. We develop and share tools to advance narrative and cultural power, equity, and justice for communities of color. We also develop and implement institutional and sectoral change strategies to operationalize racial equity. We engage government, providing training, materials, and support to hundreds of member governmental agencies nationwide that have made a commitment to advancing racial equity. Collectively, our work includes network building, skill-building, leadership development, organization- and alliance-building, issue-framing, messaging, and advancing racial equity solutions.

Race Forward is submitting perspectives on how to best encourage collaborations between the Federal government and (a) state, local, territorial, and Tribal governments; (b) researchers and research institutions; and (c) local communities that facilitate producing, accessing, and using equitable data.

1.What are examples of successful collaborations involving equitable data between the Federal government and (a) Tribal, territorial, local, and State governments, or (b) local communities?

Many governmental entities were engaged in equitable data efforts prior to issuance of Executive Order 13985. There are many examples to draw from within the local context. For instance, the city of Tacoma and Pierce County have worked together to create the Equity Index. Another example is Seattle Port Authority's Equity Index. The indices are public facing in an effort to facilitate greater community transparency and accountability. Other jurisdictions have taken it to the next level and provided open-source equity indicators data, such as the city of New York's EquityNYC. The public facing site provides indicators across a broad spectrum of policy domains and provides access to the data sources.

Within the Federal context, the U.S. EPA and the California EPA have engaged in discussions and/or shared information pertaining to spatial analysis and environmental justice. Cal EPA has "California EnviroScreen", while the U.S. EPA has EJ SCREEN. They are similar spatial analysis tools. Because one is managed by a state department and one is managed by a federal department, there are distinctions concerning information that is not collected based on policy decisions. Still, Cal EPA and the U.S. EPA have conferred and maintained communication as updates were made to their respective screen tools. Both institutions found ways to work around the limitations of policy decisions for the greater good.

Also, the U.S. EPA is supporting citizen science projects and providing communities with the information and assistance they need to conduct their own air pollution monitoring efforts, particularly in vulnerable communities. The Air Sensor Toolbox for Citizen Scientists was developed as a resource to meet stakeholder needs, and it was pilot tested in the Ironbound

Community in Newark, New Jersey. The Air Sensor Toolbox for Citizen Scientists is designed as an online resource that provides information and guidance on new, low-cost compact technologies used for measuring air quality. The Toolbox features resources developed by EPA researchers that can be used by citizens to effectively collect, analyze, interpret, and communicate air quality data. The resources include information about sampling methods, how to calibrate and validate monitors, options for measuring air quality, data interpretation guidelines, and low-cost sensor performance information. This Regional Applied Research Effort (RARE) project provided an opportunity for the Office of Research and Development (ORD) to work collaboratively with EPA Region 2 to provide the Ironbound Community with a "Toolbox" specific for community-based participatory environmental monitoring in their community.

Ironbound is a community with concerns of environmental injustice. Local air monitoring efforts are elevated because they demonstrate the potential of "citizen science" as a collaborative solution. While citizen science efforts show promise for improved government-community collaborations, experts stress it is imperative to center equity in these efforts, from design to execution. Otherwise, disproportionality in participation rates could exacerbate inequity (e.g., Pierce, 2022; Lewenstein, 2022).

2. Among examples of existing Federal collaborations with (a) Tribal, territorial, local, and State governments or (b) local communities involving equitable data, what lessons or best practices have been learned from such collaborations?

In the case of the Ironbound Community air monitoring project, lessons include:

- It is essential to establish a trusting and collaborative relationship with a community action group (CAG).
- Projects are well served by early communication between all partners, especially the state, if any collocation of monitors is desired.
- Build on the success of previous engagements. The current air monitoring project did not represent the first engagement with the impacted community. Instead, a base relationship was already established from previous projects.
- "Preparation" is as important as planning and execution. Multiple phone and web conferences occurred before the initial visit to the Ironbound Community by ORD and Region 2 scientists. The first visit included a 'meet and greet', a shared meal, and a tour of the community, highlighting areas of concern related to air pollution and potential sources.
- Parties worked together to develop a study design. Roles and responsibilities were established for each individual involved in the project, but for future projects it is recommended that this occur earlier in the process. This is an important step in order to manage expectations and ensure there is no confusion regarding roles and responsibilities.

3. What resources, programs, training, or other tools can facilitate increased data sharing between different levels of government (Tribal, territorial, local, State, or Federal) related to equitable data?

While access and use of equitable data is important, it needs to be viewed within the broader context of the data lifecycle. If equity has not been centered in the other phases of the data lifecycle, biased and inequitable data will prevail. The data lifecycle includes planning, data collection, data analysis, data dissemination. It also must consider what gets funded, who is involved, what questions get asked, what methods get used, and, ultimately, what constitutes knowledge. Equity considerations need to be centered in all of these aspects of the data lifecycle. Many frameworks exist that can help center equity across the data lifecycle.

Race Forward/Government Alliance on Race and Equity (GARE) staff contributed to the Toolkit for Centering Racial Equity published by Actionable Insights for Social Policy (AISP). The toolkit includes case studies from GARE member jurisdictions who are at the cutting edge of this area of work. The toolkit also highlights positive practices and problematic practices across the data lifecycle. Another tool that has been useful to equitable data practitioners is The Data Equity Framework from We All Count. The overall framework assists data scientists to interrogate biases and inequities across the data lifecycle. Both of these toolkits have been instrumental for local and state governments to advance their equitable data efforts.

Specific to data sharing, one of the many challenges is the lack of integrated data systems across governmental entities. Often, data is not measured at the same level or in the same manner, so data systems cannot talk to one another. In fact, data systems are often not designed to be integrated even within a given governmental entity, much less across governmental entities. Further, the data collected can be at different levels or units of measurement or altogether different measures. In order for data to talk to one another and be integrated across governmental systems, standardization is required. AISP has been assisting local and state government data experts to build equitable, integrated data systems.

Within the Federal realm, a responsible party may want to seize the opportunity to fill a gap by hosting a convening or conference. Over the span of its existence, EPA has learned to focus more on community involvement and partnership as well as consider what it means to be “an environmental regulator”. For example in 1999, the U.S. EPA hosted the first National Community Involvement Conference. It was an internally facing conference that focused on helping EPA staff to develop skills and competencies in community involvement. Federal officials may need to charge an agency or interagency working group (IWG) to start devising training as well as initiating conversations that serve to fill the gap.

Similarly, federal agencies formalized the role of chief information officer (CIO) only within the past fifteen to twenty years. Today, CIOs represent an important human resource, and they are part of the federal landscape. A key question to consider is how can CIOs be part of the solution for equitable data engagement. What charge has been issued to agency CIOs?

Also, the federal government has the discretion to create “federal advisory committees”. OSTP’s request for information is a great starting point. However, a federal advisory committee on equitable data engagement and accountability may need to be established to facilitate collecting more recommendations as well as to give thought-leaders and experts an opportunity to consider the varying nuances of the question.

4. What resources, programs, training, or other tools can expand opportunities for historically underrepresented scholars and research institutions to access and use equitable data across levels of government?

The federal government has a history of managing programs which target underrepresented scholars and research institutions. Some of these programs were in place at the U.S. EPA in the 1990s. For example, there were Minority Academic Institution (MAI) fellowship programs. In part, these were pipeline programs, and they represented useful infrastructure to have in place. When political administrations changed by 2001, there was political backpedaling on issues concerning racial diversity. As a result, many of these programs were placed in a vulnerable position. The lesson is the federal government has the ability to create programs that respond to obvious needs concerning underrepresented scholars and research institutions. The programmatic infrastructure needs to be rebuilt. It will require funding. It will require staff. It will need political cover. Equally important, managers will need to document their results, accomplishments, and narratives.

Today, it may be important to ask agency "research and development" programs to prioritize equitable data engagement as a research category that can be funded. At the same time, agencies may need to set financial goals such as making 40% of the opportunities accessible to underrepresented scholars and research institutions.

Finally, it is worth mentioning the U.S. EPA National Environmental Justice Advisory Council (NEJAC) issued a report to the EPA Administrator in 2014 entitled "**Recommendations for Integrating Environmental Justice into EPA's Research Enterprise**". The report surfaced thirty-six sets of findings, recommendations and suggestions for implementation.

5. What resources, programs, training, or tools can increase opportunities for community-based organizations to use equitable data to hold government accountable to the American public?

In Race Forward's work to advance racial equity, one of the barriers we hear most often from community-based organizations is the lack of access to resources and capabilities to perform data work. For example, while there is an increased emphasis on geospatial analysis to inform place-based, equitable policy and decision-making, community-based organizations do not have access to the software required to perform such analyses, or do not have staff who possess the analytical skills to conduct the analysis. There is also the limitation of access to the data, as not all jurisdictions provide open source access.

In part, creating a culture where equity will thrive will be most important to "opportunities for community-based organizations to use equitable data to hold government accountable".

Community-based organizations are “the experts on their communities”. They know where the inequities and gaps are. However, public officials have a history of being anxious or nervous about issues pertaining to race and equity. Inaction by public officials has resulted in community-based organizations analyzing issues while using equitable data. Today, different community-based organizations are researching the effects of institutional racism on the urban landscape. For example, spatial analysis is being conducted while leveraging knowledge of: historically black communities; communities that experienced residential redlining; communities that lack tree canopy; communities that are disparately burdened by pollution; communities that are food deserts; and social determinants. The level of overlap based on intersectional analysis is alarming, and it reveals clear patterns of structural racism can be mapped in the U.S. with the aid of spatial analysis.

As noted earlier, community-based organizations with the assistance of researchers are stepping in to fill the gap. Government needs to be fully aware of community needs, deficits, and distress to avoid needing to “put out fires” later. The latter option is not sustainable considering trends in civil dissatisfaction and even unrest as well as trends in failing infrastructure in places like Flint, MI or Jackson, MS.

6. What resources, programs, training, or tools can make equitable data more accessible and useable for members of the public?

Race Forward/Government Alliance on Race and Equity (GARE) partnered with Esri, the global leader in geospatial analysis tools. The partnership resulted in the creation of a social equity analysis tool. The tool can incorporate federal and local data to provide place-based equity analyses. GARE is working with local governmental leaders to implement the use of the tool more widely. If adoption of the tool was widespread across governmental units, the information could be shared publicly to assist with decision-making and policy. While interest in the tool is high among racial equity practitioners in government, and government entities already have access to the software, widespread adoption has been limited. This illustrates the need for enhanced capacity to assist local governments to perform place-based, equity-centered analysis.

Other tools that need to be acknowledged include EJSCREEN which is a spatial analysis tool created by the U.S. EPA. Also, PolicyLink manages the Equity Atlas.

7. In which agencies, programs, regions, or communities are there unmet needs, broken processes, or problems related to participation and accountability that could be remedied through stronger collaborations and transparency around equitable data?

A recent exploration into barriers to widespread use of publicly available tools was commissioned by the Gates Foundation. In focus groups among local decision-makers, one of the most frequently cited barriers of using publicly available tools to advance economic mobility was disparities in data. The local decision-makers noted that while some areas have strong data resources and outreach capacity, others were significantly lagging behind. This lack of prioritization toward data and outreach have adverse impacts on community-level equitable outcomes. This is but one example of limited capacity of governments to prioritize partnering with impacted communities and using a data-driven approach to their efforts.

Conversely in the federal realm, there are federal advisory committees that offer recommendations to senior officials on key issues as noted earlier. One example is the National Environmental Justice Advisory Council (NEJAC). It would be helpful to conduct an internal assessment to verify what federal agencies actually do with the recommendations that are formally submitted. For example, the NEJAC has published two reports warning EPA about the unintended consequences of urban redevelopment. The first was published in 1996, and the second was published in 2006. However, EPA has never created a mitigation strategy for its place-based programs that focus on brownfields redevelopment, smart growth, or livability. In the end, creating federal advisory committees while doing nothing with the recommendations submitted by the advisory committees challenges faith in government and is a broken process.

RIP
MEDICAL
DEBT

October 3, 2022

NSTC Subcommittee on Equitable Data,
Office of Science and Technology Policy,
Eisenhower Executive Office Building,
[redacted]
Washington, DC 20504.

Submitted via *Email* [redacted]

RE: The White House Office of Science and Technology Policy (OSTP), on behalf of the Subcommittee on Equitable Data of the National Science and Technology Council, requests information on how Federal agencies can better support collaboration with other levels of government, civil society, and the research community around the production and use of equitable data.

Dear Members of the Subcommittee on Equitable Data of the National Science and Technology Policy (OSTP):

On behalf of RIP Medical Debt, I am pleased to submit the following comments in response to the request for information (RFI) regarding how the federal government can better support the collection of and access to equitable data. RIP Medical Debt is a national nonprofit organization committed to lifting the burden of medical debt for thousands of people nationwide. Our unique debt abolishment model combines the generosity of donors with debt industry expertise to produce a high volume of debt relief return, mitigating significant financial and mental distress for millions of people. Our work also seeks to bring attention to the negative impacts caused by medical debt, to distill the causes of medical debt, and ultimately to use these findings to address its upstream causes. Our model relies on claims data and credit data in order to ensure we can provide debt relief to people below 400 percent of the federal poverty level or if their medical bills exceed 5 percent of their income.

We appreciate the opportunity to share our experience in working with medical debt data as you contemplate how to make data both representative and accessible as a tool to advance equity. As previously mentioned, we purchase medical debt for pennies on the dollar with donor-raised funds; we purchase medical debt files from debt collectors (termed, the secondary debt market) and, increasingly, directly from providers and health systems. Once we access a patient's medical debt, we perform a data matching with income data (purchased from a credit agency) to isolate debt files that meet our two criteria for abolishment: 1) an individual's income is below 400 FPL and/or 2) the amount of the debt exceeds 5 percent of the individual's income. As part of our 2022 strategic plan, we prioritized addressing the inequity of medical debt as an explicit organizational goal. Research shows that medical debt disproportionately affects Black and brown people and is concentrated in states that have less access to affordable health coverage. In addition, there is evidence of higher rates of extraordinary collection actions in communities of color, leading to toxic stress and financial insecurity. Below are some key findings from our work that may inform efforts to improve the collection of and access to equitable data.

Medical debt data is scattered and lacks a single data repository.

It is difficult to assess the full breadth of medical debt. Unpaid bills and subsequent medical debt are not data that is universally collected – it is only when bills get sent to collections that we have a snapshot of people's medical debt, albeit incomplete. When people are stretched to pay bills, they resort to multiple different tactics to stay financially afloat including borrowing from family, raising funds through crowdfunding, charging to a credit card, taking out a loan, and resorting to a payday loan – and these are just a few examples. Therefore, fully documenting medical debt is challenging. Researchers and several business entities attempt to capture the prevalence of medical debt through surveys; however, these vary widely in the types of questions asked, the race, ethnicity, language and disability (REL-D) data collected, and whether they reflect a point in time or are longitudinal. The census' Survey of Income and Program Participation (SIPP) asks a question about medical debt (re-added in 2018) that provides a snapshot of medical debt but is one of the few federal efforts to monitor the accelerating trend of medical debt. Research shows that medical debt is growing and is affecting people's health by forcing tradeoffs among basic needs such as food and housing.

Some ways to address the problem include:

- Annually, ensure that there are questions across various surveys (Federal Reserve, Labor, CDC, CMS, etc.) that address medical debt and the intersection of social determinants of health, REL-D data, and insurance type/status. This could include adding a set of questions to the Behavioral Risk Factor Surveillance System (BRFSS), particularly because studies show that medical debt is correlated with mental health issues. For example, many community benefit programs leverage BRFFS data in their assessments, and information on medical debt would shine light on community trends related to health and financial insecurity. Federal agencies could ensure that each year there is a medical debt report that draws upon various federal surveys to assist in capturing the growth trends and effects of medical debt on people, disaggregated by race, ethnicity, language, disability, chronic illness, sex, gender, age, family makeup (children/no children), income and identity. The Assistant Secretary for Planning and Evaluation (ASPE), for example, could play a helpful role in reporting on medical debt while the Office of Civil Rights (OCR) could help with aligning definitions and collection guidelines for inclusive, self-reported demographic data.
- Investigate how all payer claims databases (and a federal pathway) could monitor medical debt through billing and payment data. Not knowing the prevalence of outstanding bills is a blind spot in monitoring medical debt – a national system that monitors billing and payment would help advance the work to address inequity in medical debt. This includes debt in collections that are reported to bureaus, but also debt in collections that aren't reported, and late bills owed to the provider. Measuring these components better would be hugely beneficial.

Changes to credit reporting are critical but diminish our ability to understand the effects of medical debt, particularly for communities of color.

In March, the three major credit reporting agencies -- Equifax, Experian and TransUnion -- announced a set of actions that will remove nearly 70% of medical collection debt tradelines from consumer credit reports by 2023. Starting July 1, the actions that took effect included: the removal of all paid medical debt from credit reports and the allowance of one year during which patients can address outstanding medical bills before they are listed on credit reports. By mid-way through next year, the companies will no longer report medical debt under $500. Prior to July, medical debt in collections would remain on people's credit reports for up to 7 years, regardless of whether they were paid. These actions will increase people's chances at obtaining opportunities, both financial and of basic necessity, that are directly sabotaged by poor credit scores. At the time of the announcement, a

Consumer Financial Protection Bureau (CFPB) report revealed that four in ten Americans say they are more afraid of medical debt than of serious illness. Medical debt adversely impacts emotional and financial health. Despite these changes, people unfairly impacted by medical debt will continue to be vulnerable to (1) an increased likelihood of bankruptcy, (2) collection litigation, and (3) wage garnishment. In July, CFPB reported that while the voluntary changes to credit reporting are welcome, they disproportionately benefit people with lower debt loads that reside in the north and east regions of the country; this means that people of color with lower-incomes, living in the south and west will receive less relief.

Considering these changes will alter access to medical debt information, we suggest that:

- The Consumer Financial Protection Bureau (CFPB) should institutionalize in regulation the changes being made by National Credit Rating Agencies (NCRA) – however, there must continue to be a way to track and monitor medical debt without it affecting people's credit.
- CFPB should investigate a pathway for individuals to identify portions of credit card debt as medical debt in order to assist with national monitoring and protect their credit from negative marks. This could be one way to understand the breadth of medical debt and hold people harmless from it more fully.
- Another pathway would be to add additional questions to the SIPP, expanding on their existing medical debt question. This would allow for more consistent annual monitoring of medical debt. This will be critical as credit agencies stop collecting data on medical debt trade lines.
- As medical debt is isolated from other types of debt, it should happen in tandem with a federal effort to nationalize monitoring of medical debt.

Communities have estimates about medical debt but lack a complete picture of this social determinant of health.

As noted in a Health Affairs study from this year, "a commensurate amount of data and empiric study is lacking, and legislative reform proposals are relatively rare. Improved data collection and transparency is necessary to better understand medical debt litigation and to inform urgent legislative reform." For example, the lack of online court dockets makes it difficult for communities to analyze and understand the prevalence of medical debt lawsuits that disproportionately affect communities of color. Some states allow for this while others do not, creating a patchwork of information that deepens inequity. Improving state court system data is one example of how systems writ large need updating and connectivity to each other when assessing social drivers of poor health at the community level. Without the connections between court systems, all hospital types and provider systems reporting on medical debt alongside robust demographic data, communities will continue to be uninformed and lack the resources they need to drive better health and system accountability.

- Research shows that some communities are affected more than others – without credit/collection data on medical debt, communities will lose this vital information absent an effort to monitor medical debt. Implementing national approaches to medical debt monitoring is critical to making information available to communities and woven into their efforts to promote equity and financial security for their residents.
- SIPP census track data with easy to access and use disaggregated REL-D characteristics must be available for communities to leverage. Currently, the census data is not community accessible and requires support and communities do not have easy access to data across systems that perpetuate inequity and medical debt. Creating community level tools through a process of community engagement would increase use of census data to inform local policy change.
- Aligning definitions of REL-D and questions across key programs that address social determinants of health will allow for a more complete community picture. For example, SNAP, Medicaid and other low-income programs vary in their eligibility criteria and enrollment questions, creating barriers for seamless

integration of services. If these were better aligned, they could serve as fast-track entry points for financial assistance and other supports that mitigate debt burden.

Thank you for the opportunity to comment on this important issue. If you have further questions, please contact Eva Stahl, Vice President for Policy at RIP Medical Debt, a [redacted]

Regards,

[redacted]

Allison Sesso

CEO, RIP Medical Debt

Appendix: Data Sources on Medical Debt

Challenges in monitoring medical debt are partly due to the multiple pathways of the debt lifecycle:

- debt in collections – data source currently is national credit reporting agencies (NCRAs)
- debt in collections that is not reported – some of this show ups in Medicare cost reports or bad debt accounting by hospitals. The debt is not being collected though many patients believe they owe the debt (no national repository collects this information)
- late bills owed to the provider – this is provider group specific data, and is not reported
- debt rolled into payment plans or credit cards – difficult to identify because it shows up as credit card debt and not medical debt (same goes for borrowing from family, etc.) – the only source here would be national surveys
- Inconsistent collection and reporting of REL-D data overall

Current sources of data to disentangle medical debt prevalence and disproportionate impact:

Data sources:

- Bad debt – Medicare cost reports
    - See here https://www.hfma.org/topics/revenue-cycle/article/how-to-get-a-handle-on-medicare-bad-debt.html#:~:text=Each%20year%2C%20hospitals%20claim%20more,that%20is%20often%20inadequately%20addressed. –
    - There is a higher rate of medical debt for Black Americans in this cohort – CMS could release reporting that analyzed insurance type and amount of debt. This could help guide CMS on how to tailor programs for Medicare recipients that ensure full understanding of the coverage gaps in Medicare to shield themselves from risk.
- Charity Care – Schedule H
    - Community Benefit Insight offers a database/analysis of community benefit spending that includes financial assistance as reported on Schedule H
- National Credit Reporting Agencies (NCRAs)
    - CCP is a longitudinal, nationally representative sample of approximately 5 million de-identified credit records from one of the three nationwide credit reporting agencies (NCRAs) generated by CFPB
        - https://files.consumerfinance.gov/f/201405_cfpb_report_data-point_medical-debt-credit-scores.pdf
- National Health Interview Survey (NHIS)
    - https://www.cdc.gov/nchs/products/databriefs/db357.htm - this survey gets at “Problems paying medical bills” is based on a positive response to the question, “In the past 12 months, did you or anyone in the family have problems paying or were unable to pay any medical bills? Include bills for doctors, dentists, hospitals, therapists, medication, equipment, nursing home, or home care.” Estimates are based on household interviews of a sample of the civilian noninstitutionalized population.”
    - https://www.cdc.gov/nchs/products/databriefs/db317.htm - high deductible health plan enrollment – another element of uninsurance/risk for medical debt - examines enrollment among adults aged 18–64 with employment-based private health insurance coverage by plan type and demographic characteristics.
- Census The Survey of Income and Program Participation (SIPP)
    - In 2018, this survey added a new question about medical debt in the previous year. The survey asked whether respondents had “medical bills [they were] unable to pay in full.”

  - Most recently, a JAMA study was able to look across several years to better understand the odds of having medical debt.
- Federal Reserve's Survey of Household Economics and Decisionmaking (SHED)
  - The Federal Reserve Board has conducted the Survey of Household Economics and Decision-making (SHED) since 2013, which measures the economic well-being of U.S. households and identifies potential risks to their finances.
- Other Surveys:
  - Kaiser/NYT (2016 & 2022) – NORC runs this survey (18-64 year olds) https://www.kff.org/wp-content/uploads/2016/01/8806-t-the-burden-of-medical-debt-results-from-the-kaiser-family-foundation-new-york-times-medical-bills-survey-topline.pdf
  - Commonwealth Fund survey on out-of-pocket costs (2020) https://www.commonwealthfund.org/publications/issue-briefs/2020/aug/looming-crisis-health-coverage-2020-biennial
    - Most recent analysis highlights medical debt (2022) https://www.commonwealthfund.org/publications/issue-briefs/2022/sep/state-us-health-insurance-2022-biennial-survey
  - Private entities that survey/poll (a few):
    - Debt.com – and like private entities that run surveys on medical debt - https://www.debt.com/medical-debt/
    - Discover Personal Loans – did a survey during pandemic https://www.businesswire.com/news/home/20211208005205/en/
    - Healthcareinsider.com - https://healthcareinsider.com/majority-concerned-about-medical-bankruptcy-debt-254418
    - Lending Tree: https://www.lendingtree.com/personal/medical-debt-survey/
- Research entities that draw on NCRAs & Census data:
  - Urban Institute maps medical debt: credit bureau data are from December 2020 and contain more than 5 million records. We also incorporate estimates from summary tables of the US Census Bureau's American Community Survey (ACS). We use ACS one-year estimates (2018) where possible, but for areas with smaller populations and for metrics that incorporate zip code–level information, we use the ACS five-year estimates (2014–18). https://apps.urban.org/features/debt-interactive-map/?type=medical&variable=perc_debt_med&state=45
    - Recently Urban also reviewed hospital finances and medical debt https://www.urban.org/research/publication/which-hospital-financial-characteristics-are-associated-medical-debt
  - Peterson-Kaiser Health Tracking analyzes SIPP data at individual level
- Debt Collection Tactics – wage garnishment, legal actions
  - https://jamanetwork.com/journals/jama/fullarticle/2737183?resultClick=1&appId=scweb – court records, AHA Directory – but depends on whether court records are digitized
  - Also see the discussion of data (lack of) in this Health Affairs article: https://www.healthaffairs.org/do/10.1377/forefront.20220429.408324/

Response to Request for Information

Equitable Data Engagement and Accountability

TO: Office of Science and Technology Policy (OSTP)
[redacted]
10/3/2022

As the Founder of AIethicist.org, and the Data Science Ethics faculty at University of Michigan, I thank The White House Office of Science and Technology Policy (OSTP), and its Subcommittee on Equitable Data of the National Science and Technology Council, for the opportunity to provide public comments regarding production and use of equitable data by federal government.[1] As emphasized by the Equitable Data Working Group, in its *Vision for Equitable Data,*[2] the need for the Federal government to use equitable data is crucial to keep the policies and programs accountable to the American public. What we do not measure, we cannot change.

In her art installation "Missing Datasets", artist and researcher Mimi Onuoha, draws attention to the datasets which *should* exist but do not exist. In her words, "within many spaces where large amounts of data are collected, there are often empty spaces where no data live. Unsurprisingly, this lack of data typically correlates with issues affecting those who are most vulnerable in that context…**Those who have the resources to collect data lack the incentive to (corollary: often those who have access to a dataset are the same ones who have the ability to remove, hide, or obscure it)**."[3] By producing such missing datasets, on behalf of all members of the American society, the federal government can help narrow the persistent inequalities and structural issues. Each member of the society, as required by fundamental rights and respect for human dignity, deserves fair, just, and impartial treatment. Federal government and its collaborations should drive transparent data practices to drive accountability and support transformation to narrow the gaps for those who have been historically underserved, marginalized, and adversely affected by persistent poverty and inequality.

As advocated by feminist sociologist Ann Oakley, and re-emphasized by Data Feminists Catherine D'Ignazio and Lauren Klein, "without quantitative research, it is difficult to distinguish between personal experience and collective oppression."[4] With only individualized experiences,

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[1] The Federal Register (September 2, 2022). A Notice by the Science and Technology Policy Office. Request for Information; Equitable Data Engagement and Accountability. RFI 87 FR 54269. https://www.federalregister.gov/documents/2022/09/02/2022-19007/request-for-information-equitable-data-engagement-and-accountability

[2] The White House Office of Science and Technology Policy, Equitable Data Working Group (April 2022). A Vision for Equitable Data Recommendations from the Equitable Data Working Group. https://www.whitehouse.gov/wp-content/uploads/2022/04/eo13985-vision-for-equitable-data.pdf

[3] Mimi Onuoha . Missing Datasets. https://github.com/MimiOnuoha/missing-datasets ; https://mimionuoha.com/what-is-missing

[4] Catherine D'Ignazio and Lauren Klein (2020). "What Gets Counted Counts." In *Data Feminism*. https://data-feminism.mitpress.mit.edu/pub/h1w0nbqp

we cannot see the collective or societal impact experiences. Narrowing the narrative to 'bad apples' and resisting the efforts to collect institutional data means that the structural issues go unaddressed.

In response to the above-mentioned Request for Information, I recommend the following datasets to be created by the federal government and shared as part of open government data. Ideally, all these data can be collected without additional effort by the government agencies. If made as part of federal program funding or grants, ideally the data should be collected in a standard format by the fund-receiving entities and submitted to the federal government. All the data must be open to public to allow civil society and community organizations and researchers to support the analysis of data.

Below datasets collected in disaggregated manner, by demographic information (race, ethnicity, gender, language spoken, religion, etc.), and geographic information (*e.g.,* rural/urban, county level):

<u>Effective government spending:</u>

- Non-profits in US cover a lot of the services which should be provided by federal or state level organizations. There are **1.5 million nonprofit organizations** in the US, employing **10%** of the US workforce. **5.6%** of the United States GDP comes from nonprofits. The total US nonprofit annual revenue is **$2.62 trillion,** and **80% of all nonprofit revenue comes from government grants.**[5] Yet, little information on accountability, effective spending and results are provided in a transparent and reusable manner.
- "Since 1995, Government Accountability Office (GAO) has designated The Department of Defense (DOD) financial management as high risk because of pervasive weaknesses in its financial management systems, controls, and reporting. DOD's long-standing intradepartmental eliminations material weakness reflects DOD's inability to adequately record and reconcile its intradepartmental transactions and has affected DOD's ability to prepare auditable financial statement. Intradepartmental transactions occur when trading partners within the same department engage in business activities."[6] This effectively means that the **department with a budget of more than $700 billion, about one-sixth of federal spending goes to national defense** (as per Congressional Budget Office[7]), **does not have a fully transparent and accountable spending**.
- Breakdown of military grade equipment transferred from Pentagon to police agencies across fifty states under Program 1033 (**nearly 10,000 jurisdictions receiving more than**

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[5] Sky Ariella (April 25, 2022). [redacted]atistics. How Many Nonprofits Are In The US?" Zippia.com. https://www.zippia.com/advice/nonprofit-statistics/

[6] Government Accountability Office (January 14, 2021). GAO-21-84**.** Department of Defense: Actions Needed to Improve Accounting of Intradepartmental Transactions. https://www.gao.gov/products/gao-21-84

[7] Congressional Budget Office. Defense and National Security. https://www.cbo.gov/topics/defense-and-national-security

$7 billion of equipment[8]); the justification provided by local law enforcement agency;[9] Civil rights violations by law enforcement in same localities.

Law Enforcement:

In May 2015, the White House had launched the Police Data Initiative (PDI) in response to several of the Task Force recommendations that speak to the importance of technology and transparency.[10] Despite a significant enthusiasm which surrounded the Initiative, some law enforcement related data is still not available at national level.

- Number of police stops which failed reasonable suspicion standard
- 911 calls nationwide not responded by police
- Complaints against police officers (including type of alleged misconduct, and whether the complaint was found legitimate by an internal investigation. A nonprofit initiative, Invisible Institute's Citizens Police Data Project, comprehensively covers nearly five years of complaints against Chicago police officers.[11] This could be turned into a nation-wide dataset collection activity. Despite facing legal action by the Fraternal Order of Police, which sought to block City from releasing the police disciplinary documents, Invisible Institute succeeded in continuing its project in Chicago.[12]

Violence:

- Rape cases (including possible cases waiting testing), Intimate Partner Violence and Sexual Assault
- Public health, financial, psychological, and social toll of gun injuries
- Adults with physical disabilities or cognitive impairments subject to violence or assault
- Trans people killed or injured in instances of hate crime *(as suggested by Mimi Onuoha)*[13]
- Immigrants killed or injured in instances of hate crime
- Religious institutions (church, mosque, temple, etc) subject to instances of hate crime

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[8] Defense Logistics Agency (June 10, 2020). Then and Now: A 2020 look into LESO. https://www.dla.mil/About-DLA/News/News-Article-View/Article/2214350/then-and-now-a-2020-look-into-leso/

[9] ACLU (2021). Federal Militarization of Law Enforcement Must End. https://www.aclu.org/news/criminal-law-reform/federal-militarization-of-law-enforcement-must-end)

[10] The White House (May 18, 2015). Lanching the Police Data Initiative. Launching the Police Data Initiative. https://obamawhitehouse.archives.gov/blog/2015/05/18/launching-police-data-initiative

[11] Invisible Institute. Citizens Police Data Project. https://invisible.institute/police-data

[12] Jamie Kalven (August 16, 2018). Invisible Institute Relaunches the Citizens Police Data Project. The Intercept. https://theintercept.com/2018/08/16/invisible-institute-chicago-police-data/

[13] Mimi Onuoha . Missing Datasets

Health, Labor, Democratic Participation:

- A more extensive maternal mortality rate data collection by CDC (as detailed in ProPublica's "The New U.S. Maternal Mortality Rate Fails to Capture Many Deaths" report)[14]
- People who have left labor force since 2020 due to COVID-19 deaths, COVID-19 related disability, immigration visa issues
- People denied employment opportunities due to past criminal record
- People denied employment opportunities due to physical disabilities or cognitive impairments
- Disenfranchisement, voter disqualification, due to any prior relationship with the criminal justice system
- Disenfranchisement, voter disqualification, due to disabilities / impairments

RFI Question 5: What resources, programs, training, or tools can increase opportunities for community-based organizations to use equitable data to hold government accountable to the American public ?

Equitable and meaningful participation of community-based organizations must be a requirement for federal funding. Participation must be meaningful and not tokenize the communities. Funding reporting submitted to federal government by the receiving entity must be co-attested by community-based organizations involved.

RFI Question 6: What resources, programs, training, or tools can make equitable data more accessible and useable for members of the public?

Just more data by itself will not improve transparency, accountability, or effectiveness of any government program. There must be mechanisms and tools which allow for engagement between the public and the government actor. Access to information by civil society must be easy and not costly. In 2013, Obama Administration's interagency National Science and Technology Council released Smart Disclosure and Consumer Decision Making: Report of the Task Force on Smart Disclosure.[15] The Administration released an Open Data Policy, requiring "agencies building or modernizing information systems in a way that maximizes interoperability and information accessibility, maintains internal and external data asset inventories, enhances information safeguards, and clarifies information management responsibilities."[16] Data provided by federal

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government must be public, accessible, described, reusable, complete, timely, managed Post-Release, and machine-readable.

RFI Question 7: In which agencies, programs, regions, or communities are there unmet needs, broken processes, or problems related to participation and accountability that could be remedied through stronger collaborations and transparency around equitable data?

- If only technology tools are used for data collection from historically underserved, marginalized, and adversely affected communities, we run the risk of not including those people with housing instability, people working in the informal economy, people without access to broadband, to smart phones or computers, those without Social Security numbers or people are marginalized, for example, due to their limited asset history or interactions with credit institutions (such as younger adults, new immigrants, undocumented individuals, newly divorced individuals who were not bank / credit account holders previously, etc). As Kate Crawford suggests, "not all date is created or even collected equally.[17]

- Government services programs cannot be strictly dependent on big data. Equitable Data Vision must recognize that missing datasets and missing representation in datasets might further deepen divides in economic opportunity, democratic participation, and social mobility. What gets counted, gets resources. Missing representation should not further marginalize communities and those in need due to less money and service allocation as suggested by big data systems.

- Government procurement processes, policies and procedures must take into account the embedded bias in datasets and design of algorithmic systems and be subject to robust due diligence and oversight mechanisms. If not subject to tight controls and oversight, artificial intelligence and algorithmic systems developed and/or purchased by government entities can embed historical biases.[18]

Thank you for your consideration of my views. I would welcome the opportunity to discuss further about these recommendations.

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Towards operationalizing the communal production and management of equitable public (open) data

Lessons from a pedestrian network case study in operationalizing communal open data about accessibility in the public right of way

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Response to RFI 2022-19007

PROBLEM RESTATEMENT

As part of the President's Executive Order on Advancing Racial Equity and Support for Underserved Communities Through the Federal Government (E.O. 13985), the Administration convened a Federal Equitable Data Working Group to study existing Federal data collection policies, programs, and infrastructure to identify inadequacies and provide recommendations that lay out a strategy for increasing data available for measuring equity and representing the diversity of the American people. The request for information is a response to a work product from April 2022, *Vision for Equitable Data* —the Equitable Data Working Group emphasized the need for the Federal government to use equitable data to (1) encourage diverse collaborations across levels of government, civil society, and the research community and (2) be accountable to the American public.

1 SUMMARY

Data is an inseparable part of community management. Data openness and transparency has been a driver for change in government accountability and public engagement by providing unprecedented access to information. More prominently, there exists enthusiasm about the possibilities created by new and more extensive sources of data to improve our understanding and management of communities. This work examines a case study in collecting and operationalizing sustainable open data and specifically open government or civic data - information, public or otherwise, which anyone is free to access, analyze and re-use for any purpose - through a platform and community organizing effort in crowdsourcing open pedestrian network data. We outline a number of tensions or challenges in opening data, specifically in a number of realms where public interest stands to benefit from uses of the data, yet no single commercial or governmental entity is either liable or has a clear monetary interest associated with freely opening that data. In these specific cases, collection of these open data becomes a community-based challenge to undertake, which raises a number of additional sociotechnical, political, and data provenance considerations. The Taskar Center for Accessible Technology has been working on a suite of tools called OpenSidewalks, which are capacity-building tools (including technical, socio-technical and educational) to enable community-led collection and maintenance of accessibility data pertaining to the public right of way. Beyond the technical contributions of our framework (in the open-source tools to support community activities), our case studies contribute a number of insights and recommendations regarding community engagement, use of participatory co-design jointly with data collection tools, and planning for sustainable, equitable data stewardship in the involved communities.

2 DIRECTED QUESTION RESPONSES

2.1 What are *examples of successful collaborations* involving equitable data between the Federal government and (a) Tribal, territorial, local, and State governments, or (b) local communities?

OpenSidewalks is a suite of tools (including technical tools, socio-technical tools and educational tools) to guide and inform community-supported collection of information for the public right of way with specific focus on: equitable accessible use of the public right of way, walkability in communities, Safe Routes to Schools, Vision Zero (zero tolerance for traffic-related deaths, pedestrian and bike equity, mobility equity and environmental justice. Our tools have been used by 11 urban/rural teams with various degrees of completion in the collection of usable data about the accessibility of the public right of way. In the following responses we list lessons that could be learned about similar efforts for other types of data collections. OpenSidewalks is currently sponsored by a federal effort under the ITS4US program (USDOT). It will yield complete, detailed infrastructure data in the PROW for 6 counties in the U.S. by the end of 2024. A portion of these counties will be localized within tribal lands.

2.2 Among examples of existing Federal collaborations with (a) Tribal, territorial, local, and State governments or (b) local communities involving equitable data, *what lessons or best practices have been learned from such collaborations*

The primary lesson learned from our 6 years of experience is that with each data collection effort, there is a web of diverse challenges that is often domain-specific and needs to be well understood before a technical data collection solution is proposed. In our particular case, the collection and application of pedestrian network data is fraught with diverse challenges. On the technological end, these challenges include scalable, extensible methodologies for collecting and maintaining such a large quantity of information distributed over a large space, as well as variability in data availability, questions around open licensing, and a lack of data modeling standards. On the socio-technical side, challenges involve lack of subpopulations, or local community agreement around the modeling of how different populations might experience the domain, the infrastructure or the services over which data collection is concerned. Also at the socio-technical level are questions about the mechanisms by which to engage multiple stakeholders simultaneously, particularly agencies, the public, and advocacy organizations. Below we try to provide a rough taxonomy of these tensions that challenge the production and use of pedestrian data.

Data consistency and standardization are nearly entirely absent from the ecosystem of civic data projects; every project develops its own schema, in the case of infrastructure data, this includes the fundamental geospatial elements used to represent aspects of a pedestrian space. A data ecosystem without standardization not only makes it difficult (if not impossible) to use these data consistently between agencies and applications (interoperability), but it also places a significant hurdle to agency adoption, as the development of a new data schema is required for any agency that wants to collect these data. Local agencies in the United States do not typically employ full-time software development staff and instead procure data systems through contracts with private companies, so a lack of data standards implies a capital investment multiplied over every agency.

Data quality and validation is similarly related to capital investment and is integrally connected to data equity questions: how will the data be collected, evaluated, and maintained? By default, any data collected about a civic service or space will become stale and inaccurate as erosion and development occur, implying the need for monitoring and data upkeep. However, without data standards and interoperability, data maintainers have no means by which to easily stay on top of this information with a centralized or decentralized system.

A related phenomenon is for data to end up in a **"siloed" format**, wherein access and editing are restricted to small internal teams, even to the extent that teams within the same agency lack the technical capacity to share essential data. This is a consequence of many factors, especially lack of data systems designed for general interoperability: if the data system is not designed to work with other systems, and isn't regularly used to do so, it can adopt a "siloed" state of being without anyone noticing. A siloed dataset is unusable by outside groups by default and becomes stale without the internal group's diligence and investment. Importantly, siloed formats do not easily lend themselves to audits or other forms of accountability, further increasing the gap between government data and the populations whose experiences the data reflects.

With increasing importance for data equity and equitable collection of data, there is an inherent tension of **data stewardship and agency over public data**. While civic data is of great public interest, the public itself rarely has direct input into the collection, maintenance, or use of these data. Instead, these data usually go uncollected or, when collected, are enumerated within a proprietary database by a government contractor. Such systems strictly disallow public involvement or engagement with data about spaces and services they use and navigate through every day, preventing not just an opportunity for civic engagement and advocacy, but also distributed stewardship of the information; with government agencies lacking the resources to upkeep these data on their own, the opportunity for the public to assist in this effort is lost.

Finally, the **lack of integration of the public into the data process itself** (including defining what is being collected, how it is being collected, vetted, maintained and used, who is contributing to the collection, and other data provenance concerns) itself limits the extent to which members of that public will be included and modeled by the approach. Specifically, specific populations who are impacted most by the data should be involved, and these voices ought to be centered in the conversation about data processes. To make this tension tangible: our research has shown that many projects, while well intentioned, advance the idea of people with disabilities as monolith - that is, the projects directly store data such as "wheelchair-friendly" and promote data with such labels, whereas wheelchair users exhibit significant diversity in their navigational preferences and are better-accommodated through the interpretation of less subjective, physical data on the pedestrian environment. Some stand-outs examples that avoid stereotyping are AXSMap [20], AccessNow [21], which are carried out by and with their potential users: people who are disabled and who identify a gap in more mainstream mapping technologies. Globally, other concerns around crowdsourcing data "about" subpopulations rather than "with" subpopulations involve messaging (i.e., how they promote and educate the public about the concerns of a subpopulation), lack of standardization in the 'ratings' and 'labels' produced, and ignorance of language, cultural and geographic differences regarding the concerns of a community. We documented how the collection of data _about_ accessibility of the PROW by people who do not have experience with barriers in the PROW has partially explained the use of inappropriate data models.

2.3 What resources, programs, training, or other tools can facilitate increased data sharing between different levels of government (Tribal, territorial, local, State, or Federal) related to equitable data?

OpenSidewalks originated as a project to define equity-focused pedestrian-centered **data standard** about the public right of way. We quickly learned that in order to functionalize both **community-centered data collections and sustainable stewardship**, we had to integrate a complete suite of tools encompassing domains that are technical, socio-technical and educational in nature.

SUITE OF TOOLS FOR EQUITABLE CIVIC DATA COLLECTION

In the following paragraphs we detail the specifics of the OpenSidewalks suite of tools and the related tools that we have built in response to the challenges we identified above regarding equitable collections of civic data.

1. Technology tools: Software solution architecture

The software system we deployed can be broken down into three major components:

- A data transformation pipeline that splits municipal regions into crowd-collectible task areas.
- An instance of a tasking manager website that enables the self-driven team coordination collection about civic spaces.
- A fully functional user-facing accessible trip planning tool (that represents a specific downstream use case for the civic data) that drives engagement and provides a way by which to audit data accuracy specifically centering the use of the data by a subpopulation group whose lived-experience and information needs about the domain space have been largely marginalized before.

The first mentioned- data transformation pipeline- breaks down a large region of interest into smaller areas that can be audited for specific data elements by a single individual. The resulting tasks must balance several factors:

- The task should be completable within a relatively short period of time, ideally less than a few minutes. This increases the likelihood that contributors will concretely finish tasks rather than beginning and then abandoning them part-way through.
- The task should minimize cognitive overhead: the contributor should not need to remember or be cognizant of too many mapping rules, as this may increase the chance of erroneous data.
- The task sets should be organized to prioritize map correctness: once completed, the map should not be left in an invalid state.

2. Community engagement tools and pathways
    a. Progressive, iterative community engagement

The community engagement pathway strategy was designed for a two-way learning process based on progressive adaptation to local community needs and foci (Figure 1).

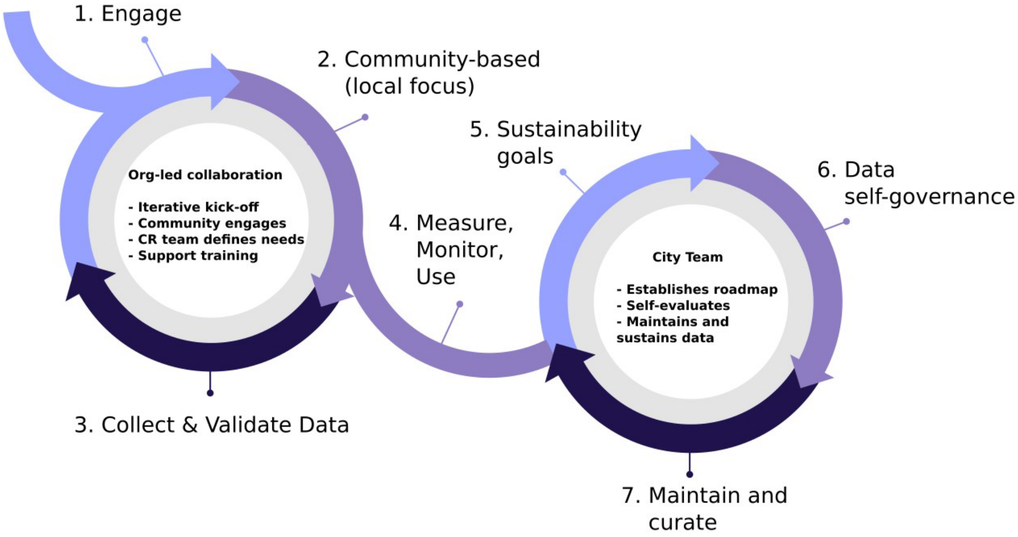

Figure 1: (OpenSidewalks case study) pathways tool to sustainable community-led data stewardship. The first iteration cycle (left) is focused on training and direct engagement between our organization and city representatives and teams while the second iteration cycle (right) is focused on city teams becoming independent stewards of their data. Iterations in the first cycle consist of driving engagement through events and challenges, tailoring work to local community needs, and collecting and validating data. It is expected that city teams will transition into an independent maintenance mode following a review of data completeness and direct engagement and use of the data by local agencies and community members (4). The second cycle's iterations consist of city team-defined sustainability goals, local data governance strategies, and data maintenance.

Two main considerations drove the development of our process: first was the self-awareness that as the developers of the data schema, data collection and assessment tools, our team stands to have undue influence on the data production process and we were keenly interested in allowing local concerns influence data outcomes; second was the sustainability goal of eventually delegating full data stewardship responsibilities in the hands of local actors. This process is divided into two stages of iteration cycles, where the first is focused on two-way learning and adaptation between the city teams and our organization and the second is focused on cities independently managing their own open data systems. In the first stage, city teams and our organization engaged in numerous cycles of training workshops, communication of community needs from country representatives, evaluative feedback on contributor data accuracy, and evaluating whether our training materials were adequate for training new contributors. The second stage is an ongoing process premised on the (near) completion of a given city's basic pedestrian network and integrations between the data system and local communities. For example, these data are expected to be open and useful for pedestrians, local agencies, and advocacy groups, with sustainability requiring active use - stakeholder investment. Once the basic network has been mapped, the data system should naturally shift to a primary data maintenance activity: whereas the first stage is focused on mapping large numbers of previously unknown pedestrian network elements, the second stage will disproportionately track changes to the pedestrian environment.

b. Guarding Data Correctness through teams' interdependent work

We developed tools to guard data correctness through dependent task mapping where different teams rely on each others' inputs. For example, separately mapping sidewalks from crossings mitigates the likelihood of conflicts in neighboring tasks but introduces a new challenge: data mapped as part of a task immediately enters the OpenStreetMap data, so if contributors map sidewalks first, OpenStreetMap will have a disconnected street and pedestrian network. These disconnected networks can cause issues for downstream tools, and our pathway to data stewardship creates cross-collaborative goals that have the data quality underly successful outcomes even as data collection is happening, rather than well downstream after the collection is completed and the data is getting used downstream.

Our structured collaborative mapping approach implements the concept of a spatial data dependency. This dependency was enforced through contributor training and instructions present on every task set but could be built into the mapping system software in future work.

In the past thirty years, many governments began providing open data to their public constituents, in a manner that is used to enhance transparency and accountability of government. Despite the motivation to serve the public good, much of the data collected and published is provided in non-standard formats, or even in forms that are not machine-readable. Our team, while primarily focused on the technical issues that confront open data provisioning, is increasingly aware of the role of tool developers as influential intermediaries and the importance of data distribution in formats that increase the overall value of open data by focusing on deep community engagement. Specifically, such engagements expose the data to nontechnical end-user access and foreground the use of the data by previously marginalized stakeholders, through technical artifacts that provide useful data analyses, integrations with other data sources, visualizations, or generalized and accessible data collection tools.

The case study we have described constitutes a limited experiment in the possibilities for deep community engagement in data collection, application, and maintenance by and for the public interest - as well as other stakeholders, including agencies and academic groups. While the results are preliminary and variable, at least one of the five cities has developed an accelerated and likely sustainable pedestrian network data crowdsourcing effort (Quito, Ecuador) as part of a dedicated training, recruitment, and engagement effort with the local community that has become so engaged that they have mapped well beyond the minimal pedestrian network requested. This model is preliminarily feasible and presents an alternative to siloed, one-off data collection efforts launched by public agencies via proprietary contracting methods. It also serves as an alternative to the now common (and concerning) practice of governments delegating information intermediary functions, such as data collection, publishing and distribution, to corporate or private entities [13].

Throughout our work, we explored the topics of data stewardship and agency, working with both academic groups and local agencies as part of developing country representatives and their teams and involving the public at the level of design, data collection, and data dissemination. The theoretical capabilities of this approach are wide-ranging, as all data produced and edited is immediately available for review by all stakeholders, allowing an interpretation of the OpenStreetMap data commons as a communication medium by which agencies, the public, and companies can suggest their own views of our shared spaces. However, this decision raises its own challenges, including questions of liability, of how agencies may provide a seal of approval or official copy of a dataset that is publicly editable, of partial data sharing such as when an agency must associate private information against a public dataset, and how data conflicts may be resolved. Additional questions are raised about the role of the technology team as the information intermediary and the complex interdependencies created when a team like ours may not identify local stakeholders who are able to assume data stewardship.

Future work should focus on factors that distinguish the success of each city, including a debrief of member participation, demographics, and strategies independently developed by country representatives. Additional experiments such as this case study are required to elucidate the challenges described above, challenges inherent to a nascent multi-stakeholder field in data systems. The success of (more developed) platforms such as these have the potential to drive equitable infrastructure investment, empower the public to address infrastructure problems within their communities and see data modeled to their own needs, drive a deeper understanding of our collective pedestrian (and otherwise) spaces through analysis of city-scale data, and new methodologies for governmental transparency.

2.4 What resources, programs, training, or other tools can expand opportunities for historically underrepresented scholars and research institutions to access and use equitable data across levels of government?

This past summer the Taskar Center for Accessible Technology launched a conversation series called "Changemakers in Civic Action: Storytelling and Data Science." The conversations recruited 8 individuals who self-identify as BIPOC and Disabled. The conversations engaged the group in a journey through building story maps about their lived experiences with transportation and mobility and in the second part engaged the participants in use of data collection tools and practices in order to capture data at scale that reflected on the personal stories they discussed in the earlier part of the conversation. We would be happy to share our report (currently in preparation stages) with any and all interested parties.

2.5 – 2.8 We believe that the remaining 3 questions asked by the RFI are in various ways answered through our previous responses.

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Journal of Public Health Policy
https://doi.org/10.1057/s41271-021-00309-7

ORIGINAL ARTICLE

Timeliness of provisional United States mortality data releases during the COVID-19 pandemic: delays associated with electronic death registration system and weekly mortality

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Accepted: 20 October 2021

Abstract

All-cause mortality counts allow public health authorities to identify populations experiencing excess deaths from pandemics, natural disasters, and other emergencies. Delays in the completeness of mortality counts may contribute to misinformation because death counts take weeks to become accurate. We estimate the timeliness of all-cause mortality releases during the COVID-19 pandemic for the dates 3 April to 5 September 2020 by estimating the number of weekly data releases of the NCHS Fluview Mortality Surveillance System until mortality comes within 99% of the counts in the 19 March 19 2021 provisional mortality data release. States' mortality counts take 5 weeks at median (interquartile range 4–7 weeks) to completion. The fastest states were Maine, New Hampshire, Vermont, New York, Utah, Idaho, and Hawaii. States that had not adopted the electronic death registration system (EDRS) were 4.8 weeks slower to achieve complete mortality counts, and each weekly death per 10^8 was associated with a 0.8 week delay. Emergency planning should improve the timeliness of mortality data by improving state vital statistics digital infrastructure.

Keywords All-cause mortality · Excess mortality · Covid-19 · Vital statistics · Death certificates · Reporting delay

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Introduction

Mortality is often underestimated for pandemics, natural disasters, and other emergencies [1], but estimated excess mortality can yield a more complete assessment of the mortality impact. Excess mortality can be estimated using statistical models to evaluate whether the number of deaths during the pandemic is greater than would be expected from past mortality patterns by comparing the actual number of deaths for each week (or any other increment) with the number of expected deaths for each week, based on the population, time of year, and secular mortality trends. If excess mortality estimates exceed the official death count from the pandemic, that suggests that the official death count is an under-estimate. Excess mortality greater than the official death counts has been observed from causes including influenza [2], extreme temperatures [3], and hurricanes [4]. During pandemics, natural disasters, and other emergencies, policymakers can use estimates of excess mortality to identify populations at greatest risk. Accurate and timely estimation of excess mortality allows policymakers and clinicians to formulate appropriate policy and clinical responses quickly enough for these responses to save lives.

During the COVID-19 pandemic, the U.S. Centers for Disease Control and Prevention found that excess mortality exceeded the official COVID-19 mortality count [5]. COVID-19 deaths may have been under-counted for several reasons, including under-diagnosed COVID-19 due to low test access, lack of surveillance testing [6], atypical disease presentation, sudden COVID-19 declines [7], sudden COVID-19 deaths [8], not seeking care because many COVID-19 patients did not perceive hypoxia and lung damage [9], or etiologically nonspecific death reporting [10] due to guidelines that limited post-mortem testing [11]. Additional excess deaths may have been due to delays in seeking healthcare for acute non-COVID-19 conditions, such as stroke or heart attack [12]. Under-counting deaths permitted the minimization of the extent of the COVID-19 pandemic [13]. Timely and accurate excess death estimates could be important tools to combat disinformation [13], encourage non-pharmaceutical interventions [14], and also inform about the importance of seeking health care, for both acute non-COVID-19 illnesses and for COVID-19.

In the United States, public health statisticians often estimate excess mortality from weekly provisional all-cause mortality data from the National Vital Statistics System, that exclude deaths not yet reported and are updated in successive weekly releases [15]. States differ from each other in the timeliness of death reporting, in part because states vary in the extent of adoption of the Electronic Death Registration System [16]. Timeliness of death reporting has improved in recent years: within 13 weeks, all-cause death data were 84% complete in 2015 [15] and 95% complete in 2017 [17]. We estimated the time until all-cause mortality counts for each state are complete. Past research does not explore a variety of reasons for the timeliness of provisional mortality estimates, so in an exploratory analysis, we also evaluated potential explanations for timeliness, such as the extent of electronic death registration adoption, death investigation system, weekly mortality, and state resources measured by GDP and public health budget. Public health authorities and researchers can rapidly estimate excess mortality for a variety of emergencies using weekly all-cause mortality, which makes this measure important.

Methods

Data

We archived 35 weeks of provisional mortality counts by state from the National Vital Statistics System between 3 April and 4 December 2020 distributed by the National Center for Health Statistics Mortality Surveillance System using the Fluview web interface (https://gis.cdc.gov/grasp/fluview/mortality.html). The federal government updates provisional mortality data every Friday on the Fluview web interface. The provisional counts are stratified into 52 jurisdictions: all 50 states and the District of Columbia, with New York City (NYC) and non-NYC New York State separated.

Measures

Primary outcome

Our primary outcome is the weeks of delay until mortality counts are complete for each of the 23 weeks from 3 April—5September 2020. This estimation resulted in 1196 mortality delay observations from 52 jurisdictions. We measure delay as the number of weekly data releases until mortality counts reached at least 99% of the counts in the most recent provisional data release: 19 March 2021. We chose the ending date, 5 September 2020, 12 weeks before the most recent data release at the time of the first analysis, 4 December 2020.

For example, the 17 April 17 2020 release is the first provisional data release for deaths during the week of 3 April 2020. A 4-week delay until completeness would mean that the provisional count of deaths for 3 April exceeded 99% of the count in the most recent provisional release 4 weeks later, on 8 May 2020. We assessed the face validity of these mortality reporting delay estimates by comparison with a spaghetti plot for each jurisdiction, where each line represents a weekly release (Figs. S1, S2, S4).

Primary predictor

The primary predictor variable was adoption of the electronic death registration system (EDRS) prior to the starting point of this data. We assessed EDRS in two forms: as a binary variable and as an ordered categorical variable. In 2020, prior to the pandemic, 4 states did not use electronic death registration (CT, NC, RI, WV); the binary indicator of non-adoption of electronic death registration was coded as 1 for these four states and otherwise 0. In addition to this binary indicator of adoption of electronic death registration, we used an ordered categorical variable from the most recent report of the extent of electronic record adoption assessed in 2018 [16]: 9 states have fewer than 75% death certificates filed with electronic death registration (AR, CO, MD, MI, MS, NY, PA, TN, VA), and the 38 remaining jurisdictions (37 states, NYC, and DC) file more than 75% of death certificates with electronic death registration [16]. This report did not provide the numerical percentage of death certificates filed electronically in 2018, only these categories. It is reasonable to believe that the closer jurisdictions get to 100% of death certificates filed electronically, the smaller the delay to mortality count completeness. We confirmed electronic death registration implementation with each state's public health vital statistics website.

Additional predictor variables

We hypothesized that during weeks with more all-cause deaths, the completeness of mortality counts would have greater delays, due to the resources needed for processing additional deaths; we tested whether weekly deaths or weekly deaths per hundred million were associated with delay. Weekly deaths per population to hundred million ranged from 1 to 10, with a median of 2, so coefficients were most interpretable on this scale.

We hypothesized that states with more economic resources would have faster death certificate processing because they have more money to upgrade state vital statistics infrastructure. We measured economic resources for the 50 states and the District of Columbia using the Bureau of Economic Analysis's 2018 per capita GDP; although New York State's delay excludes NYC death certificates, the tax base of New York State includes NYC. We retrieved the public health budget per million residents from public records and used it as a separate measure of economic resources.

To assess whether our delay measure is associated with a prior measure of data completeness, we used a 2017 measure of the percent of death certificates available within 13 weeks as a covariate [17].

Deaths that occur outside a physician's supervision require a death investigation process to identify the cause of death (disease or injury and any underlying causes) and whether the death was natural, accidental, homicide, suicide, or undetermined (manner of death). We hypothesized that the death investigation system may be associated with delay. Death investigations may be conducted by medical examiners, who are physicians, or by coroners, who are usually non-physicians with no special qualifications, except in 4 states (Kansas, Louisiana, Minnesota, and Ohio) that require coroners to be physicians. Having a medical examiner or physician coroner is a marker of a professionalized death investigation system [18], so we hypothesized that death investigations conducted by physicians may have fewer delays. States also differ in whether they have centralized offices for death investigations at the state level or decentralized ones at the county or district level. We defined a variable based on the CDC's coding of death investigation system type [19]: centralized (state-level) medical examiner system, county- or district-based medical examiner system, county-based system with a mixture of coroner and medical examiner office, or a county-, district-, or parish-based coroner system. New York City created the first centralized medical examiners system in 1918, so NYC was coded as having county/district medical examiners and having a medical examiner system [18].

We used date as a continuous variable because there may be changes over time. We also evaluated whether the month of the year was associated with delay because states may differ in reporting practices over time, such as if they learned from other states' experiences. We created binary indicators for the month: April, May, June, July, and August and the first two weeks of September.

Statistical analysis

We used Poisson regression with weeks of delay as the outcome variable, with varying intercept by states [20]. We plotted these varying intercepts for the null model (Fig. 1) [21]. The residuals were not overdispersed, based on the estimated dispersion factor for the general linear mixed model [22]. We estimated the delay associated with paper-based systems using fixed slope and varying intercept regression models [20]. The model used a categorical variable for no adoption, less than 75% adoption, and more than 75% adoption assessed in 2017 [16]. As a robustness check, we repeated the model using only a binary indicator for no electronic death registration adoption, which yielded similar estimates. In exploratory analysis using a log-likelihood ratio test to identify variables that improve the fit of the model, we evaluated additional covariates: weekly mortality per hundred million population, state gross domestic product (GDP) per capita, population, state public health budget per capita, the 4-level death investigation variable, whether the state has a medical examiner, whether a state uses only coroners, the 2017 electronic record submission measure, date, and month of the year. Weekly mortality per hundred million population was associated with delay, but the other variables were not.

This study is an analysis of publicly available data from United States federal sources in broad categories such that individuals cannot be identified, so it is not human subjects research and is exempt from requiring human subjects board review. We have made the raw data and code publicly available through a Github repository: https://github.com/Misreporting/mortality-reporting.

All analyses were performed in R 4.0.3 between April and December 2020 with revisions in March 2021.

Results

On average, all-cause mortality counts take 5.6 weeks to become complete with less than 1% increases subsequently. Figure 1 shows a plot of delay in reporting all-cause mortality count completeness from all 52 jurisdictions, the outcome variable for the regression. Figure 2 shows the average number of weeks of delay until mortality count completeness for all 52 jurisdictions. The slowest states are North Carolina, Alaska, Connecticut, and West Virginia, which are respectively delayed by 12.4, 11.1, 10.9, and 10.9 weeks on average, and the fastest states are Maine, New Hampshire, and Vermont, which are delayed by 2.5, 2.8, and 3.0 weeks, a gap of almost 10 weeks between the slowest and fastest states.

The jurisdictions with quicker than average time until mortality counts are complete were Pennsylvania, Illinois, Florida, Arizona, Wisconsin, New Jersey, New York City (NYC), Washington, Massachusetts, Hawaii, Idaho, Utah, New York State

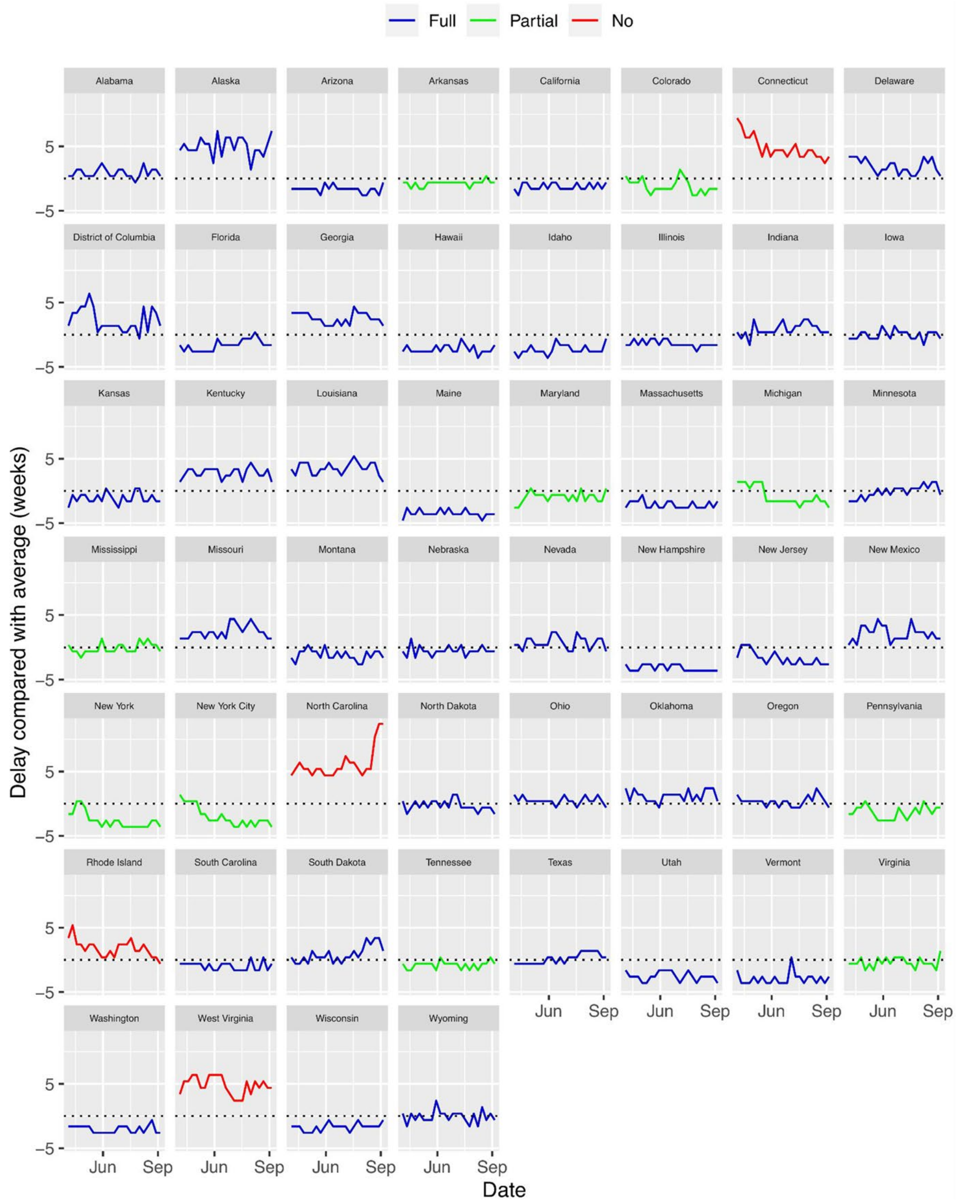

Fig. 1 Delay in mortality reporting by date and adoption of electronic death registration system, compared with average (dotted line)

(excluding NYC), Vermont, New Hampshire, and Maine (Fig. 2). The states with average time until completeness are Ohio, Oregon, Texas, Iowa, Wyoming, Minnesota, Mississippi, North Dakota, Virginia, Nebraska, Arkansas, Tennessee, Michigan, South Carolina, Maryland, Kansas, Montana, Colorado, and California (Fig. 2).

Adjusted for weekly deaths, the jurisdictions that were quicker than average and average were the same as unadjusted for weekly deaths, but the order changed (Fig.

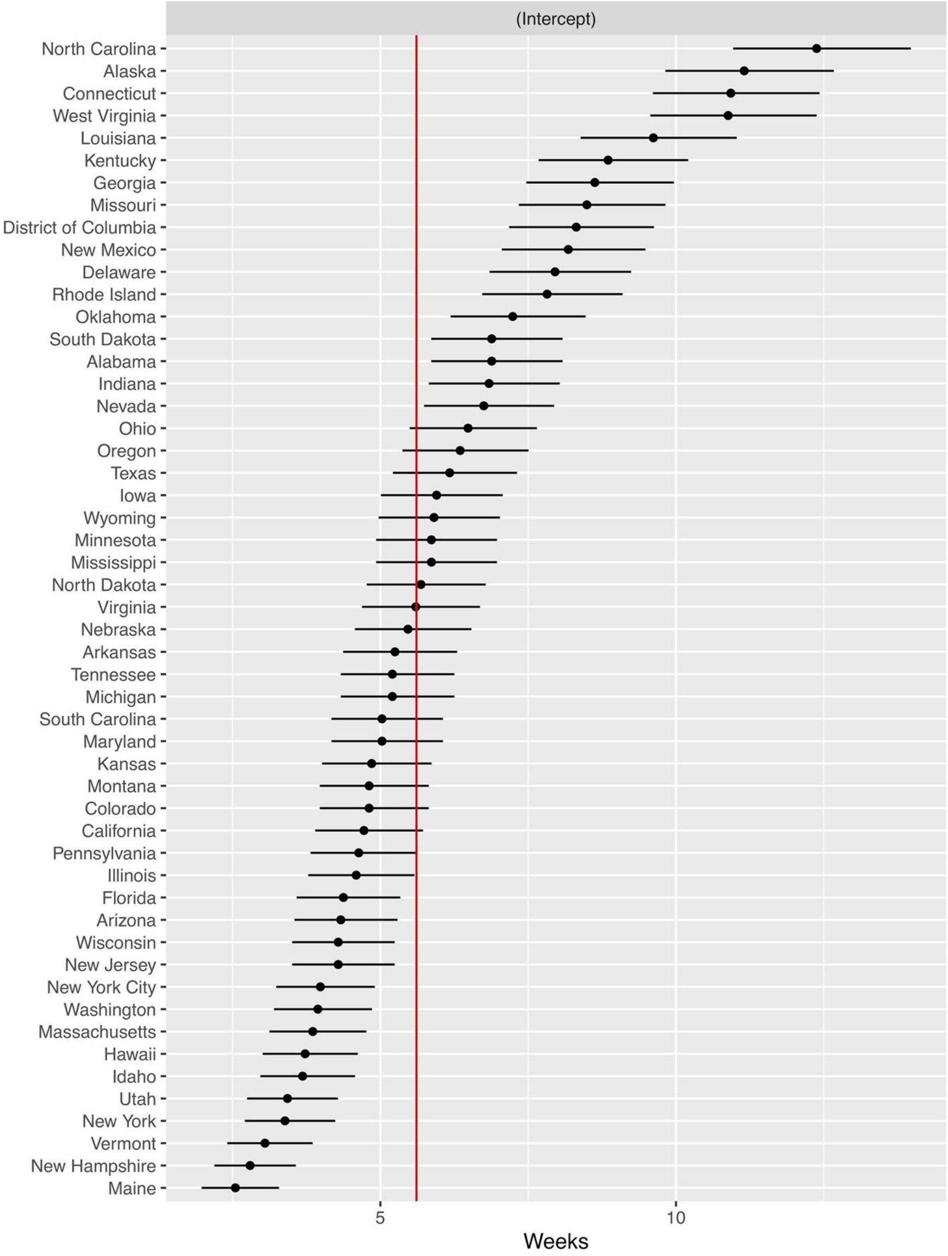

Fig. 2 Weeks until all-cause mortality counts are complete for April 3-September 5, 2020. The red line shows the mean delay

S3). Jurisdictions with high incidence of COVID-19, such as NYC, had a slightly lower delay adjusted for COVID-19 cases.

Table 1 shows the regression results predicting delay in mortality count completeness with varying intercept by state. Compared with full electronic death registration adoption (greater than 75% of death certificates reported electronically) and

Table 1 Poisson regression to predict delay in mortality reporting with varying intercept by state ($n = 1196$ observations of 52 jurisdictions)

	IRR	95% CI	p
Intercept	3.96	(3.42, 4.56)	< 0.001
Weekly deaths per 10^8	1.14	(1.09, 1.20)	< 0.001
Electronic death registration system			
Full adoption	Ref.		
Partial adoption	0.84	(0.66, 1.06)	0.1
No adoption	1.85	(1.31, 2.61)	< 0.001

IRR incidence rate ratio, exponentiated coefficients of Poisson regression

95% CI = 95 percent confidence interval

controlling for weekly deaths, states without electronic death registration adoption took 85% longer (1.85, 95% confidence interval (1.31, 2.61)), which translates to 4.8 weeks longer. The delay for states with partial electronic death registration did not differ from states with full electronic death registration adoption.

Weekly deaths per 100 million population ranged from 0.9 to 9.6 with a median of 1.9 deaths per 100 million; the interquartile range was 1.7 to 2.2 weekly deaths per 100 million population. Each additional weekly death per 100 million population was associated with 14% more weeks of delay (95% CI (1.09, 1.20)), which translates to 0.8 more weeks.

All states that did not yet implement EDRS used a centralized state-based medical examiner.

Delay is associated with death investigation system type: centralized state medical examiner offices (median (*M*) 6 weeks, interquartile range (IQR) 3–9 weeks), county-based mixture of medical examiner and coroner offices (*M* 5 weeks, IQR 4–6 weeks), county/district-based coroner offices (*M* 5 weeks, IQR 4–6 weeks), and county/district-based medical examiner offices (*M* 4 weeks, IQR 4–5 weeks) (Kruskal–Wallis test $p < 0.001$) (Fig. 3). The association between death investigation system and delay remained after excluding states that did not implement EDRS (Kruskal–Wallis test $p < 0.001$), but there was no association in the Poisson regression with varying intercept by state.

In Poisson regression with varying intercept by state, delay was also not associated with state resources, per capita GDP, per capita public health budget, all-cause mortality completeness within 13 weeks in 2017, population, date, or month, based on likelihood ratio tests of nested models that included these variables.

We performed three robustness checks for our model that did not change the model results substantially. To address slight autocorrelation in the residuals (Durbin-Watson statistic = 1.5), we repeated the analysis using penalized quasi-likelihood with autocorrelation-moving average residuals with a correlation structure of order ($p = 2$, $q = 2$) [23]. We identified the autoregression parameter of 2 using the marginally significant lags (0.25 and 0.1) in the partial autocorrelation function plot and the moving average parameter of 2 using the marginally significant lags (0.25 and 0.18) in the autocorrelation function plot. The result changes were negligible: states without electronic death records took 92% longer (1.92, 95% CI (1.37, 2.69)), which

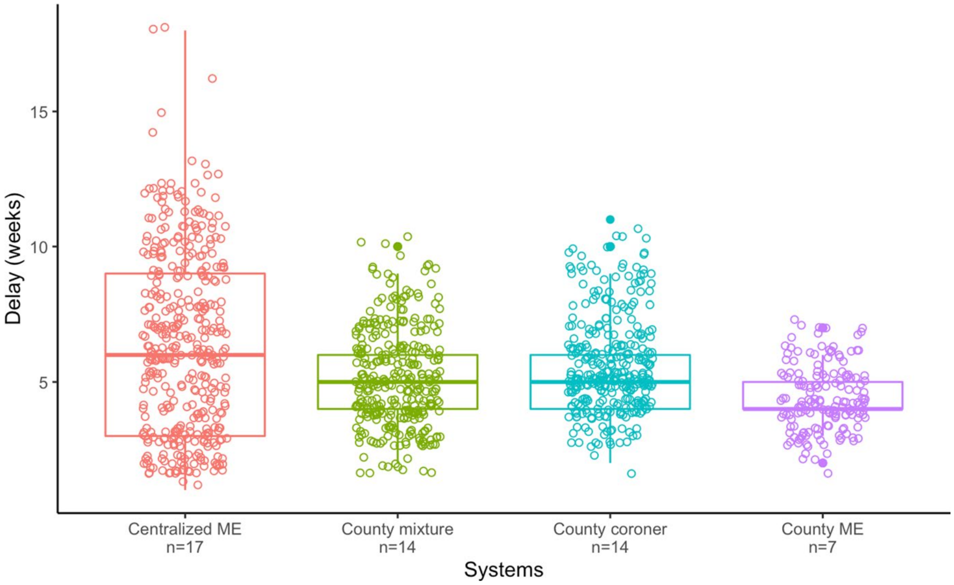

Fig. 3 Association between death reporting system and weeks of delay ($n=52$: 50 states, NYC, and DC). Centralized ME: Centralized state medical examiner office (median (*M*) 6 weeks, interquartile range (IQR) 3–9 weeks, $n=17$ states). County mixture: County-based mixture of medical examiner and coroner offices (*M* 5 weeks, IQR 4–6 weeks, $n=14$ states). County coroner: County/district-based coroner offices (*M* 5 weeks, IQR 4–6 weeks, $n=14$ states). County ME: County/district-based medical examiner offices (*M* 4 weeks, IQR 4–5 weeks, $n=7$ states/jurisdictions)

translates to 5.2 weeks longer (Table S1). Our measure of EDRS adoption dates to 2018, so as a second robustness check we repeated the analysis with a binary variable for EDRS adoption that was accurate at the time of the data as a robustness check. The result changes were negligible: controlling for weekly deaths, states without electronic death registration took 92% longer (1.92, 95% CI (1.31, 2.64)), which translates to 5.2 weeks longer (Table S2). As a third robustness check, we repeated the analysis using log deaths per log million population and the results changed negligibly. States without electronic death records took 93% longer (1.93, 95% CI (1.33, 2.79)), which translates to 5.2 weeks longer and the number of deaths remained associated with delay (Table S3).

Discussion

All-cause mortality is a vital public health tool for understanding the true mortality burden of natural disasters and health emergencies, when causes of death may not be coded accurately. Quickly reporting all-cause mortality data can improve public health policy by identifying populations with death burdens larger than the official count in time to intervene with these populations. The large differences in delays between states suggest that many states could improve the timeliness of their all-cause mortality data. Delays in reporting mortality result in provisional counts lower than actual mortality. Perceived risk of disease is an important determinant of health behavior [24], so delays in reaching complete provisional mortality counts may contribute to the pandemic misinformation that COVID-19 mortality was exaggerated [25] and reduce public adherence to non-pharmaceutical interventions such as mask-wearing [14], 26].

These delays in reaching complete mortality counts are not attributable to state resources: high-resource states are no faster than low-resource states. The three slowest states, North Carolina, Connecticut, and Alaska, are the 33rd, 4th, and 8th richest states, and the three fastest states, Maine, Vermont, and New Hampshire, are the 43rd, 36th, and 18th richest states.

County-based medical examiner death investigation systems are fastest on average, which may be because medical examiner systems are more professionalized than coroner-based systems [18]. State-based medical examiner offices are the slowest at median, so they may be under-staffed relative to county-based offices or require more steps for investigation.

Connecticut and North Carolina began to pilot electronic systems respectively in July 2020 [27] and October 2020 [28]. However, our results suggest that substantial delays in all-cause death counts occur even in states that fully implemented electronic death registration. Further, Connecticut's delays decreased in mid-May when mortality decreased, rather than in July when the electronic system began implementation; among Connecticut's 5 weeks with the largest delays (12 + weeks), 4 weeks were also the highest mortality weeks.

Strengths and limitations

In contrast with the completeness measure disseminated through FluView, this analysis uses a measure of data timeliness that can identify delays in reporting deaths during a period of high mortality. The completeness measure disseminated through FluView compares the number of reported deaths with the average number of deaths from prior years, so the FluView completeness measure is accurate only during periods of average mortality. Although we could not measure the delay in reporting each death—that is, the time between a death occurred and the death certificate was counted—we were able to assess the delay until mortality counts came within 1% of the count in the March 19, 2021 provisional mortality release.

It is possible that the delays estimated in this study were due specifically to the COVID-19 pandemic. We do not have access to states' internal documentation regarding death reporting procedures and we do not know whether states required additional review steps because of the COVID-19 pandemic. After the COVID-19 pandemic, future research can evaluate mortality reporting delays in order to evaluate the need for state reforms to improve timeliness.

Delays are not due only to state-level differences in coding causes of death and reporting these to the NCHS. Delays may be due to differences that occur at the federal level when the National Center for Health Statistics reviews death certificates, ICD-10 codes, and processes data that are reported to the public. NCHS must manually assign ICD-10 codes for new causes of deaths and multiple causes of death, both likely in the case of COVID-19. States with more COVID-19 deaths would be expected to have more federal delays. If these federal delays differ systematically between states, these federal differences could explain the observed delays, not the states themselves [29].

The ordered categorical variable for the extent of adoption of electronic death records dated from 2018, which may explain why states categorized in 2018 as filing less than 75% of death certificates electronically did not differ in mortality count timeliness. However, we verified the binary indicator of non-implementation of electronic death records to be accurate as of the time of the data in 2020, and the results were the same using this variable. Alaska is considered to be a full adopter of electronic death registration [15] with 95% completeness within 13 weeks in 2017 [16], but Alaska was among the slowest states by our measure of number of weeks of delay. Alaska is likely *sui generis* because it is uniquely disadvantaged among US states by the lack of roads to the most remote locations in the state, which may explain the lack of timeliness.

Public health implications

As suggested after earlier pandemics [30], increasing resources to improve the timeliness of mortality data is necessary for pandemic planning. Improving mortality data timeliness will also benefit natural disaster planning, when excess deaths can be used for mortality estimation. The vital statistics infrastructure is under-funded [31]. State and federal pandemic planning should seek resolution for delays in mortality reporting so that all-cause deaths can be used to estimate excess deaths to identify areas and populations in need of additional intervention.

The specific features that make a vital statistics system highly efficient likely include many details we could not measure. Likely, there are many details known primarily to the career civil servants that run state vital statistics systems. States could likely benefit from consulting more efficient but otherwise similar states. For example, Utah has substantially lower delay than 4 of its 6 neighboring states. Funeral directors, who enter demographic information on death certificates, adopted electronic death registration quickly, but medical examiners have lagged [16]. California and Arizona allowed electronic death registration submissions by fax machine [16], and our analysis found that these states were faster than average. States that consider unconventional approaches for electronic death registration submission that meet the needs of all stakeholders may have similar success.

The CDC includes percent completeness metrics in the Mortality Surveillance System, defined as the number of deaths divided by the average number of deaths from the most recent 4 years. This completeness measure cannot measure completeness accurately during a period of excess deaths, which is when these measures are most crucial and subject to the most public scrutiny. Data completeness measures that can remain accurate during periods of high mortality may reduce misinformation, such as claims that mortality counts are exaggerated.

All countries can estimate delays in mortality completeness. We estimated the timeliness of mortality data using United States data because delays were noticeable in our analysis of excess mortality during the early COVID-19 pandemic [14]. On a global scale, the World Health Organization (WHO) [32], the European monitoring of excess mortality for public health action network [33], data journalists at the *Economist* [34] and *Financial Times* [35], and researchers have estimated country-level excess mortality using all-cause mortality data. The WHO has also estimated mortality data completeness and other markers of adequate vital statistics systems (32). Any entity that estimates excess mortality can use our method to estimate the timeliness of mortality data to identify jurisdictions with large delays in mortality reporting. Our findings suggest even high-GDP jurisdictions may have large delays in mortality reporting and lower-GDP jurisdictions may have timely mortality reporting. In the United States context, the adoption of electronic death registration systems predicted more timely mortality reporting, but the most important factors in other jurisdictions may differ.

Conclusions

This exploratory analysis found that the time for states' provisional mortality counts to become complete varies greatly between states: the quickest states had complete provisional mortality counts within 4 weeks, and the slowest states took 3 times as long as the fastest states. Three of the slowest states have adopted the electronic death registration systems since collection of these data. Given the importance of provisional mortality counts to understand excess mortality during health emergencies, all states should improve the timeliness of vital statistics reporting by replicating more efficient states with similar characteristics. Funding to improve vital statistics infrastructure should be included in emergency planning budgets because vital statistics systems are crucial for understanding all emergencies that increase mortality.

Supplementary Information The online version contains supplementary material available at https://doi.org/10.1057/s41271-021-00309-7.

Declarations

Conflict of interest On behalf of all authors, the corresponding author states that there is no conflict of interest.

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October 3, 2022

RE: Docket 87 FR 54269, Request for Information; Equitable Data Engagement and Accountability

To Whom It May Concern,

RuralOrganizing.Org Education Fund thanks President Biden's commitment to advancing equity to underserved communities by improving access to equitable data. We are particularly focused on underserved rural communities in our response for the Request for Information; Equitable Data Engagement and Accountability.

RuralOrganizing.org Education Fund is a national network of civic leaders, organizers, and activists fighting for our hometowns and rural communities. We are a 501c3 non-profit based out of Columbus, Ohio. The primary purpose of our organization is to rebuild a rural America that is empowered, thriving, and equitable through policy research and education to address some of the biggest challenges facing our communities.

We would like to highlight our perspective from our work in response to question 7, "In which agencies, programs, regions, or communities *are there unmet needs, broken processes, or problems related to participation and accountability* that could be remedied through stronger collaborations and transparency around equitable data?"

In February 2022, USDA Secretary Tom Vilsack released the USDA Equity Action Plan in Support of Executive Order (EO) 13985 Advancing Racial Equity and Support for Underserved Communities. In the plan, USDA made a priority action plan to address the barriers to equitable outcome in relation to the complicated and intimidating program paperwork. This barrier is a known problem within rural communities but the data on which communities and persons are most impacted by these barriers is not well quantified. Without this data measuring the impact of the action plan cannot be measured. This would make dedicated long term funding to technical assistance and stakeholder partnerships hard to validate. The Action Plan that was written includes a foundational approach at sound and practical steps within USDA's community offices. We want to raise up this report and stakeholders in their response to Executive Order 13985 as an important aspect of bringing equity to USDA.

One area of interest that we believe would be an easy place to capture data regarding those who are unable to obtain federal services because of the overburden of paperwork is at USDA local offices is through the USDA receipt for service. The USDA receipt for service began after the 2008 farm bill and in response to the landmark Pigford Settlement Case. The receipt for service is required to be given by USDA local offices to any current or prospective producer or landowner who requests one. The issue remains, as this provision of a receipt is only required upon request. There have been many stakeholder campaigns to educate individuals on requesting the receipt to protect themselves for future evidence of discrimination. However, these receipts could be made a requirement for any individual who requests information from

USDA on programs and used by the federal government to better quantify data on what populations are requesting assistance and those who do not move forward on application submission. This small change may allow for larger data sets in order to better address the full Equity Action Plan set forth by USDA.

To request follow-up dialogue or discussion, please contact Annie Contractor, Policy Research Analyst at [redacted]

Sincerely,
Annie Contractor
Policy Researc Analyst
RuralOrganizing.org Education Fund
[redacted]
[redacted]

Title	Organization	Location	Awarded	Year ˅	Topics
Employing an intersectionality framework in revising Office of Management and Budget standards for collecting administrative race and ethnicity data	University of New Mexico	Albuquerque, NM	$1,558,500	2021	Health Disparities

ABOUT

To (1) convene scholars, policymakers, and key leads of federal administrative agencies for a symposium examining how to revise Office of Management and Budget Guidelines (OMB) to include intersectionality; (2) conduct qualitative case studies on the historical context, institutional dynamics, and power relations shaping the genealogy, development, and trajectory of OMB guidelines and census questions from the 1960s to the present; and (3) conduct a quantitative analysis of intersectionality in existing datasets that will be used in a summer institute for quantitative-research methods.

DETAILS

Amount awarded: $1,558,500
Awarded on: 10/7/2021
Timeframe: 11/14/2021 - 11/13/2024
Grant number: 79072

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SOUTHERN ECONOMIC ADVANCEMENT PROJECT
Together, Progress is Possible

TO: National Science and Technology Committee Subcommittee on Equitable Data and the White House Office of Science and Technology Policy
FROM: Southern Economic Advancement Project
DATE: October 3, 2022

Dear Office of Science and Technology Policy:

The Southern Economic Advancement Project (SEAP) is submitting comments regarding Federal Register document 87 FR 54269 - **Request for Information on Equitable Data Engagement and Accountability** by the Office of Science and Technology Policy (OSTP). We appreciate that OSTP and the Subcommittee on Equitable Data are interested in how to collaborate with community groups on the production of equitable data. These comments focus on how to engage with and support community groups regarding their data needs.

SEAP is a public policy, and technical assistance organization focused on the 12-state Southern region. The South suffers some of the greatest economic disparities, disproportionately due to the high concentrations of vulnerable populations, rural areas lacking healthcare access, and the brittle nature of public infrastructures for health, social welfare, and economic security.

SEAP partners with dozens of organizations, from small nonprofits to state and federal government agencies, to tackle these challenges. Our partners frequently look to us for up-to-date data on these issues. Responding to this need, we utilize existing and create or curate new datasets. We develop data resources with three key principles - awareness, accessibility, and representation. The quality and usefulness of any data, most importantly, depends upon accurate representation. Based on SEAP's experience in the South, we offer the following comments.

AN EXAMPLE OF SUCCESSFUL COLLABORATION

The American Rescue Plan Act (ARPA) is an example of successful collaboration between the Federal government, local communities, and organizations like SEAP. Shortly after the legislation was signed into law in March 2021, SEAP received numerous assistance requests from local governments in understanding the legislation and learning how other local governments were utilizing the funds. Responding to this need, we work as a bridge, elevating questions up to the US Department of Treasury and subsequently distributing information throughout the region.

SEAP created a suite of data resources utilizing Federal data and curated data that was missing in the ARPA conversation. We have dashboards to help local leaders understand their existing populations (Census Bureau data), where their communities felt ARPA funds would be best spent (SEAP survey data), and how ARPA funds are allocated at the local level (SEAP-collected data from local government websites). The bridgework with Treasury has led to national recognition of SEAP's work, including participation in a Pandemic Response Accountability Committee roundtable. This collaboration is successful because communication to our Federal partners and throughout the South is open and frequent; no question goes unanswered and there is a dedication to consistently updating data and resources.

INCREASE OPPORTUNITIES FOR COMMUNITY-BASED ORGANIZATIONS

There are a variety of opportunities to hold government accountable by increasing the opportunities to use data through data formats and feedback mechanisms. SEAP recommends the following:

- Make the resources public and in easily accessible formats, like spreadsheets and interactive images, that can be downloaded. PDFs and other documents that are difficult to machine read and parse provide limited accessibility.
- Offer live trainings and then have those available as bookmarked videos for search ease, so people can reference how to use data for accountability. A live training also offers an opportunity for a real-time conversation to quickly

respond to questions. The corresponding video posted on an Agency's webpage creates an additional resource that people can access as needed.

- Create a public reporting mechanism for flagging issues - like the "reporting waste, fraud, and abuse" on pandemicoversight.gov or the Count Question Resolution program at the Census Bureau. This shows that government is invested in making data resources better and also gives the public an idea of how quickly it takes to resolve issues.
- Gain understanding of how people utilize data by surveying end users and community groups. Asking who folks go to with questions or data needs will indicate the community data leaders.

MAKING DATA MORE ACCESSIBLE

In addition to public resources and training opportunities, ensuring this content is widely accessible is essential for reaching all Americans.

One significant thing to consider is the infrastructure where data is made available as well as where it is consumed. Understandably, many datasets are available in digital formats; however, the reliability of internet access is not equal throughout the country. In addition, the devices used to access data vary. An analog support system, such as a phone number, where community groups and other members of the public can request data could fill those infrastructure gaps.

Another significant, and far too overlooked, accessibility issue is developing data resources for the multitude of audiences that need access to it. One piece of that is creating data resources in non-English languages, with specific attention paid to ensuring those represented in the data understand the data. For example, Georgia has a small Haitian-speaking population. If there is data available that represents that community, it should be available in Haitian.

Developing resources with visual and audio support is important. Visual cues such as alt-text and image descriptions provide useful context for people with difficulties viewing images. Enabling closed captioning for videos aids people with auditory challenges. Providing sign language during presentations and transcripts after presentations also provides auditory support. Similarly, developing resources for people with different levels of cognitive abilities allows for additional accessibility and use of data.

Providing data in consistent structures and formats, across the Federal datasets, ensures that data can be compared and utilized for many purposes. Supporting documentations such as data dictionaries and how-to guides are useful for understanding Federal data. Finally, including information such as frequency of data updates, contact person, and any other support like working groups is essential for data use. SEAP is happy to engage in more depth on any of these topics.

Sincerely,

[redacted]

Data Director
The Southern Economic Advancement Project

SEARAC

October 3, 2022
Denice Ross
U.S. Chief Data Scientist
White House Office of Science and Technology Policy

Re: Regarding Equitable Data Engagement and Accountability
Docket ID: 2022-19007

Dear Ms. Ross:

Thank you for the opportunity to provide comments on the Office of Science and Technology Policy's (OSTP) Request for Information (ROI). The Southeast Asia Resource Action Center (SEARAC), the Hmong Cultural Center of Butte County (HCCBC), and Coalition for Asian American Families and Children (CACF) submits this comment in response to questions 1, 2, 3, 5, and 7 of the ROI. These responses also reflect community-based organizations and partners. Our comments will focus on Asian American, Native Hawaiian, and Pacific Islanders (AANHPI) and how data collection and use impacts this unique population.

SEARAC is a national civil rights organization that empowers Cambodian, Laotian, and Vietnamese American communities to create a socially just and equitable society. As representatives of the largest refugee community ever resettled in the United States, SEARAC works to ensure that Southeast Asian refugees and their descents have equitable access to health and mental health care. Specifically, SEARAC aims to increase culturally and linguistically competent care and eliminate barriers to care for our the most vulnerable members of our communities, including children, elderly, female identifying, and LGBTQ+ individuals, that allows them to heal from the trauma they carry in their escape from war, political persecution, and genocide.

SEARAC supports expanded demographic data collection and reporting as part of federal and state policy. Federal and state agencies can do more to collect and publicly report specific ethnic data for a range of programs and services (i.e. education performance and attainment data). While the Office of Budget Management's Statistical Policy Directive No. 15 allows federal agencies to collect demographic data beyond the five major racial/ ethnic categories[1], few agencies are actively expanding racial data collection beyond the minimum requirements, outdated and insufficient as they are to address inequities across and within these categories.

Southeast Asians in historical context

For SEARAC, Southeast Asian American (SEAA) is a political identity that comes from the shared experiences of people who came to this country as refugees from the U.S. occupation of Cambodia, Laos, and Vietnam. SEAAs now number nearly 3 million, and unlike most other Asian American immigrant communities, the vast majority of SEAAs resettled in the United States as refugees. While the initial wave of the refugees was relatively educated, had familiarity with English, and were from largely higher economic backgrounds, the vast majority of the 1.3 million SEAA refugees resettled between 1997 and 2005 lacked formal education and knew little to no English. The limited English proficiency within SEAA communities continue to persist to this day. According to U.S. Census estimates from 2011-2015, 38.3 percent of Cambodian, 36.7 percent of Hmong, 34.5 percent of Lao, and 48.6 percent of Vietnamese households that speak English less than "very well," compared to 8.6 percent of total U.S. households. These innate challenges are compounded by existing mental health trauma from the war and violence in the broader Southeast Asian region and their escape from the area, resulting in high rates of post-traumatic stress disorder among refugees.

Data disaggregation is one of the most important civil rights issues for AANHPIs today. More data is needed to better understand the unique challenges that the AANHPI communities face and provide appropriate solutions.

Question 1: The Department of Education's Asian American and Pacific Islander Data Disaggregation Initiative is an example of successful collaboration involving equitable data between the Federal government, State government, and local communities.

In 2016, the Department of Education launched the Asian American and Pacific Islander Data Disaggregation Initiative (D2) grants. The goal of the D2 grant program was to provide grants to State Education Agencies (SEAs), in partnership with Local Education Agencies (LEAs), to

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[1] American Indian, Black, White, Hispanic, Asian, Native Hawaiian and Pacific Islander

obtain and evaluate disaggregated data on English Learner (EL) AAPI subpopulations beyond the existing seven racial and ethnic categories within.

In preparation for the rollout of this grant program, local education advocates in Minnesota and Washington State worked with SEA staff to apply for the D2. Three states received grants to improve data collection practices in Minnesota, Washington, and Hawaii. The Department provided a total of $836,000 to these three states. While Minnesota, Washington, and Hawaii had already begun implementing or considering collecting disaggregated racial and ethnic data for AANHPI LEP students, the grants allowed the states to accelerate implementation. Specifically, based on our conversations with staff from staff at SEAs and local education advocates in Minnesota and Washington, local campaigns led to successfully passing data disaggregation policies in education research. Currently, these states are working on implementing their data disaggregation policies and reporting the data publicly.

Additionally, the grants provided an opportunity for SEAs and LEAs to work directly with local communities to identify the racial and ethnic data that needed to be collected and the format in which the data would be collected. The D2 grant opened a line of communication between the Federal government and local communities to gather feedback from those communities.

The D2 program is a great opportunity for the Department to continue to cultivate innovation and improvement to expand state data collection and reporting systems and should be revamped. However, while implementation of systems as complex as data improvement and management requires continuous investment, this program was never renewed nor has the Department of Education released findings from the one year grant period, as promised. Continued funding for this program would have allowed these states to follow-through with monitoring implementation, reviewed lessons learned, and created opportunities for other states, such as Rhode Island, New York, and New Jersey, to follow this lead. Regardless, the D2 grant program illustrates a successful collaboration between the Federal government, State government, and local communities.

Question 2: States cannot reshape their data collection infrastructure without Federal government support, and local communities are unable fully engage in data equity policy implementation without knowledgeable, consistent staffing in state departments overseeing data collection.

For example, data is limited for local community organizations to get involved. In Rhode Island, local community-based organizations had to step up and provide technical assistance when data disaggregation policy was passed due to a lack of guidance on how school districts could implement the policy. CBOs in the state reached out to districts and found that the state agency did not provide communications or guidance around expanded data collection and that districts didn't know how to collect expanded racial data. Our partners had to extend their capacity to help shape the questionnaires for updated data collection and assisted in outreach and communications efforts. This shows the resiliency of our SEAA community to push for data equity policy and implementation as well as the lack of preparedness by state - and federal - agencies to follow-through with fidelity after data collection policies are passed. The federal government could do more in setting examples for expanded data collection, reporting, and implementation so that the people campaigning for data equity are not also fulfilling the roles of government agencies.

Question 3: Provide training and in multiple languages on how to access public federal and state agency data.

Our communities need training on resources, programs that can be shared with community organizations, local, and state governments so that all can be at the same page for serving the community and meeting their needs. With regards to resources and training, federal and state government should provide guidance on how to access and read state and federal data (i.e., educational achievement on state and federal agency websites). Federal and state agencies should also provide this resource in several different languages, including Khmer, Hmong, Vietnamese.

Question 5: Increased, consistent funding for SEAs and LEAs to reshape their data collection systems and disaggregate data collected would allow for larger data teams within the state departments overseeing this implementation. That consistent staffing would ensure that local communities have a regular point of contact and open line of communication with these agencies. Additionally, creating opportunities, such as public portals, for the Federal government and states to share accessible, publicly available disaggregated data would allow local communities to hold the government accountable to the American public.

In Washington State, funding resources provided by SEARAC enabled the Southeast Asian American Education Coalition (SEAeD) to hire staff to lead a state campaign regarding data disaggregation. SEAeD's staff educated and organized community members about the lack of data collection and data access regarding their SEAA community. In addition to collaborating with other organizations, the effort resulted in state level advocacy efforts that made it possible for Washington State to pass state legislation to enhance data collection efforts. This would have not been possible without staff funding capacity as our communities and organizations are already stretched thin and lack such resources.

One example of the type of collaboration that is being encouraged are language learning sessions for community-based organizations on how to access and use federal data to help identify and address social and economic disparities facing their cities and towns. While groups may not have had the opportunity to comment on this FRN, we are looking to collect ideas on how these sessions could be structured to provide further feedback. SEAA community-based organizations have also asked for more resources to provide staff with equity training to the community that they serve.

For National Center of Education Statistics (NCES) data collected by the Institutes of Education Statistics (IES) at the Department of Education, it is important that for the Asian American demographic categories, specific Southeast Asian American ethnicities are included in the data. Currently, NCES collects Asian American ethnicities that disaggregate by a few country of origin, including a category for Southeast Asian countries that include Cambodian, Laos, Vietnam and Thailand in its restricted data set. Due to the unique experiences of war, trauma, and refugee migration patterns for Cambodian, Hmong, Laos, and Vietnamese people, NCES should consider separating Thailand from grouping "Southeast Asian" together. NCES can also consider separating all Southeast Asian ethnicities and improve the over-sampling of these ethnic communities to yield a high enough sample size needed to provide analysis. Further, NCES and IES should improve their collection and reporting of disaggregated racial and ethnic data such that it is publicly available data. In instances where raw data cannot be provided publicly, NCES should produce yearly reports of how Southeast Asian American populations are faring in schools, including achievement patterns and school climate responses.

Efforts must also be taken across federal education agencies to equitably collect, analyze, and report disaggregated AANHPI data by race and ethnicity, not citizenship and nationality, in order to better inform the policy.

SEARAC

Question 7: There is a need for increased allocation of resources, increased access to educational data, and increased spotlighting of Asian American, Native Hawaiian and Pacific Islanders in schools. Our communities' stories deserve to be visible in the data and our call for data equity deserves policies that hold teeth and are followed-through.

Federal: At the federal level, AANHPI communities have asked for disaggregated Asian data for several decades, yet the federal government has stalled on developing a plan to implement data equity. In education, the AANHPI community is still awaiting feedback from the Department of Education on several data equity-related projects. The AANHPI community is eagerly waiting on the Department's report from the D2 data disaggregation grant program that was supposed to come out fall 2021 and have requested on numerous occasions that the Department provide more information on when we can expect this report.

California: At the state level, agencies like the California Department of Public Health are accountable to laws that mandate the collection and reporting of disaggregated health indicators for wider AANHPI communities, yet the lack of standardization in requirements and processes across public health stakeholders (i.e. from providers, labs, and hospitals to local public health departments) create barriers to meaningful data. For example, CDPH are unable to collect uniform public health data due to different local electronic health records/systems (which may be through private or public entities), and local health departments are unable to collect uniform public health data as providers and laboratories are not required to gather and report information in standardized ways. There are significant inconsistencies in the level of data reported and collected at all levels, especially at root levels of service providers and local counties.

Thank you for your consideration of the issues and recommendations we have brought forth. For more information or questions, please contact Natalie Truong, [redacted] and Kham Moua, [redacted]

Sincerely,

Quyen Dinh, Southeast Asia Action Resource Center
Seng S. Yang, Hmong Cultural Center of Butte County
Lloyd Feng, Coalition for Asian American Children and Families

SOCIAL
FINANCE

October 3, 2022

To the Office of Science and Technology Policy:

We are writing in response to the Request for Information on Equitable Data Engagement and Accountability. At Social Finance, a national impact finance and advisory nonprofit, we seek to implement innovative, data-driven practices that deliver better results for the public sector. In the past decade, we have worked with more than 65 governments at the state, county, and city level to improve data analysis and outcomes across policy areas, including early childhood, behavioral health, education, housing, and economic mobility. Based on our experience working with the public sector and commitment to the production and use of equitable data, we are pleased to provide our feedback on how to strengthen the production, accessibility, and usability of equitable data. Our comments are centered on two questions in the RFI.

Response to question 3: *What resources, programs, training, or other tools can facilitate increased data sharing between different levels of government (Tribal, territorial, local, State, or Federal) related to equitable data?*

Guidance and support on data governance. Many state and local government agencies struggle with the resources, expertise, and capacity to fully understand the legal landscape for data sharing and data access, particularly when trying to parse overlapping local, state, and federal laws and policies. Many government agencies revert to a conservative approach involving a narrow interpretation of data governance statutes to ensure data protection over data access due to legal concerns and liability. While it is critical to ensure data protection and security, this also limits the ability of government agencies to learn from their data sets, leverage the analytical capacity of external academic and nonprofit stakeholders, and allow for cross-sharing of data between agencies.

State and local governments would benefit greatly from federal guidance on data governance. The federal government has an important role to play here in setting clear and uniform data protection standards that facilitate the ability of government agencies to efficiently share data between agencies and with external partners. Federal grants to states to cover legal expenses could help government agencies ensure compliance with state laws without hindering data sharing. The federal government could also provide templates of data sharing agreements and memorandums of understanding to streamline the legal process for entities to enter into data sharing with state and local government agencies. Such documentation should take into account the inherent power dynamics between those providing data and those storing and using the data.

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617.939.9900 **socialfinance.org**

Some governments are doing this type of work very well and could be models for other states that are earlier in the process. For example, in Connecticut, the Office of Policy Management is establishing a statewide governance structure for cross-agency data sharing with an enterprise memorandum of understanding, creating a more flexible and durable data sharing agreement template, and developing guidelines for staff to speed up the data sharing process.

Guidelines on recommended data infrastructure. Government agencies use a wide range of data platforms and even within one agency there may be multiple platforms. This creates challenges for sharing data across agencies and at different levels of government. The federal government could play an important role here by providing recommended specifications on data infrastructure and platforms for state and local government agencies to use. They could also provide the needed funding to allow agencies to upgrade their data systems so they are able to connect data systems within an agency, across agencies, and among different levels of government. Congress made a historic $550 billion investment in infrastructure spending with the passage of the Infrastructure Investment and Jobs Act, and specific matching funds should be allocated to jurisdictions for IT infrastructure upgrades, specifying that new systems must be interoperable and prioritizing applicants looking to build cross-agency integrations. Another avenue could be including dedicated funding for government IT infrastructure as part of existing state grants.

Relatedly, an important component to improve data infrastructure is how to uniquely identify an observation to facilitate merging across data sets. Along with guidelines on data infrastructure, the federal government could share best practices for structuring unique IDs with and across government agencies, including how to do so in a way that protects privacy and secures data. The federal government could draw on learnings from state agencies that received funding to develop their State Longitudinal Data Systems (SLDS) when sharing out recommendations.

Align on terms and definitions for equitable metrics. Many government agencies are working to collect user data to be able to construct equity metrics and hold themselves accountable to the people they are serving. One challenge is that there are not always common standards on how to define key demographic fields, including race and ethnicity. Census Bureau definitions are often too broad for certain jurisdictions to result in meaningful policy analysis. For example, according to the Census Bureau, Black or African American includes groups as diverse as Haitians, Francophone West Africans, and Black Americans whose families have lived in the U.S. for generations.

Some government agencies struggle with understanding how best to include an equity lens when creating performance metrics. The federal government could provide support here by working to align terminology and definitions for equity metrics and by sharing a recommended list of equity metrics as a starting place for state and local government agencies.

Support data and IT leaders within government agencies. There is diffuse knowledge across government agencies on data analytics and IT. The team members responsible for those functions are critical for increasing accessibility and usability of equitable data. The federal government could do more to support data and IT professionals and leverage their collective knowledge and diverse experiences. This could include bringing those leaders together across states and agencies for trainings and peer-to-peer learning. Using a cohort model, leaders could learn from one another as they innovate and try new approaches at the state and local levels. In addition, the federal government could provide more dedicated resources to ensure agencies are able to make the necessary investments in hiring and retaining data and IT professionals. The federal government could sponsor a state-level data leaders fellowship to encourage individuals with non-government IT experience to join the public sector, connect with their peers through cohort convenings organized at the federal level, and be empowered to lead projects that have the opportunity to make a big difference in people's lives.

<u>Response to question 5:</u> *What resources, programs, training, or tools can increase opportunities for community-based organizations to use equitable data to hold government accountable to the American public?*

Streamline process for community-based organizations to obtain data. It can be a lengthy, cumbersome, and opaque process to legally obtain data from government agencies. The rules and processes for obtaining data often differ between agencies and among levels of government, creating additional barriers to community-based organizations (CBOs) that may have limited resources and time. Related to the earlier feedback in this letter on support for data governance, the federal government could help develop and recommend common policies and procedures across jurisdictions for data sharing. It is key to reduce barriers (time, money, and legal expertise) for CBOs to access equitable data.

Ensure clear codebooks for each data set. Once CBOs have received equitable data, they need to be able to quickly understand and process it. To do that, it is important that each data set has a clear and comprehensive codebook that describes and defines each variable. The federal government could provide resources to agencies on codebook structure and examples.

Increase use of public data dashboards. Data dashboards are an excellent tool to allow non-technical users to examine government data quickly, easily, and without having to go through a cumbersome data sharing process. Data dashboards demonstrate government commitment to transparency and accountability in a way that increases accessibility. The federal government could encourage the development and use of public data dashboards by recommending the functionality needed to ensure data can be accessed using an equity lens, such as filters to disaggregate metrics by key demographic and location variables, color palettes that do not reinforce stereotypes, and legends that use inclusive language.

Connected to the earlier recommendations in this letter, the federal government could provide additional financial resources that support data dashboarding, including by supporting data and IT leaders within government so that agencies have the skills and expertise to develop, publish, and maintain the dashboards. There may be opportunities for the federal government to provide funding for partnerships between publicly funded universities and governments for the associated technical assistance for these efforts.

Relatedly, for organizations that are providing data that feed into public dashboards, there should be a concerted effort to ensure that those organizations can see and understand their data and how it connects to other organizations operating in the same space. One strategy that Social Finance employs in this area is to lead provider data conversations to discuss visualizations of their data, identify key learnings, and unpack any surprising findings.

In conclusion, we agree with the Federal Data Working Group's final report that developing the collection and use of equitable data is a critical step to support collaboration across stakeholders and for government accountability. Thank you for this opportunity to provide feedback. If you have any questions or would like to discuss further, please contact Sandra Salstrom, Vice President, Government Relations at [redacted] or [redacted]

About the UCLA Center for Health Policy Research

Since its founding in 1994, the UCLA Center for Health Policy Research (UCLA CHPR) has produced high-quality, objective, and evidence-based research and data that have informed effective policymaking and improved the lives of millions of Californians. In 2001 UCLA CHPR launched the California Health Interview Survey (CHIS), the largest state-based population health survey in the U.S. CHIS collects data on health status, health habits, insurance status, and social determinants of health for adults, teens and children. CHIS continues to collect an annual sample of over 20,000 households with a constant commitment to producing data centered on health equity.[i] To ensure the data was accessible by all organizations and health leaders regardless of technical skill, the UCLA CHPR created a free, easy-to-use, web-based query system, AskCHIS. Throughout the years we have used metrics from the system and feedback from users to inform additional tools, including AskCHIS Neighborhood Edition (NE), and Health Profiles, which deliver health estimates on top topics for multiple age groups, racial/ethnic groups, and geographic regions (including counties, legislative districts, regions, SPAs and HHAS). Additionally, UCLA CHPR offers training on utilizing CHIS data tools and harnessing the power of data in advocacy. We have also provided special training for media and legislative staff. Through the success of CHIS, we have expanded our equitable data research portfolio with the creation of the UCLA Data Equity Center and the Native Hawaiian Data Policy Lab. It is through the lens and experience from CHIS and these two projects that we provide our comments to the RFI.

UCLA Data Equity Center

The Data Equity Center is a new center based at the UCLA Center for Health Policy Research, created to provide technical assistance to data projects around the country to help improve data equity. The mission of the Data Equity Center is to increase representation of marginalized populations in data and to reduce barriers in access to data especially among marginalized communities who have been unrepresented or invisible in the data platforms that inform policies. The Data Equity Center will also be curating a repository of resources to address barriers to data equity that will be publicly available. We encourage agencies, programs and organizations to turn to the Data Equity Center as a repository of expertise, resources, and tools, as well as a source of technical assistance.

In addition to the Data Equity Center itself, our team would like to share the following comments and suggestions.

Some recommendations across several of the questions posed in the RFI. For example, having a strong commitment to Dissemination of data and data products is likely to produce resources and tools that will facilitate data sharing across levels of government (Q3), expand opportunities for historically underrepresented scholars and research institutions to access and use data (Q4), increase opportunities for community-based organizations to use data (Q5), and make data more accessible and useable for members of the public (Q6). For example, the California Health Interview Survey is a state level survey that is widely used at the state, county and local levels.[ii] The data and products are used by advocates, policy makers, community organizations, and state and local health departments. This is due in part to dissemination efforts which have produced a number of resources and tools including:

1. Reports and publications targeted to a variety of audiences from the general public, to community-based organizations, to policy makers, as well as academics.
2. Online query system that supports quick and easy searches for health statistics for the state of California as well as for counties and regions in the state
3. Data dashboards that provide data on smaller population groups or on timely topics
4. Public Use Data Files that provide comprehensive statewide data files on a variety of topics and are free and downloadable

In addition, survey data are an essential source of monitoring the health and health care needs of the U.S. populations as a whole and identifying the specific needs of smaller populations or communities. Users of health datasets seeking to identify and quantify the health disparities of smaller communities often encounter challenges of measurement and racial-ethnic classification. These challenges include: inconsistent data collection and coding methods and survey weighting decisions that affect the representativeness of samples of respondents across surveys. Imprecision in health estimates for smaller racial/ethnic group can lead to poor public health planning and policy formulation and may dampen opportunities for wider allocation of non-health social protection resources that impact health.

In our work with survey researchers, they have routinely expressed the need for more guidance on approaches to collecting, tabulating, and disseminating data on race and ethnicity; they have also expressed challenges with regards to accessing datasets. The following are high-level areas we have identified as those which would make data more accessible and useable to the public:

- Release pooled multiyear public-use files that include more detailed race/ethnicity data. Pooling multiyear data reduces the disclosure risk that may be associated with providing more detailed race data.
- When small sample sizes prohibit the inclusion of any of racial/ethnic subgroups, datasets should include information on the overall population. For example, with the American Indian and Alaska Native (AIAN) population it is preferable to include the overall AIAN category along with the single-race AIAN category to expand tabulation options for the AIAN population. In cases where disclosure risk prevents the release of measures identifying any AIAN subgroup, such as single-race non- Latino AIAN, survey administrators should consider publicly releasing at a minimum an overall AIAN indicator that combines single-race AIAN and AIAN of more than one race into one category. This indicator would allow continued access to data on AIAN populations when disclosure concerns prevent the analysis of AIAN subgroups. The Native Hawaiian/Pacific Islander group should also be separately reported from the Asian American group.
- Reduce cost/time for accessing restricted data. If it is not possible for smaller community information to be included in public-use datasets for some surveys, the accessibility of that survey's restricted data becomes extremely important for obtaining information. This is especially critical for surveys that are the primary source of information on a health topic. Current procedures for accessing federal statistical research data centers are time-consuming and expensive and demand resources that

are often unavailable to members of these marginalized populations. Enabling access to this data in ways that protect respondents will help to reduce these inequities and encourage efforts to develop policies to improve the health of communities.

The Native Hawaiian Pacific Islander (NHPI) Data Policy Lab
The NHPI Data Policy Lab was born of the COVID-19 pandemic,[22] when community groups throughout the United States approached the UCLA CHPR about the lack of NHPI data in counts of infection rates in known diasporas in different states. Anecdotal data in April 2020 indicated high rates within the community but monitoring systems aggregated NHPI data with Asian-American or 'Other' designations, masking the true extent of the impact in this culturally tight-knit community. Soon after, The NHPI Data Policy Lab developed data mining techniques to expose the real numbers of those impacted in this community, alerting community groups to the need, and enabling health officials to create specific outreach programs for this population.

The NHPI Data Policy Lab is now a reputable source for NHPI data translators, educators, collaborators, and conveners. Since its formation in May 2020, the NHPI Data Policy Lab has supported the targeted community by increasing their access to health and health indicator data for use in program planning, community building, advocacy, and informing policy. The NHPI Data Policy Lab has an extensive track record in assisting NHPI community groups through in-language data education, group data trainings, and conducting data needs assessments to address barriers and gaps in data. Because of the Lab's support, community partners have successfully advocated at the U.S. House of Representatives Ways and Means Committee, the Congressional Asian Pacific American Caucus, the Congressional Tri-Caucus, and several state and county health jurisdictions throughout the U.S.

Additional comments in response to specific questions are below:

1. What are examples of successful collaborations involving equitable data between the Federal government and (a) Tribal, territorial, local, and State governments, or (b) local communities?

In California, the NHPI Data Policy Lab has been integral in helping local community coalitions in COVID-19 response. Members of The NHPI Data Policy Lab regularly attend virtual community convenings to provide COVID-19 data reports and education on case, death and vaccine rates. The NHPI Data Policy Lab has also produced a California county-level dashboard to visualize COVID-19 impacts on NHPIs across the state that the community relies on for accurate and reliable data. We provide thorough trainings on how to navigate the platforms to ensure usability among community and health professional data users. This support has shown high impact in regions such as the Inland Empire where an NHPI coalition successfully leveraged the Lab's data and data-education to make disaggregated NHPI COVID-19 data publicly accessible. This advocacy effort uncovered hidden NHPI disparities, giving community-based organizations the evidence needed to garner support for NHPI-targeted interventions.

Recently, the NHPI Data Policy Lab has given recommendations to the California Department of Public Health on the shortcomings of the Califronia Health Places Index, which fails to capture vulnerable NHPI communities. The metric disproportionately lacks consideration of NHPIs in resource allocation and vaccine distribution. This effort to educate and communicate with data producers on NHPI data inequities further emphasizes the NHPI Data Policy Lab's role as a local data intermediary.

2. Among examples of existing Federal collaborations with (a) Tribal, territorial, local, and State governments or (b) local communities involving equitable data, *what lessons or best practices have been learned from such collaborations*?

Form the NHPI Data Policy Lab Collaborations, we have learned the following:

1. We are using the findings of a Community Data Needs Assessment to inform the development of the data platform and training materials.
2. We conduct "report back" meetings to provide community respondents to findings from the Community Data Needs Assessment.
3. We work not only with traditional organizations, but also civic clubs, and school districts to address and improve outcomes among the targeted population groups.
4. Relationships of mutual benefit, and provision of technical assistance are useful in asking the community for a formal commitment to partnerships.

3. What resources, programs, training, or other tools *can facilitate increased data sharing between different levels of government (Tribal, territorial, local, State, or Federal) related to equitable data*?

The Data Equity Center is housed in the National Network of Health Surveys (Network). The Network, a project of the UCLA Center for Health Policy Research, is a group of over 200 health survey leaders, data custodians and users all interested in advancing data projects across the country at national, state and local levels. Because the Network membership includes representatives and users of data across different levels of government, the Network can be a resource for facilitating data sharing across levels.

In addition, the Network curated a series of technical assistance workshops designed to improve the disaggregation of race and ethnicity measures in health data sources. Workshop topics include: considerations for data collection and processing, question wording and response sets, mitigating disclosure risk, user experience, weighting strategies, disaggregating data decision-making, and legal and regulatory guidance. Recordings and slides from these workshops are available.

The NHPI Data Policy Lab has established dashboards that have automated data scraping from publicly available datasets. With the shared resources from the UCLA CHPR, we have a bench of researchers in data science, statistical analysis, data dissemination and training specialists, and policy analysts. Through our Communications team, we have hosted webinars featuring the NHPI Data Policy Lab dashboards—both for the state and national levels.

The Health Data program, a program of the UCLA Center for Health Policy Research, could help expand opportunities for underrepresented scholars and research institutions to access and use data. Through in-person and on-line workshops, the Health DATA Program helps policymakers, community groups and health and advocacy organizations to understand and use credible data in their programmatic and policy development work. Although the program's training and workshops has focused on health data, the concepts can be applied to other types of data.

5. What resources, programs, training, or tools *can increase opportunities for community-based organizations to use equitable data to hold government accountable to the American public*?

The Health Data program, a program of the UCLA Center for Health Policy Research, could help increase opportunities for community-based organizations to use data. Health DATA conducts training courses, in-person and online workshops, and technical assistance sessions to build knowledge and skills to access, understand, and apply data to program planning, advocacy, and policy development. One initiative of the Health Data Program was the Data & Democracy Initiative which had the goal of increasing data and research capacity of community-based organizations. Results of an evaluation of this initiative suggest that this intensive, short-term training program led to significant gains in data and research self-efficacy among community-based organization staff.[iii]

6. What resources, programs, training, or tools *can make equitable data more accessible and useable* for members of the public?

User friendly data access tools and training are key components to improving access to data and allowing communities the ability to understand themselves better and develop solutions and policy ideas. With COVID-19 data a number of innovative data dashboards were developed by various academic and non-academic entities, allowing for quick visual display of data that could be easily interpreted and used by communities. Training community users as well as building a pipeline of data scientists, particularly from communities have been historically underserved, would improve access, use, and interpretability of data by the public it the data are intended to serve.

7. In which agencies, programs, regions, or communities *are there unmet needs, broken processes, or problems related to participation and accountability* that could be remedied through stronger collaborations and transparency around equitable data?

American Indian/Alaska Native/Indigenous populations:

American Indian and Alaska Native (AIAN) people are underrepresented and often invisible in data and research. AIAN health data capacity is impeded by the quality of information collected, released, and reported on AIANs in population-based surveys. AIANs are either put in a residual "other" category or, typically, depicted as single-race non-Latinx AIANs.[iv] Moreover, variations in approaches to classifying racial and ethnic populations in federal and state health statistics have substantial implications for how we measure health status, access to healthcare, healthcare quality, and health equity.[v] There is considerable variation across surveys in their measurement of the AIAN population based on survey classification, tabulation, and weighting approaches. Administrators should consider the effects of rendering politically and socially marginalized populations invisible in public use data sets when making decisions about whether to release this data. Recommendations for improving AIAN data capacity include releasing pooled multiyear public use data files that include more detailed race/ethnicity data, including information on the overall AIAN population in data files, noting when conclusions about the AIAN population are based solely on single-race non-Latinx AIANs, and streamlining access to restricted use data files that contain more detailed racial/ethnic information.

Native Hawaiian and Pacific Islander (NHPI) populations:
Health inequities in Native Hawaiian and Pacific Islander (NHPI) populations have been perpetuated and exacerbated by decades of data inequity. The COVID-19 pandemic underscored the public health neglect of small communities, such as NHPIs, in part due to a lack of publicly accessible data compounding a community that has gone unreported and underreported, not just in health, but in all social determinants of health (SDoH).

Asian Americans:
Asian Americans are the fastest-growing racial/ethnic group in the U.S., representing more than 50 ethnic groups and speaking over 100 different languages, but national health data rarely collect information needed to disaggregate AANHPI into smaller groups to capture this diversity.[vi]

"Invisible Subgroups in Aggregated data"
Although large national surveys may include racial and ethnic and sexual subpopulations and sexual orientation and gender identity classification in data collection, sample sizes are often too small to permit meaningful data analysis. Barriers to disaggregation cited included the lack of stakeholder interest, inadequate funding, lack of space on questionnaires, as well as methodologic challenges, such as the inability to obtain an adequate sample size and poor questionnaire design. Recommendations include mandating disaggregation; establishing research community resources for addressing challenges in following mandates and guidelines; publishing best practices on oversampling, identifying community needs, and collecting data when resources are limited.

Thank you for considering this comment.

Ninez Ponce, PhD, MPP – Director of the UCLA Center for Health Policy Research

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United Spinal Association
www.unitedspinal.org

October 3, 2022

NSTC Subcommittee on Equitable Data
White House Office of Science and Technology Policy
Eisenhower Executive Office Building
[redacted]
Washington, DC 20504

RE: Request for Information; Equitable Data Engagement and Accountability

Dear Sir/Madam:

United Spinal Association thanks the White House for distributing this Request for Information which builds on the White House Equity Plans and Executive Order 13958 - Advancing Racial Equity and Support for Underserved Communities Through the Federal Government. There are 61 million people with disabilities in the United States and there are so many millions of those disabled individuals who are disconnected from being able to participate in society, use transportation, join the workforce, or access programs and services online, due to accessibility challenges and are therefore not being counted.

United Spinal Association is the largest non-profit organization, founded by paralyzed veterans, dedicated to enhancing the quality of life of over 5 million wheelchair users living with paralysis, neurological conditions and mobility disabilities including veterans and providing support and information to loved ones, care providers and professionals. United Spinal has over 75 years of experience educating and empowering wheelchair users in the United States to achieve and maintain the highest levels of independence, and personal fulfillment. United Spinal has over 59,000 members, 48 chapters, close to 200 support groups and more than 100 rehabilitation facilities and hospital partners nationwide including 18 distinguished Spinal Cord Injury Model System Centers that support innovative projects and research in the field of SCI. United Spinal Association is also a VA-accredited veterans service organization (VSO) serving veterans with disabilities of all kinds.

Data collection specific to persons with disabilities is critical to the ability of the federal government, health plans, and health care providers to meet the needs of this population. There is ample evidence of health disparities in the disability population. Health and health care disparities are compounded when disability intersects with race, ethnicity, gender identity, and age. United Spinal Association endorses the Coalition to Preserve Rehabilitation's and the ITEM Coalition's comments to the Department of Health and Human Services' Request for Information on Data Collection, Section 1557 of the Patient Protection and Affordable Care Act (ACA) and supports enhanced collection of demographic data on disability in order to improve care, reduce disparities in health status and access to health care services, allow providers to better understand and accommodate the needs of the disability population, and better equip the federal government to monitor compliance with civil rights protections. The electronic health record (EHR) is an essential tool in linking demographic and clinical data within and across health care systems and public health databases. Data collected within the EHR is crucial to understanding and addressing inequities that negatively impact health and healthcare outcomes of marginalized communities, including people with disabilities.

Medical Diagnostic Equipment Standards: United Spinal Association recommends that HHS reference and incorporate the 2017 Standards for Accessible Medical Diagnostic Equipment ("MDE Standards"), 36 C.F.R. Part 1195, into § 92.203. The MDE Standards, which implement Section 510 of the Rehabilitation Act, set forth minimal technical criteria for the accessibility of MDE in facilities where health programs or activities are conducted.[1] Incorporating these standards into Section 1557 is a necessary step towards improving access to health care services for individuals with disabilities.

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[1] 29 U.S.C. § 794f; 36 C.F.R. pt. 1195.

United Spinal Association recommends that the White House facilitate work groups with representatives from the cross-disability space and coordinate the data collection and relationships across the federal government via the White House Domestic Policy Council – the Centers for Disease Control and Prevention, the Department of Health and Human Services and its Administration for Community Living's National Institute of Independent Living and Rehabilitation Research, including the National Institute of Minority Health and Health Disparities and the National Institute of Neurological Diseases, the Department of Transportation, the Federal Communications Commission, United States Census Bureau to name a few.

Thank you considering these comments. If you have any questions, I can be reached at [redacted] or at [redacted]

Sincerely,

[redacted]

Alexandra Bennewith, MPA
Vice President, Government Relations

Critical Public Health

ISSN: 0958-1596 (Print) 1469-3682 (Online) Journal homepage: https://www.tandfonline.com/loi/ccph20

Critical ‘street race’ praxis: advancing the measurement of racial discrimination among diverse Latinx communities in the U.S

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To cite this article: Edward D. Vargas, Melina Juarez, Lisa Cacari Stone & Nancy Lopez (2019): Critical ‘street race’ praxis: advancing the measurement of racial discrimination among diverse Latinx communities in the U.S, Critical Public Health, DOI: 10.1080/09581596.2019.1695040

To link to this article: https://doi.org/10.1080/09581596.2019.1695040

CRITICAL PUBLIC HEALTH
https://doi.org/10.1080/09581596.2019.1695040

RESEARCH PAPER

Critical 'street race' praxis: advancing the measurement of racial discrimination among diverse Latinx communities in the U.S

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ABSTRACT
Research demonstrates a causal link between increased exposure to racial discrimination and adverse health outcomes among diverse racial and ethnic populations in the U.S. However, most research on Latinx communities overlooks how discrimination varies according to individual accounts of how their race is perceived by others. To address this gap, our study draws from critical race theory to analyze a new multi-dimensional measure of racial status – 'street race' and its association with discrimination experiences. We analyzed data from the 2015 Latino National Health and Immigration Survey (n = 1,493). Our main dependent variables are experiences of everyday discrimination and our explanatory variables are five mutually exclusive categories of 'street race.' We estimated a series of logistic regression models, which disaggregated the 'street race' measure, to better understand everyday discrimination experiences across street race categories. We found that Latinxs who are racialized on the street as Black or as Arab/Middle-Eastern relative to White were more likely to have experienced discrimination because of their race/ethnicity. They were also more likely to have experienced discrimination in the employment domain, by police, in the housing market, as consumers in shops or restaurants, and while receiving medical care. Employing a critical race approach, our study expands the conceptual measurement of discrimination to incorporate a more nuanced approach that captures interpersonal racism based on 'street race.' Further research will benefit from employing our 'Critical Street-Race' theory for developing equity-focused multi-level interventions at the interpersonal, community, and policy levels.

ARTICLE HISTORY
Received 27 November 2018
Accepted 9 November 2019

KEYWORDS
Street race; critical race theory; Latino/a/x; racism; discrimination; population health

Introduction

Research demonstrates links between health, social outcomes, and various experiences with discrimination among diverse populations (Harrell, 2000; Leonardelli & Tormala, 2003; Viruell-Fuentes et al., 2012; Williams et al., 1997). While the connections between discrimination and adverse health outcomes are well documented, less is known about the heterogeneous experiences with racial discrimination among diverse Latinx[1] communities in the United States (US) (Juárez, 2018). To address this gap, we use 'street race' – a new multidimensional measure of racial status, to examine if perceptions of discrimination vary among Latinxs according to how they perceive others ascribe their race.

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Supplemental data for this article can be accessed here.

We build on our previous work, which highlights the importance of race measures in survey research (López, 2014). Our previous study on street race examined the relationship between this measure and other multidimensional measures of race (e.g. self-reported, ascribed race) in predicting physical and mental health outcomes for diverse Latinx men and women (López et al., 2017). We found that street race was correlated with negative mental health outcomes among Latinxs, specifically for men whose street race is Latino or Arab. Latinas whose street race is Mexican had higher odds of reporting poor physical health status.

Our research approach for this study is anchored in the key tenets of critical race theory (CRT) and Public Health Critical Race (PHCR) praxis (Ford & Airhihenbuwa, 2010). A fundamental pillar of critical race is the acknowledgement of the systemic white supremacy that operates at every level of society. Racism, the primary manifestation of white supremacy, functions across domains of power to affect every aspect of daily lived experiences and across societal domains (i.e. work, housing, migration). Race operates as a visual social marker – a heuristic that allows the placement of individuals within complex, global hierarchies of power shaped in part by white supremacist ideas of Black inferiority (Omi & Winant, 2015). White supremacy, and its racialization of individuals and entire communities, is often the basis of privilege for those at the top of the racial pyramid, and of disadvantage for visible minorities that fall to the bottom of the color line. Relevant to this particular study of street race is internalized racism, where white supremacy is internalized at the individual level and the prescriptions of this oppressive ideology are used to measure the person's own value and the value of those around them (Jones, 2000; Monk, 2015).

CRT identifies color blindness as a key mechanism for the maintenance of white privilege and white supremacy at the individual, institutional, and structural levels in society (Bell, 2004; Bonilla-Silva, 2018; Crenshaw, 1995). We argue that denying the existence of a color line and internalized racism among Latinx communities can result in color-blind data, which inhibits our ability to advance equity-based policy for Latinxs and maintains structures of white privilege (López 2013a, 2013b). Accordingly, we extend the color-conscious principle to our research analysis.

PHCR praxis acknowledges the systemic, ingrained, endemic and ordinariness of racism that operates at every level of society – from everyday interactions, to institutional arrangements, laws and structural realities such as settler colonialism, the dynamics of the racialized prison industrial complex, and militarization of the U.S.-Mexico border region. Racial realism grapples with the centrality of history and context and the permanence, rearticulations, but yet enduring nature of racism to sustain structural inequities. Using a critical race lens, our analysis draws from three specific areas within the extant literature: 1) identification of contributors to discrimination within the relatively lesser studied Latinx population; 2) the role of street race (how strangers view one on the street) on discrimination; and 3) how street race maps onto various types of social discrimination experienced in everyday life. The purpose of our study is to advance the measurement of discrimination by testing a new measure of how being viewed on the street drives discrimination experiences across the heterogeneous and growing Latinx population. Given that discrimination is a major determinant of health, our analysis fills a sorely needed gap in critical race public health theory in the social and health sciences (Ford & Airhihenbuwa, 2010; Williams David & Mohammed, 2013).

Street race: contextualizing socially assigned race

Once widely debated, most scholars now agree that the notion of race is a socio-political construct with real-world implications. Thus, social science research is now providing various approaches to measure race, such as self-identification, socially assigned race, ascribed race, and phenotype (i.e. skin color, hair texture). Research exploring disparities across racial/ethnic groups has typically relied on asking respondents to self-identify their race/ethnicity in surveys (Campbell & Troyer, 2011; López et al., 2017; Roth, 2010; Saperstein, 2006). While this approach has considerable value, it is limited in that some contend that an individual will decide about another's race before asking them how they self-identify (Cheng & Powell, 2011; Garcia et al., 2015; Irizarry, 2015; Pereira & Telles, 2014; Song &

Aspinall, 2012; Stepanikova, 2010; Vargas et al., 2015; Vargas & Stainback, 2016). This accounts for a majority of biases and the racial process of 'othering' – whereby dominant public views are anchored in socially favorable values towards 'whiteness' and discriminatory attitudes towards others who are perceived as 'non-white.'

Socially assigned or ascribed race (i.e. the notion that others may define a person's race regardless of that person's own identity) has proven to be a very important measure in predicting the level of discrimination an individual will encounter as well as their health outcomes. In their groundbreaking work, Jones et al. (2008) demonstrated that if respondents self-identified as Hispanic, Native American, or mixed-race, but were socially assigned as White, they were more likely to report very good and excellent health compared to respondents who self-identified as the same race, but who were ascribed as non-White (i.e. White advantage of health).

In the most recent work on ascribed race among Latinos, Vargas, Winston, Garcia, and Gabriel (2016) attempted to unpack the response category of ascribed as Mexican and show that Latinxs who are ascribed as Mexican reported the highest levels of discrimination. Moreover, they showed that once respondents who are ascribed as Mexican are separated into those who are of Mexican origin, and those who are misclassified as Mexican (i.e. ascribed as Mexican but not of Mexican origin), those who are misclassified report the highest level of perceived discrimination. This study was also the first to use ascribed race and national origin to understand discrimination experiences among Latinx populations in the US.

To better contextualize socially assigned race, we developed a new measure called 'street race' that asks respondents how they are racialized on the street: '*If you were walking down the street, what race do you think other Americans who do not know you personally would assume you were based on what you look like?* (López, 2014; López et al., 2017).' We argue that this query grounds respondents to their respective community and day-to-day routines, thus allowing us to contextualize the lived experiences of minority populations at the micro-level. This is a particularly important facet of our concept, as previous research finds that experiencing daily 'othering' raises awareness about one's own positionality and influences how one describes their stigmatized status (Viruell-Fuentes, 2007).

Socially assigned race is meaningful for Latinxs as their phenotype varies from light skin-blue eyes to dark skin afro-textured hair and everything in between. Thus, we hypothesize that Latinx respondents who are viewed by others on the street as being white are less likely to report experiences with discrimination than all other street race categories (Haslip-Viera, 2018). We test the measure of street race within the Latinx populations by asking: What are the consequences associated with being street race white, as opposed to street race Latinx, Arab, Black, or Mexican?

Data and methods

We utilize the 2015 Latino National Health and Immigration Survey (LNHIS) funded by the Robert Wood Johnson Foundation Center for Health Policy at the University of New Mexico. The unique survey design focused exclusively on Latinx populations, thus allowing us to examine the relationship between street race and discrimination experiences in this population. A total of 989 Latinos were interviewed over the phone and an additional 504 Latinos were sampled through the internet to create a dataset of 1,493 respondents. Of these respondents, 963 of these Latinos were registered voters and 530 were non-registered Latinos. The non-voter sample was added for the specific purpose of ensuring that our ability to explore the relationship between street race and discrimination and included non-citizen Latinos, who are excluded from registered voter samples. All phone calls were administered by Pacific Market Research in Renton, Washington. The survey has an overall margin of error of ±3.1%. Latino Decisions selected the 44 states and Puerto Rico with the highest number of Latino residents, states that collectively account for 91% percent of the overall Latino adult population. The voter sample was drawn of registered voters using the official statewide databases of registered voters, maintained by election officials in each of the 44 states. A separate list of Hispanic households was used to identify respondents for the non-voter sample, which was designed to be proportionate to the overall population in those states. Probability sampling methods were employed in both samples based on the respective lists used to identify the universe of potential participants. Respondents were interviewed by telephone and could choose to be interviewed in either English or Spanish. All interviewers were fully bilingual. A mix of cell phone (35%) only and landline (65%) households was included in the sample, and both samples are weighted to match the 2013 Current Population Survey universe estimate of Latinos and Latino voters, respectively, for these 44 states with respect to age, place of birth, gender and state. The survey was approximately 28 minutes long and was fielded from 29 January 2011 to 12 March 2015.

Measures

The primary outcome variables are everyday experiences with discrimination, based on responses to LNHIS survey questions. Respondents were asked five yes/no questions to contextualize their discrimination experience. These were: 1) '*Have you ever … Been unfairly fired or denied a job or promotion?; 2) Been treated unfairly by the police or law enforcement; 3) Been unable to get a home or apartment because someone unfairly refused to sell or rent to you or your family? 4) Been treated unfairly at restaurants or stores, such as being ignored, treated badly, or followed?; and 5) Been treated unfairly at a doctor office, clinic, or hospital*'?. We also estimated a model that includes the broad question, '*Have you ever been treated unfairly because of your race, ethnicity, or national origin here in the United States*?' This measure asks specifically about discrimination due to racial/ethnic discrimination, making it ideal for our analysis. To provide context for this latter measure, a 2007 study by the Pew Hispanic Center showed that among Latinx adults, 31% responded that they or a family member had experienced discrimination in 2002, 38% responded that they experienced discrimination in 2006, and 41% responded that they or a family member had experienced discrimination in 2007 (Pew Research Center, 2017).

Our main explanatory variables are five mutually exclusive categories of street race. Our specific question on 'street race' was: '*If you were walking down the street, what race do you think other Americans who do not know you personally would assume you were based on what you look like?*' The street race categories of Asian American (n = 29), Native American/American Indian (n = 27), some other race (n = 60), and don't know (n = 63) or refused (n = 10) were dropped due to small sample sizes. The five street race categories are White, Latino, Black, Arab, and Mexican.

We also controlled for measures that previous studies have correlated with discrimination experiences, including skin color (Gee et al., 2006; Gee Gilbert et al., 2008; Krieger et al., 2005; Monk, 2015). For socio-demographic variables, we included standard measures of income, educational attainment, age, marital status, gender, and insurance coverage. Income was represented by a categorical variable (less than $19,999; $20,000-$39,999; $40,000-$59,999; $60,000-$79,999; $80,000-$99,999; $100,000-$149,999; $150,000 and above), with less than $19,999 serving as the reference category. We also included a variable of 'unknown' income as a means of retaining respondents who did not answer that question. Finally, we controlled for U.S. citizenship status, the language of the interview, and whether respondents are of Mexican-origin, as this population has been found to have unique health outcomes relative to Latinxs from other backgrounds (Vargas et al., 2016). For our citizenship question, we asked foreign-born respondents, '*Are you currently a U.S. citizen, a Legal Permanent Resident, or a non-citizen?*' The options were, '*Currently a U.S. citizen, Legal Permanent Resident, Eligible for deferred action for childhood arrivals or have DACA status, Non-Citizen but qualify for the President's recent Executive Action, Non-Citizen but DO NOT qualify for the President's recent Executive Action, Don't know, Refused.*' We also ran separate models that additionally (?) included generational status and length of time in the U.S. The LNHIS asks respondents about both their country of birth as well as their parents' country of origin. Respondents who reported being foreign born were coded as first generation; those who reported being U.S. born with either parent being foreign born were coded as second generation; and those who reported being born in the U.S. themselves, and both parents being born in the U.S., were coded as third generation.

Respondents of Puerto Rican decent were coded as foreign born if they reported being born in Puerto Rico. Because citizenship status and generational status are highly correlated, we ran these models separately and our tables only report results of models including citizenship status (these results are provided online in the supplemental file). For length of time in the U.S., we compared U.S.-born respondents with respondents who had been in the U.S. for 1) ten years or less, 2) 11 to 20 years, and 3) more than 20 years.

Statistical analysis

We used logistic regression to examine associations between street race and discrimination experiences among a nationally representative sample of Latinx adults. Six models were run, corresponding to the six available measures of discrimination experiences. In the first model, we examined the broad measure of discrimination experiences based on race, ethnicity, or national origin. We then ran five additional models, one for each of the specific discrimination experiences (i.e. employment, by police, housing, while shopping, job market, and receiving health care) to better understand the association between street race and experiences with discrimination. All models controlled for covariates noted above and used street race white as the reference category. We applied survey weights to all analyses to account for the complex survey design.

Results

Summary statistics for all variables used in this analysis are listed in Table 1.

After dropping the missing data, we had a total sample of 1,194 respondents. The majority of missing data (n = 189) was on the street race variable. In addition to missing data, respondents who answered '*Asian, Native American/American Indian, some other race, Don't Know, or Refuse*,' options were dropped from our analysis due to small cell sizes.

Overall, 37% of respondents reported discrimination based on race, ethnicity, or national origin. In terms of everyday discrimination, 17% reported being fired or denied a job or promotion, 18% reported being treated unfairly by police, 8% reported being refused to sell or rent their home or apartment, 26% reported discrimination or unfair treatment while shopping and 11% reported discrimination while seeking medical care. In terms of reported street race, 46% responded Latino/a, 24% responded Mexican, 22% responded white, and 4% each responded Arab and Black, respectively.

The mean age in our sample was 46 years, and the majority reported a high school education. Just over half of our sample completed the survey in English, and just under half was female. In regards to citizenship, 77% of our sample reported being a U.S. citizen and the remaining 23% reported non-citizenship status (9% undocumented, 14% legal permanent residents). In terms of generational status, the percentage of first-, second-, and third-generation was 51%, 29%, and 20%, respectively. The average length of time in the U.S. among foreign-born respondents was 28 years, with 11% being in the U.S. 10 years or less, 26% 11–20 years, and 63% for 21 years and above. Overall, 55% of respondents were of Mexican origin. The median skin color in our sample was 3, correspondent to medium skin color, on a 1–5 point scale (very light, light, medium, dark and very dark).

The results of our logistic regression models are depicted in Table 2. For parsimony, we only show the odds ratios from our analysis.

The first column shows the results of the model assessing the association between street race and overall discrimination experiences based on race, ethnicity, or national origin. In terms of covariates, results show that higher educated Latinxs experience more discrimination relative to lower educated Latinxs. Respondents who took the survey in English reported more discrimination relative to Spanish-speaking respondents. Moreover, U.S. citizens reported more discrimination relative to non-citizens, and relative to respondents who make less than $19,999, respondents who made between $20,000 and $59,999 are statistically less likely to report discrimination.

Table 1. Summary statistics using 2015 Latino decisions national Latino health and immigration survey (n = 1,493).

Variable	Mean or %	Median	Std. Dev.	Min	Max
Discrimination	37%	–	–	0	1
Employment	17%	–	–	0	1
Police	18%	–	–	0	1
Housing	8%	–	–	0	1
Consumer	26%	–	–	0	1
Medical Care	11%	–	–	0	1
Street Race Categories					
White	22%	–	–	0	1
Latino	46%	–	–	0	1
Black	4%	–	–	0	1
Arab	4%	–	–	0	1
Mexican	24%	–	–	0	1
Female	62%	–	–	0	1
Educational Status[a]	5.52	6	2.36	1	6
Age in Years	45.87	45	17.00	18	98
English Language[b]	58%	–	–	0	1
US Citizen	77%	–	–	0	1
Generational Status[c]	1.69	1	0.79	1	3
Length in US in Years[d]	2.26	1	1.36	1	4
Married[e]	53%	–	–	0	1
Income Missing	21%	–	–	0	1
Less than 20K	20%	–	–	0	1
Income: 20K-39K	21%	–	–	0	1
Income: 40k-60k	13%	–	–	0	1
Income: 60k –80k	9%	–	–	0	1
Income: 80k-100k	6%	–	–	0	1
Income: 100k-150k	7%	–	–	0	1
Income: 150k+	4%	–	–	0	1
Mexican Origin	55%	–	–	0	1
Skin Color[f]	2.54	3	1.01	1	5

[a] Education (1 = Grade 1–8, 2 = Some HS, 3 = HS, 4 = Some College, 5 = College Grad, 6 = Post-Grad).
[b] Language of Interview (0 = English, 1 = Spanish).
[c] Generation Status (1 = First, 2 = Second, 3 = Third).
[d] Length in US in Years (1 = 0, 2 = Less 10 Years, 3 = 11–20 Years, 4 = More than 21Years).
[e] Marital Status (0 = Single, Divorced, Widowed, Other, 1 = Married).
[f] Skin Color (1 = Very Light, 2 = Light, 3 = Medium, 4 = Dark, 5 = Very Dark).

The next five columns (columns 2–6) in Table 2 show results of the models assessing associations between street race and specific circumstances of everyday discrimination. For discrimination in the employment sector, street race Black respondents were 2.5 times more likely to report discrimination relative to street race White respondents, holding all else constant, while street race Latinx respondents were less likely to report employment discrimination relative to street race White Latinxs. For discrimination by police, street race Black and street race Arab/Middle Eastern respondents were each more than 2 times more likely to report unfair treatment relative to street race White respondents, holding all else constant. For housing discrimination, street race Arab/Middle Eastern respondents were over three times more likely to report being treated unfairly relative to street race White respondents, holding all else constant. For consumer discrimination or being treated unfairly while shopping or at a restaurant, street race Blacks, street race Arab/Middle Eastern, and street race Mexicans were each more likely to report discrimination relative to street race White respondents, holding all else constant. Lastly, for discrimination while receiving medical care, street race White respondents were more likely to report unfair treatment relative to street race Latinx respondents. In our models that controlled for generational status and time in the U.S. (not shown), these associations between street race and discrimination experiences did not change; suggesting that the street race of Latinx populations matters for discrimination experiences regardless of generational status and time living in the U.S.

Table 2. Logistic coefficients for regressions of street race on discrimination experiences using the 2015 national Latino health and immigration survey.

	Racial/Ethnic	Employment	Police	Housing	Consumer	Medical
VARIABLES	OR	OR	OR	OR	OR	OR
Reference Category: Street Race White						
Latino	0.889	0.610**	0.993	0.705	1.384	0.574**
Black	2.959***	2.548**	2.338**	0.619	3.191***	1.555
Arab	1.715*	1.571	2.442***	3.341***	3.855***	0.518
Mexican	1.162	0.686	1.085	1.061	2.423***	0.619
Female	0.786*	0.746*	0.431***	0.864	1.268*	1.275
Education^{a}	1.135***	1.159***	0.946	0.900	1.008	0.953
Age	0.994	1.020***	0.987**	0.998	0.985***	0.983**
Spanish^{b}	2.003***	0.887	1.941***	2.131**	2.219***	0.689
US Citizen	1.576**	1.284	2.459***	0.997	1.930***	1.446
Married^{c}	1.036	0.666**	1.044	0.902	1.094	1.111
Reference Income: Less than 20						
Income Missing	0.810	1.149	0.766	0.181***	1.283	0.716
Income: 20K–39K	0.601**	1.153	1.101	0.413***	1.336	0.519**
Income: 40k–60k	0.579**	1.095	0.754	0.530*	1.229	0.883
Income: 60k–80k	0.721	0.454*	0.637	0.280**	1.965**	0.876
Income: 80k–100k	0.885	0.825	0.563	0.430*	1.693*	0.793
Income: 100k–150k	0.759	0.841	0.560	0.304**	2.244**	0.573
Income: 150k+	0.509*	0.507	0.286**	0.715	2.306**	0.872
Mexican Origin	1.215	0.981	1.176	0.474***	1.360**	0.979
Skin Color^{d}	1.038	1.148	0.994	0.898	1.091	1.265**
——————						
Constant	0.189***	0.035***	0.264***	0.449	0.051***	0.230**
Observations	1,189	1,187	1,196	1,194	1,196	1,194
Akaike information criterion (AIC)	1.300	0.828	0.983	0.544	1.112	0.690
Bayesian information criterion (BIC)	−6772.185	−7318.454	−7198.058	−7708.279	−7043.612	−7534.391

*** $p < 0.01$, ** $p < 0.05$, * $p < 0.1$, Using Complex Survey Weights.

[a] Education (1 = Grade 1–8, 2 = Some HS, 3 = HS, 4 = Some College, 5 = College Grad, 6 = Post-Grad).

[b] Language of Interview (0 = English, 1 = Spanish).

[c] Marital Status (0 = Single, Divorced, Widowed, Other, 1 = Married).

[d] Skin Color (1 = Very Light, 2 = Light, 3 = Medium, 4 = Dark, 5 = Very Dark).

Discussion

Overall, our study augments the field of Critical Race Public Health Praxis by using a novel measure of 'street race' and demonstrating a link between discrimination and social subordination. During the 1980s and 1990s, Latinx legal scholars challenged the hegemonic assumptions about race neutrality and meritocracy, arguing that laws and lawmaking should be understood and interpreted within their historical and cultural context. This scholarship was coined as LatCrit or Latino Critical Theory (Bernal Delgado 2002). Immigration scholars have embraced a CRT approach in investigating relevant issues, such as racial profiling, anti-immigration sentiment, and the increased militarization of the US–Mexico border, among other historical systemic inequities (Romero, 2008).

Our findings regarding the increased likelihood of experiencing discrimination by those whose street race is Black or Arab/Middle Eastern, relative to those whose street race is White, are parallel to the current sociopolitical climate against these groups (Golash-Boza & Hondagneu-Sotelo, 2013). According to official statistics from the Federal Bureau of Investigations (FBI), hate crimes against Muslims rose by 67% from 2014 to 2015 (Mapping Police Violence Database, 2017). Killings of Blacks by police, which have risen substantially in the past decade (852 murdered in 2018), have sparked one of the most intersectional social movements in recent history – #BlackLivesMatter.

Our findings also suggest Latinxs' experiences are much more complex than traditional homogeneous conceptions imply. Research on Latinx communities should no longer assume that all individuals from Latinx communities experience the same racial status. It may seem counterintuitive that street race Latinxs (read: visible 'brown' minority) reported experiencing less discrimination in employment and medical care settings, compared to street race White Latinxs. Our findings highlight the heterogeneity within Latinxs in terms of everyday discrimination. Yet, more research is needed to unpack how these and other dimensions of intersectional positionalities, such as sex and gender, relate to social and health outcomes across Latinxs.

Expanding research methods away from a 'one size fits all' approach and elucidating nuanced color-conscious experiences helps to give voice to, and empower, marginalized communities, many of which are rendered invisible within the intersectionality of oppression and privilege. Our continued use of the terms 'people of color' or 'racial and ethnic minorities', without acknowledging that there is a color line within these communities, is antithetical to antiracist praxis.

One limitation of this study is that we did not have sufficient AfroLatinx respondents to explore how colorism may operate in unique ways among light-skinned AfroLatinxs versus dark-skinned (Monk, 2015). Our study is also limited by our inability to understand the role of co-ethnic discrimination; in other words, are respondents encountering this discrimination from whites, other minorities, or their co-ethnics? Future research should examine how co-ethnic discrimination maybe having negative impacts on health and overall wellbeing.

Conclusion

Our study adds to a growing body of scholarship that offers multi-dimensional measures of race and racialization to explore racial status as a marker of exposure to racial discrimination. It also underscores the reality that not all Latinxs are racialized the same way and therefore may not experience the same levels of racial discrimination, based on what they look like in the public sphere. Given the current political and social narrative regarding Latinxs, street race can be an important measure for mapping distinct experiences along the color line continuum for diverse Latinx groups. We hope that as a new measure of racialization for better understanding racism, 'street race' fosters additional research on the multi-dimensional nature of race and the ongoing dynamics and rearticulations of white privilege, honorary white status, and racial inequities across heterogeneous Latinx communities (Bonilla-Silva & Glover, 2006; Haslip-Viera, 2018). Our findings highlight experiences of unique social locations within the diverse Latinx community, which may remain invisible when the race of Latinxs is reported in the aggregate.

Achieving social justice and ameliorating inequities calls for purposeful action that challenges color-blind logics, values everyone equally, and attempts to address avoidable inequalities, historical and contemporary injustices (Paula & Gruskin, 2003). Our study suggests that an expanded 'critical street-race praxis' lens is a promising approach for advancing racial equity in health and social outcomes because it calls for focused action not only at the interpersonal level but also at the institutional, and structural, and policy levels.

Note

1. Other than direct citations, this study utilizes the term 'Latinx', which encompasses multiple aspects of identity that are subverted within gendered terms such as 'Latino' and 'Latina.'

Acknowledgements

The Latino National Health and Immigration Survey is supported by a grant from the Robert Wood Johnson Foundation to the Center for Health Policy at the University of New Mexico. The project described is supported, in part, by an NICHD training grant to the University of Wisconsin–Madison (grant number T32HD049302). The content is solely the responsibility of the authors and does not necessarily represent the official views of the Eunice Kennedy Shriver National Institute of Child Health and Human Development, the National Institutes of Health, or the Robert Wood Johnson Foundation.

Disclosure statement

No potential conflict of interest was reported by the authors.

Funding

This work was supported by the Eunice Kennedy Shriver National Institute of Child Health and Human Development [T32HD049302]; Robert Wood Johnson Foundation Center for Health Policy.

Data deposition

The data that support the findings of this study are available from the corresponding author, upon request.

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October 3, 2022
Submitted electronically t [redacted]

Attn: NSTC Subcommittee on Equitable Data
Office of Science Technology Policy
Eisenhower Executive Office Building
[redacted] NW
Washington, DC 20504

We appreciate the opportunity to respond to the White House Office of Science and Technology Policy request for input about advancing equity through community data partnerships. We have a bold vision for a modern social safety net that is easy to navigate, puts the needs of the individual who is seeking help first, and makes it easier for healthcare providers and community-based organizations (CBOs) to do their jobs. We appreciate the time and attention that your office is giving to the role technology partners can play in transforming community health.

Founded in 2010, findhelp (formerly Aunt Bertha), a Public Benefit Corporation, runs the largest social care network in the United States and has served more than 17 million Americans. Our mission is to connect all people in need with the programs that serve them with dignity and ease. As part of fulfilling this mission, we will always maintain findhelp.org, a free and anonymous search tool for self-navigation to free and reduced cost programs in every U.S. Zip Code. Our network is used by nearly 500 customers, including 250 health systems, health plans, community health centers, and health departments in the U.S. to manage social care referrals, as well as tens of thousands of CBOs. With a network that includes at least 1,500 program locations in every U.S. county, findhelp's interoperable social care technology works with electronic health records (EHRs) and other Systems of Record (SoRs) to help clinicians and navigators seamlessly connect individuals' with free and reduced cost social care services.

Below, we provide feedback on select topics identified in the RFI.

1. What are *examples of successful collaborations* involving equitable data between the Federal government and (a) Tribal, territorial, local, and State governments, or (b) local communities?

At findhelp we are proud to have committed partners across the United States working to advance health equity in their communities. Below are two examples of successful initiatives that positively impact community health through locally driven cross-sector collaboratives composed of findhelp, regional healthcare, government, and social services, CBOs, and others. With our partners, we have worked to build trust in the communities we serve, and assisted in the development of robust governance structures that protect consumer-directed privacy and permission-based access to ensure the privacy of individuals' most sensitive personal information. We believe that these local initiatives can have a national impact through providing examples of successful collaborations producing better outcomes and data transparency.

Connect Inland Empire (Connect IE) is a multi-sector community resource platform that enables the four million residents of the Inland Empire region of California to easily access free and reduced cost social services. Inland Empire Health Plan (IEHP), a local health plan that serves over 1.5 million Medi-Cal (Medicaid) and Cal MediConnect (Medicaid/Medicare dual eligible) members of Southern California, has leveraged findhelp since 2018 to support members navigation to social care services aimed at addressing upstream factors that impact health and well-being.

In 2020, the IE region launched *Connect IE* to better meet the needs of their community. Through a partnership that includes IEHP, SoCal United Way/211, the Desert Healthcare District and Foundation, the Central Inland Health Information Exchange Organization (CIHIO), and findhelp, Connect IE enables self-navigation to social services and navigator-supported closed-loop referrals. Connect IE is open to all community members, regardless of location or health plan affiliation. To specifically address food needs, IEHP sponsors a food box program for local clinics. Any patient that presents with a food need can immediately be connected with IEHP's food box program and receive food during that same visit. In 2021, over 155,000 searches for social services were conducted through Connect IE, and the platform enabled tens of thousands of closed-loop referrals.

The Central Texas Model Community in the greater Austin, Texas area is a multi-sector collaboration that strengthens the health of a large and diverse community. Funded by the Michael and Susan Dell Foundation, the partnership between United Way for Greater Austin, Austin Independent School District, FQHCs, UT Dell Medical School, community organizations, and findhelp, Central Texas Model Community is working to close social services gaps through cross-sector collaboration and develop a comprehensive, longitudinal understanding of individuals' needs. While these partners utilize their findhelp platforms to place closed-loop referrals for patients and clients, community organizations and anyone searching for help can use United Way's findhelp-powered ConnectATX platform to find housing, food, utilities support, and other social services can easily access over 3,800 programs and resources privately and securely. United Way for Greater Austin also offers a specialized Navigation Team that assists in routing the highest-risk individuals to social care programs through SDOH screening.

In addition, Dell Medical School works with healthcare providers, mental health providers, and findhelp to gather anonymized health and social care data to study how social care interventions are associated with improved health outcomes. This research helps inform partners and funders about the efficacy of interventions, allowing for more strategic infrastructure, funding, and partnership decisions. Findhelp and the funder also work with United Way Austin to offer a specialized Navigation Group that assists in routing the highest-risk individuals to social care programs.

2. Among examples of existing Federal collaborations with (a) Tribal, territorial, local, and State governments or (b) local communities involving equitable data, *what lessons or best practices have been learned from such collaborations* ?

Our foundational principles of maintaining privacy through per-referral consent and ensuring interoperability have led to long-lasting, successful partnerships and multi-sector collaborations. We have found that these themes resonate across the country, regardless of geography or population.

Privacy at the Forefront

Incorporating referrals to social care into our healthcare infrastructure relies on the collection, storing, and sharing of some of the most private and personal information. As organizations and municipalities invest in technology infrastructure for facilitating referrals beyond traditional healthcare entities, it is imperative that the protection of privacy is at the center of this conversation, with individuals maintaining control over their personal information.

In some cases, states are defaulting to the same all-in consent model used within the healthcare system, where sharing health information is needed to ensure continuity of care. In the healthcare context, participating entities are governed by HIPAA standards. But within these growing social care referral networks, many participating entities are not governed by HIPAA. Using a one-time all-in consent in this context, to allow a broad network of service providers to access information in a centralized database, compromises the privacy of an individual's most personal information.

We believe that best practices build upon a per-referral consent model, where individuals opt-in to share their information for each referral and network members' access to referral history is permission based. While HIPAA dictates how health information is shared between HIPAA-covered entities, in the social care context, data sharing must be driven by the individual, and only can be shared with appropriate consent and permissions.

Interoperability

A truly interoperable approach is founded on agreed upon data standards and incentivizes vendors to support consistent data reporting. Approaches like the Accountable Health Communities (AHC) Grant Model, which requires documentation, reporting, and standards consistency, provides a good model in which any vendor can be certified to support a state's reporting needs. As part of efforts to build CBO capacity, it is critical that we continue to focus efforts in building a robust data sharing infrastructure and incentivize vendors to develop integrations that allow existing systems to communicate with each other.

In recent years, a few states have adopted models that mandate health care plans and providers exclusively use a single vendor and require CBOs to sign exclusivity contracts as a condition of funding. This type of single vendor approach is a shortcut around building interoperable technology solutions, and has not been successful in practice.

We believe CMS can play a leadership role by providing local organizations and state Medicaid agencies with guidance on interoperability standards, as has been done with US Core Data for Interoperability (USCDI) through the Office of the National Coordinator for Health IT (ONC). For example, we are encouraged by the roll-out of USCDI+, an federal interagency interoperability initiative seeking to establish interoperable datasets that extend beyond the USCDI. This work will shape a more sustainable and equity-driven path moving forward through standardizing data across federal agencies.

Following federal interoperability guidance, the private sector is beginning to work together to ensure equitable data exchange. In 2022, findhelp, along with five leading social care technology platforms signed the Michigan Health Information Network (MiHIN) Interoperable Referrals Pledge. Through this pledge, we have committed to collaboratively reduce the traditionally siloed data ecosystem by promoting data transparency, adoption of national interoperability standards, and supporting existing health information networks. We are encouraged by this unique opportunity and hope to replicate it across the country.

5. **What resources, programs, training, or tools *can increase opportunities for community-based organizations to use equitable data to hold government accountable to the American public* ?**

While it may be simple to group community-based organizations (CBOs) together when discussing their role in coordinated community health efforts, we must understand that each organization serves a unique purpose in their communities, and each has their own set of strengths and challenges. CBO challenges can include access to technology tools through funding limitations, or implementation challenges once technology is acquired. In addition, many CBOs are beholden to contracts that stipulate how funding can and cannot be used, and FTE requirements.

In order to help alleviate burden on CBOs, we believe the best approach is maintaining open networks that allow self-navigation to services. An open network ensures that members have access to a broad array of services, including services that are trusted in their community and are culturally competent. An open network can also be focused and include preferred providers, meaning that health plans and providers have targeted, and sometimes contractual, relationships with specific CBOs to target specific member needs. Health equity advancement requires an active open and focused network of service providers, to meet the needs of all communities. In addition, members should be empowered and afforded the opportunity to seek services through self-navigation, without being required to have someone else do it for them. This is especially important in rural areas, where navigators and services aren't as readily available.

State-led approaches that attempt to mandate use of a single technology platform have struggled with adoption for a number of reasons, including inadequate investment in interoperability and integrations with existing systems of record, and insufficient incentive for CBOs to participate. By intentionally narrowing networks that CBOs can engage in, the entire community is disadvantaged by limiting the number of services people can access. CMS can provide policy direction that promotes a health-equity driven model and prohibits exclusive networks that limit individuals' access to services.

A paper, co-authored by findhelp and Dr. Scott Allard of University of Washington, entitled 'Volatility in Local Nonprofit Safety Nets: Expansion and Contraction of Human Service Organizations in the Inland Empire during COVID-19' examines how human service provision varied during the first two years of the COVID-19 pandemic. This paper uses unique granular human service data gathered from findhelp's database of over 500,000 program service locations between 2019 to 2021 in Riverside and San Bernardino counties of California.

Because programs are heavily reliant on public funding, many health and human service programs see funding cuts during economic downturns because of falling tax revenues and public expenditures. Thus, there is evidence that during economic downturns, funding and availability of human services is typically reduced. (Allard 2009; Allard and Pelletier 2022). However, the paper found a noticeable increase in human service programs during the first few months of the pandemic in the Inland Empire, providing evidence that funding and availability for safety net offerings may have grown during the pandemic to support community- based organizations. Thus, the initial experience of COVID-19 offers insight into how federal, state, and local actors might come together to support human service providers during times of crisis or economic recession in the future.

7. In which agencies, programs, regions, or communities *are there unmet needs, broken processes, or problems related to participation and accountability* that could be remedied through stronger collaborations and transparency around equitable data?

Community Information Exchanges, or "CIEs" are developing across the country to alleviate burden on providers and communities, improve coordination across sectors, and promote community wellbeing. These community-wide information sharing networks pick up where traditional healthcare networks leave off, and allow for healthcare, government agencies, social services, and CBOs within a region to both communicate and collaborate with each other, often enabling bidirectional exchange of SDoH assessments and referrals through integrated technology, shared language, and resource databases.

We are encouraged by the development of CIE networks, as incorporation and participation of non-traditional healthcare entities into a data ecosystem can help meet unmet community needs, alleviate burden to the healthcare system, and strengthen bidirectional exchange to ultimately improve community care and wellbeing. In order for these networks to succeed, our core principles of maintaining privacy through per-referral consent, fostering an interoperable approach, and maintaining open networks that allow for CBO choice and self navigation.

We appreciate and extend our gratitude to the White House OSTP for the opportunity to highlight the great work of findhelp, and look forward to future partnerships, collaborations, and engagement. Please feel free to reach out to Anna Lipton Galbraith a [redacted] t any time.

Submitted on behalf of findhelp, A Public Benefit Corporation

Expanding State Research Capacity in Child Welfare: The Need for State Institutional Review Boards (IRBs)

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https://doi.org/10.38126/JSPG190113
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Keywords: IRB, human subjects research, child welfare, practice-based research

Executive Summary: In 2018, funding for child welfare programs drastically changed under the Bipartisan Budget Act: Family First Prevention Services Act (FFPSA). To pull Title IV-E funding for prevention programs, all states must evaluate outcomes of children and families involved in child welfare. To meet these guidelines, state agencies need research structures, including internal Institutional Review Boards (IRBs). IRBs allow state governments to conduct ethical research, and expand research within the discipline. As researchers pursue careers outside of academia, these structures are pivotal and lead to policy contributions and knowledge in the discipline. This study evaluates the following in all 50 US states: How many states have internal IRBs? How many states have IRBs that are accessible to the state's child welfare agency? How have states set-up internal IRBs to function within a government context? The analysis found 34 states have at least one federally registered IRB of which 31 appear active within the state. However, only 11 of the 31 states have an IRB accessible to child welfare departments. These 11 states provide a blueprint for how to establish and maintain an IRB that supports child welfare agencies. Three distinct set ups emerged: holistic multi-department IRB, singular department/agency IRB, or those governed by an inter-agency sharing agreement. These findings show multiple states use an internal IRB to support state researchers. However, these IRBs are not currently accessible to the child welfare agency. For agencies to meet the requirements of FFPSA, IRBs must be expanded to the child welfare agency or built within the state.

I. Introduction

Federal agencies are continually writing policies and best practices that promote the importance of evidence-based decision making within the government. However, for child welfare, evidence-based decision making, and rigorous evaluation became required by federal law under the Family First Prevention Services Act (FFPSA) in 2018 (FFPSA 2018). FFPSA dictates that to receive federal funding, states must conduct rigorous evaluations of internal programs for rating by the Title IV-E clearinghouse and use the evidence-based programs that are rated by the Title IV-E clearinghouse (FFPSA 2018).

Since the law's passage, the call to bring research and evaluation teams into state child welfare agencies has significantly increased. As governments strive to increase the evaluation capacity and use of evidence-based decision making, increasing research structures within child welfare agencies is pivotal. In order for the state government to retain researchers as they transition from academic institutions, they will need access to an Institutional Review Board

(IRB) to comply with federal law and conduct ethical evaluations. IRBs are required to oversee state-sanctioned research and protect human research subjects. Through setting up internal state IRBs, agencies allow researchers outside of universities to perform ethical human subjects research, contribute to their academic discipline, and instruct policy.

i. Understanding Child Welfare Funding and the Implications of FFPSA

The "Bipartisan Budget: Family's First Prevention Services Act of 2018" changed child welfare funding by modifying how states could use Title IV-E funds (*id. At 170*). Prior to FFPSA, Title IV-E funding supported children in out-of-home care including foster care, adoption assistance, and guardianship assistance programs (Social Security Act 1995).

FFPSA fundamentally changed the focus of the Title IV-E federal support from out-of-home foster care to in-home prevention services, (Social Security Act as amended 2018). The shift in this funding asks states to focus on services and interventions that they can provide for families to keep children in their home of origin. In addition, not only did the law change to allow for support of in-home care programs, the eligibility for in-home programs for Title IV-E funding was directly tied to the strength of sustained, statistical significance of the program. The validity of statistical evidence is determined by the creation of the Title IV-E Prevention Services Clearinghouse, and the requirements dictated under The Prevention Services Clearinghouse Handbook of Standards and Procedures as dictated by the FFPSA, (Social Security Act Section 470 et seq).

ii. Research Requirements Dictated by FFPSA

Under The Prevention Services Clearinghouse Handbook of Standards and Procedures, states must use specific guidelines when assessing and evaluating programs for use within the state if they are to pull Title IV-E funding. All programs must be evaluated and rated by the Title IV-E Prevention Services Clearinghouse to receive federal funding as established by the Social Security Act as amended in 2018. In order for a program or practice to be eligible for potential Title IV-E prevention funding, the program must meet the following general requirements of the Title IV-E Prevention Services Clearinghouse (Wilson et al. 2019):

- The practice/program must have a book or manual that specifies the protocol and practice,
- There is no empirical basis suggesting that compared to its likely benefits, the practice constitutes a risk of harm to those receiving it,
- If multiple outcome studies have been conducted, the overall weight of evidence supports the benefits of the practice,
- Outcome measures are reliable and valid and are administered consistently and accurately across all those receiving the practice,
- Outcome measures must address one of four categories; mental health prevention and treatment programs or services, substance abuse prevention and treatment programs or services, in-home parent skill-based programs or services, and kinship navigator programs;
- There is no case data suggesting a risk of harm that was probably caused by the treatment and that was severe or frequent.

If the program meets these minimum standards, the program will be evaluated and rated as one of four ratings. The four ratings are hierarchical in terms of amount and significance of evidence. The ratings criteria are: *Does not meet criteria*, *Promising*, *Supported*, and *Well supported* (Wilson et al. 2019).

These standards now require states to be responsible for designing, conducting, and publishing rigorous randomized controlled trials or quasi-experimental designs for any program that they wish to pull Title IV-E funding. Additionally, federal funding will only reimburse states for 50% of the cost of the evaluation, requiring each state government to fund the remaining 50% from local state budgets (Social Security Act as amended 2018). This shift of federal financial support pushed child welfare agencies to assess their current programs and strategies away from out-of-home care programs to programs that safely keep children in their homes while claiming federal dollars for approved Title IV-E programs only. While the sentiment behind this shift in focus is one that embraces the mission of child welfare agencies across the country to keep families together, it required large internal changes to be made in order for agencies to meet the rigor required in utilizing approved Title IV-E programs within their prevention work. Thus, although FFPSA prioritizes research and evaluation within the state government, there is a need for ethical oversight of research and an IRB accessible to the department—all while maintaining fiscal responsibility.

The need to conduct rigorous evaluation extends beyond new programs that have yet to be rated by the Title IV-E Prevention Services Clearinghouse. The law further states when the state pulls federal Title IV-E funding for programs rated as supported or promising, the state must submit a rigorous evaluation design to continually monitor and ensure fidelity to the practice model and determine outcomes achieved (Social Security Act as amended 2018). This requires states to continually invest in meeting evaluation requirements even after the program has been federally reviewed and found to lead to better outcomes for children and families. This constant cycle of evaluation and re-evaluation of each promising and supported program is required until a program meets the well-supported rating. Thus, states must continually evaluate a program until the well supported ranking has been met, which includes two rigorous evaluations with non-overlapping populations with at least one study showing sustained positive impacts one year post treatment (Wilson et al. 2019).

iii. Practice vs research does this research fall under IRB Review?

Under CFR 45 Section 46.102, not all research meets the requirements for IRB review. Research that is not required to be reviewed by an IRB includes research that is done in a practice setting, does not include the collection of identifying information, data is publicly available, or research that is conducted for the sole purpose of internal improvement of the agency or department. (Common Rule of 2018). Review by an IRB is needed both for research that is conducted or supported by a federal department/agency and for research that is not conducted or supported by a federal department or agency but falls under the definition of research set by The Common Rule of 2018. Under FFPSA, these rigorous evaluations must be "carried out in a practice setting" (FFPSA 2018) which implies the research may not automatically fall under IRB review. However, when we consider the populations that child welfare agencies work with – children, pregnant women, and potentially incarcerated individuals – these individuals fall under the category of a vulnerable population. Thus, state child welfare agencies are placed in the uncomfortable position of determining if IRB review must be sought for any program with the potential of Title IV-E funding. The Belmont Report argues "the general rule is that if there is any element of research in an activity, that activity should undergo review for the protection of human subjects" (National Commission for the Protection of Human Subjects of Biomedical and Behavioral Research 1979). This guideline argues that any state that may hope to use Title IV-E funding, must have access to an IRB to ensure the protection of vulnerable human subjects represented in child welfare.

As agencies must also publish their findings to meet FFPSA requirements, federal requirements are not the only governing body that child welfare agencies must navigate. Academic journal publishing guidelines also push the field towards needing IRB approval. *Children and Youth Services Review*, a popular journal in child welfare, states "All manuscripts that deal with human subjects must be accompanied by an Institutional Review Board (IRB) or Ethical Committee Approval, or national or regional equivalent in your geographic area" (Guide for Authors 2021). A review of journals in clinical psychology found that at least 40% of the journals sampled are likely to reject any human subjects research that has not been reviewed by an IRB (Osbourne and Luoma 2018). Due to the regulations dictated by federal research standards, and academic policies, IRB access for state researchers will be needed to meet the requirements of FFPSA.

iv. Current Alternatives to Internal State IRBs

While IRB review is needed in child welfare, internal state IRBs are not the only way in which state researchers can access IRBs. Currently, there are two main structures that provide IRB access to state agencies without internal IRBs: university partnerships and private IRBs. While each of these structures offer a stop gap measure, they are unsustainable and fiscally untenable under the new evidence-based driven environment needed in child welfare. When accessing a university IRB, many state programs may use employees that have adjunct faculty appointments with local universities or collaborate with a university researcher to gain access to an IRB. However, many universities may not allow adjunct faculty to access IRBs, and university collaborations only succeed when the interests of the state researchers align with the research interests of the university's Principal Investigator (PI) (Osbourne and Luoma 2018).

While private IRBs allow state researchers to avoid the need to obtain adjunct faculty appointments and like-minded research groups, they can be exceedingly costly. Osbourne and Luoma found that initial reviews provided by private IRBs could cost thousands of dollars, and this cost was noted as a barrier to practice-based research (2018). Additionally, FFPSA federal funding will only cover 50% of the administrative costs of the evaluation, (FFPSA 2018) requiring state agencies to fund the rest of this cost. Considering the amount of research that will need to be produced by state agencies under FFPSA, this highly expensive solution is unsustainable.

v. Purpose of the Study and Research Questions

As state child welfare agencies work to build the knowledge base of child welfare and meet the demands of FFPSA Title IV-E funding, state child welfare agencies will need access to a consistent and cost-effective IRB to adequately protect the vulnerable populations that come into child welfare. The following analysis seeks to understand how many state agencies have an internal, federally registered IRB and also ask the question: Of the state agencies that have an internal IRB, how many of these IRBs are accessible to the child welfare agency in the state? We explore how IRBs that are available to child welfare agencies are set up and function in the context of state government. Finally, we offer suggestions on how state agencies can implement internal IRBs to support state researchers within all departments with a specific focus on child and family serving agencies.

II. Methodology

If an IRB is going to sanction research on human subjects or their identifiable information, or receives funding from the United States Department of Health & Human Services (USDHHS) or the United States Food and Drug Administration (FDA), and will be published, the IRB must be registered with the United States Department of Health & Human Services Office for Human Research Protections (USDHHS/OHRP). Additionally, USDHHS/OHRP maintains a database for all registered IRBs, and Federal Wide Assurances (FWA), accurate up to the last sixty days. In this database, one can search for any federally registered IRB.

Information on state access to a federally registered IRB was done using the USDHHS/OHRP website, with both the basic and advanced search functions. For the first round, all fifty state names were put into the USDHHS/OHRP basic search bar under "IRB Name." For example, when looking for federally registered IRBs in Illinois, "Illinois" was put into the basic search bar labeled "IRB Name." Typically, state IRBs are named according to the state and department in which they reside. If this naming convention existed, the state would be marked as "1," which indicated the state had at least one federally registered IRB. To account for states that did not use this naming convention, each state was checked using the "advanced search" feature in which the name of the state was used in the "hosting" state search bar. This allowed the register to pull up all IRBs hosted within that state regardless of the naming convention.

To confirm the federal registry with acting state government practice, individual state's websites were searched for confirmation of the IRB and any documents explaining the IRB protocols and procedures. For states that had multiple IRBs within their state government, each individual state website pertaining to the IRB department was explored and confirmed.

While searching individual state websites, a few states claim to have IRBs that were not listed under the federal registry. More often than not, these IRBs are internal review committees that release data for use outside the state agency and cannot conduct evaluations or sanction Human Subjects Research. Considering these IRBs cannot be used to publish research or solely protect human subjects under a research framework, IRBs that are not federally registered were marked as 0.

To determine if the child welfare agency within the states with IRBs were accessible to child welfare employees, the organizational chart, rules and procedures governing the IRB, and research scope of the IRB, were obtained for each state. If the child welfare department/office or agency fell under the IRB hosting department, the state was marked as having access to an IRB. If the child welfare department/office or agency did not fall under the hosting department, the state was marked as not having access. Individual state IRB coordinators were contacted when it was not clear if the IRB applied to both the hosting department and state child welfare agency. Additionally, a listserv that contains 67 child welfare data leaders was consulted for additional sources of IRB use within child welfare agencies, to ensure accuracy of state registries and alternative solutions. If an IRB could not be confirmed to be accessible to the child welfare agency, it was marked as unclear.

III. Literature Review

i. Human Subjects and Ethical Underpinnings

The following govern human subjects and how they should be handled in IRB proceedings: the Belmont Report (National Commission for the Protection of Human Subjects of Biomedical and Behavioral Research 1979) and HHS regulations under 45 CFR part 46 (The HHS Protection of Human Subjects in Research 2018). While this report and law are directed at the federal government, these laws are typically the base of state IRB policy in addition to any applicable state laws governing human subjects research.

The Belmont Report, authored in 1979, sets forth the ethical principles and guidelines which should be conducted to protect those human subjects of research. It emerged due to the enactment of the National Research Act, which was signed on July 12, 1974. That Act led to the development of the National Commission of the Protection of Human Subjects of Biomedical and Behavioral Research. The Commission's task was, in short, to ensure human subjects research considered the boundaries, appropriateness, participation, and informed consent as it relates to participants. The Belmont report sets forth the Commission's ethical principles and guidelines of these aforementioned topics and was made available on the Federal Register. The Report itself is immersed in policy and is not recommendation based.

An outgrowth of the Belmont Report is the HHS regulations under 45 CFR part 46. Subpart A of this regulation is known as the "Common Rule," which is "Basic HHS Policy for Protection of Human Research Subjects." The rest of the subparts are as follows:

- Subpart B: Additional Protections for Pregnant Women, Human Fetuses and Neonates Involved in Research
- Subpart C: Additional Protections Pertaining to Biomedical and Behavioral Research Involving Prisoners as Subjects
- Subpart D: Additional Protections for Children Involved as Subjects in Research
- Subpart E: Registration of Institutional Review Boards

The Common Rule was published in 1991 and has been updated and amended as of 2018. The Rule outlines how federal agencies must handle IRB research. The federal agency conducting the research is governed by their agency's regulations.

ii. Federal Requirements of IRB

The Common Under 45 CFR 46.107(a)-(f), a minimum of five individuals are required to serve on an IRB. In addition to the minimum requirement, the five individuals must meet diverse criteria. The following requirements are dictated by CFR A 10-1-16, 46.107 section IRB membership.

- No IRB can consist entirely of one gender, nor a single profession.
- An IRB must contain at least one individual who has a scientific background, and at least

one individual who does not have a scientific background.
- The IRB must have at least one representative that is not affiliated with the hosting department, nor a family member of an individual on the committee from the hosting department.
- If research involves a vulnerable category of subjects, which includes children, pregnant persons, prisoners, handicapped or mentally disabled persons, the IRB must include an individual knowledgeable in these areas (CFR A 10-1-16).
- Research specifically involving prisoners as subjects must include a board member who is a prisoner or prisoner representative to review all research proposals on individuals in this population (CFR A46.305).

While the board must consist of a minimum of five individuals that span the aforementioned categories, IRBs must also designate special positions within their membership to coordinate the activities of the IRB. At least one member of the board must be labeled as the IRB Chairperson, and one individual must be labeled as the IRB Administrator. Depending on the institution's policies governing the IRB, one individual can occupy both roles. However, each role requires specific responsibilities, and the IRB Chairperson must be registered with USDHHS/OHRP.

The IRB Administrator is responsible for updating and maintaining federal registration of the IRB with USDHHS/OHRP, scheduling meetings, keeping appropriate documentation and minutes of convened meetings, communicating with researchers on IRB decisions, and ensuring department heads approve of any research submitted to the IRB. This position can be a voting or non-voting member when separate from the IRB Chairperson/s.

The IRB Chairperson/s is a position mandated by the Common Rule. The Chairperson/s is responsible for reviewing and assigning reviewers for expedited research, leading the meetings of the IRB and serving as the senior leading member of the IRB. In addition, the IRB can appoint alternates when full time members cannot attend, or when specific vulnerable populations are used in the research proposal.

iii. Federal Procedure for Registering an IRB

The majority of work to set up and register an IRB is done by the hosting agency. There is no cost to federally register an IRB and submission is done online. The "cost" of registering would be the time and effort needed to compile the information needed for the registration. The information required to register is as follows and comes from USDHHS/OHRP "IRB Registration Process FAQs" (n.d.). One must designate the hosting institution and provide all necessary contact information for the hosting institution. One must then designate the individual who will run the IRB and be responsible for maintaining the federal registration, typically your IRB Chairperson and/or Administrator. One must designate how many full-time employees are dedicated to the IRB. For state IRBs there are few full-time positions devoted to the IRB, with many employees splitting their IRB responsibilities with other responsibilities. However, states that hire and support a standalone IRB Administrator would record this individual as a full-time employee. The host must provide an estimate of the number of active protocols reviewed by the IRB and the number of active protocols conducted or supported by USDHHS. The host will need to provide a member list that includes the IRB Chairperson/s and additional members voting status, name, sex, highest earned degree, scientist vs. non-scientist, specialty, vulnerable population specialty, if applicable, and institutional affiliations. If the hosting institution dictates alternative members for the primary members, these individuals must also be reported to USDHHS/OHRP. Thus, for states that elect to add IRB responsibilities to current employee positions, there is no additional hiring cost for forming an IRB.

Once the policy and procedures are developed for the IRB, the hosting agency must also have a Federal Wide Assurance (FWA). A FWA is needed for any "institution engaged in human subjects research that is not exempt from the regulations and conducted or supported by any USDHHS agency must be covered by a OHRP FWA" ("Assurance Process Frequently Asked Questions (FAQs)", n.d.). An FWA indicates that an "institution commits to USDHHS that it will comply with the requirements in the USDHHS Protection of Human Subjects regulations at 45 CFR part 46" (Assurance Process Frequently Asked Questions (FAQs) n.d.). FWA registry is done online and must be updated every five years or if the IRB membership roster changes with no cost to the hosting agency. To register for an FWA, the hosting agency will need to submit the membership roster of the IRB, the policies and procedures governing the IRB including ethical principles, designate a Human Protections Administrator (IRB Administrator or Chair), the signature of the hosting department director, departments covered under the FWA, scope of the research covered under the IRB, and assurance of compliance with the terms of the FWA (Assurance Process Frequently Asked Questions (FAQs) n.d.).

iv. General Structure of State Government Agencies

Generally, IRBs are under the executive branch of state government in order to oversee the various departments. State agencies vary in terms of the size and position of the cabinet, departments, divisions, and/or agencies. Typically, a department is the highest agency within the executive branch. Divisions, agencies, and offices are nested within the various departments. Heads of the department are traditionally members of the cabinet. The most common departments across state governments are department of public health, department of agriculture, department of child services, and department of interior or environment. No two state governments are the same. It is also possible that these common departments can be divisions under a unifying department in some states. Each department is governed independently by its own internal policies and procedures. Thus, understanding the individual state government structure is pivotal to creating functional IRBs within the state.

For the purposes of understanding where child welfare agencies fall within state government structure, there are a few variations among states. A few states consider the child welfare agency a division under the Department of Health, or Department of Health and Human Services like the structure found in Michigan, Kentucky, and Georgia ("Michigan Department of Health and Human Services" 2021; "Cabinet for Health and Family Services" 2017; "Georgia Department of Public Health" n.d.). However, most states are organized with the child welfare departments as independent departments as seen in Indiana, Colorado, and Louisiana (Indiana Department of Child Services 2021; Child Welfare 2021; Department of Children & Family Services n.d.). How a state develops the scope, policies and procedures governing the IRB is pivotal to the ability of the IRB to oversee multiple departments. Departments that are housed within the department of health or human services, must write their policies to cover all divisions under the department, and all researchers. Single child welfare departments only need to worry about writing policy that covers their individual department and employees. Departments that are made of multiple divisions require leadership buy-in from each executive of the division and increase coordination between divisions.

IV. Results

i. General State Access to IRB

Using the federally registered database, we found that thirty-four States host at least one federally registered IRB and 16 States do not host any federally registered IRBs (Fig. 1). Twenty-two out of the forty federally registered state IRBs fall under a state's health department (Table 1) and only cover research conducted by the department of health, or employees of the department of health. However, for child welfare divisions that do not fall under the department of health's jurisdiction, very few states have IRBs that are accessible to the child welfare departments. Of the thirty-four states that do host at least one IRB, only eleven have IRBs that are accessible to the child welfare agency (Figure 2), due to the separation of departments. State IRBs policies and procedures are written to only cover the hosting department employees and research, thus, if a division/department is outside of the hosting division/department, the researchers of that agency will not have access to an IRB.

ii. IRB Models Accessible to Child Welfare

Of the eleven states in which child welfare agencies have access to an internal state IRB (Figure 2), three distinct models emerge: single department/agency IRB, inter-agency sharing agreement IRB, and a holistic multi-department IRB (Table 2). Single department/agency IRBs are internal IRBs hosted solely within a specific state department and only review research that includes that agency's employees, or internal data records. States with an accessible IRB to the child welfare department that host this type of IRB are Michigan, Minnesota, Oklahoma, Utah, and Virginia (Table 2). Typically, these state agencies have more than one IRB within state government, and each IRB operates independently within the hosting department.

Table 1: State Government Departments with IRB Access within the United States

State Government	Federally Registered IRBs (#)	Hosting Department/s	Accessible to State Child Welfare Department?
Alabama	1	Public Health	Unclear*
Alaska	1	Federal HHS Indian Affairs	No
Arizona	1	Health Services	No
Arkansas	0	NA	No
California	1	Health and Human Services	Yes
Colorado	1	Health and Environment	No
Connecticut	2	Public Health, Office of Early Childhood	No
Delaware	0	NA	No
Florida	2	Health	No
Georgia	1	Public Health	Yes
Hawaii	1	Health	No
Idaho	1	Health and Welfare	Unclear*
Illinois	1	Public Health	No
Indiana	0	NA	No
Iowa	0	NA	No
Kansas	1	Health and Environment	No
Kentucky	1	Cabinet for Health and Family Services	Yes
Louisiana	1	Health	No
Maine	0	NA	No
Maryland	1	Department of Health and Mental Hygiene	No
Massachusetts	2	Mental Health, Public Health and Human Research Review Committee	No
Michigan	2	Public Health, Health and Human Services	Yes
Minnesota	2	Health, Human Services	Yes
Mississippi	1	Health	No
Missouri	1	Health and Senior Services	No
Montana	0	NA	No
Nebraska	0	NA	No
Nevada	0	NA	No
New Hampshire	0	NA	No
New Jersey	0	NA	No

New Mexico	0	NA	No
New York	2	Health	No
North Carolina	2	Correction, Health and Human Services Division of Public Health	Unclear*
North Dakota	1	Health	Yes
Ohio	1	Health	No
Oklahoma	3	Health, Human Services, Mental Health Substance Abuse Services	Yes
Oregon	0	NA	No
Pennsylvania	2	Health, Education	No
Rhode Island	1	Health	No
South Carolina	3	Public Safety, Mental Health, Health and the Environment	No
South Dakota	0	NA	No
Tennessee	0	NA	No
Texas	2	Health and Human Services	No
Utah	3	Health, Human Services, Education	Yes
Vermont	1	Agency of Human Services	Yes
Virginia	2	Health, Social Services	Yes
Washington	1	Health and Human Services	Yes
West Virginia	1	Education	No
Wisconsin	0	NA	No
Wyoming	0	NA	No

**search of state website was unable to confirm federal USDHHS/OHRP registry. NA is not available or no IRB within the state.*

Table 2: Type of IRB Model Accessible to Child Welfare

State Governments	**Type of IRB Accessible to Child Welfare**
California	Holistic Multi-Department
Georgia	Inter-agency Sharing Agreement
Kentucky	Holistic Multi-Department
Michigan	Single Department/Agency
Minnesota	Single Department/Agency
North Dakota	Inter-agency Sharing Agreement
Oklahoma	Single Department/Agency
Utah	Single Department/Agency
Vermont	Holistic Multi-Department
Virginia	Single Department/Agency
Washington	Holistic Multi-Department

An inter-agency sharing agreement IRB is an IRB in which the hosting department sets up sharing agreements across other state departments. These states typically hold one IRB within the state and have agreements with the other internal departments to access the hosting department's IRB. These IRBs can charge outside agency departments a fee for their review. States with this set up include Georgia and North Dakota (Table 2).

The third IRB model available to child welfare agencies, is a holistic multi-department IRB. Holistic multi-department IRBs are internal state IRBs typically hosted within a cabinet office that review research from all departments or agencies that fall under the cabinet. The states that operate a holistic multi-department IRB are California, Kentucky, Vermont, and Washington (Table 2). In order to understand the specific, make up of each IRB model a representative state was chosen based on accessibility to the IRBs policies and procedures within the state representing each IRB model.

Single Department/Agency IRB Oklahoma: Oklahoma operates its IRBs under the singular department/agency model. Oklahoma operates three federally registered IRBs hosted by its Department of Health, Department of Human Services, and Department of Mental Health and Substance Abuse Services. Child welfare services is a division under the Department of Human Services and through the Department of Human Services IRB, the child welfare agency is able to conduct and submit research. Each of these individual IRBs maintain independent membership, independent federal wide assurance, and independent policies and procedures. Each IRB supports an independent membership roster. The Department of Health IRB (OSDH IRB) hosts a nine-voting member IRB (Oklahoma State Health Department (OSDH) Institutional Review Board Members (as of 11/17/2020) 2021), while the Department of Human Services (DHSIRB) hosts a seven-voting member IRB (340:2-39-8 Membership), and the Oklahoma Department of Mental Health and Substance Abuse Services (ODMHSAS IRB) hosts a minimum of five voting members (Title 450 Chapter 1 Administration 450:1-11-8). Each of the three Oklahoma IRBs also host individual chair and IRB administrator positions. Finally, each policy governing the three IRBs states that the hosting IRB will only cover employees and data under the hosting department IRB (Scope 310:10-1-2, Institutional Review Board n.d., 450:1-11-16), which dictates each IRB operates independently of other agencies and does not cover research or data outside of these department jurisdictions.

Inter-agency Sharing Agreement IRB, Georgia: The State of Georgia hosts a singular IRB in the Department of Public Health (Institutional Review Board 2018). The IRB consists of eight members with four alternates (IRB Board Members 2019). Through an inter-agency agreement, Georgia's Department of Human Services, which houses the Division of Family & Children Services, partners with the Georgia Department of Health IRB. Currently, one member of the board represents the Georgia Department of Family & Children Services as a scientific member (IRB Board Members 2019). Through this agreement, both the Department of Public Health and the Department of Human Services can utilize the singular IRB without fees to either department unless the research is funded outside of a state agency (Institutional Review Board 2018).

Holistic Multi-Department IRB, Kentucky: The most widely used model of State IRBs accessible to child welfare agencies is a holistic, multi-department IRB (Table 2). Kentucky State Government is an example of how this model of IRB functions across multiple departments. The IRB is hosted within the Cabinet for Health and Family Services (CHFS IRB) (IRB Guidelines 2008). The CHFS IRB hosts a non-voting IRB Administrator who acts as a liaison between the cabinet and USDHHS/OHRP (IRB Guidelines 2008) and ensures all research projects reviewed by the IRB have been approved by the individual department heads. In addition to providing additional protections for CHFS clients and employees involved as subjects in research, the IRB also provides protections for subjects of research conducted, supported, endorsed, approved or sponsored by the Cabinet. This includes research conducted by individuals, students, employees, professors, universities, profit institutions, non-profit institutions, government agencies, or any other entity (IRB Guidelines 2008). There are six departments served within this cabinet and covered under the CHFS IRB, including the Department for Community Based Services which houses the child welfare division (Cabinet for Health & Family Services Organizational Chart n.d.). All six departments are represented on the IRB membership roster and represent the majority of agencies that need IRB review within the state.

V. Discussion

i. Single Department/Agency IRB Model

The single agency/department IRB model is beneficial for state governments that are not centralized under a cabinet, or overall department. States in which the departments of health, child welfare, correction and/or education are all separate entities can benefit from the single agency/department model. However, this model primarily benefits departments with a robust research team and staff. Smaller departments that only need a few research proposals reviewed per year or have a smaller research team may find that a single department/agency IRB is not sustainable due to the federal membership requirements, or time commitment of maintaining a full time IRB for few studies. The single department/agency model also requires the state to have significant access to both scientific and non-scientific individuals to serve across the multiple IRBs. Oklahoma's IRBs at a minimum are run by twenty-two individuals across the three, single department/agency IRBs. This model is the second most popular set up for State IRBs that are accessible to child welfare agencies (Table 2). However, this model allows agencies to specialize their IRB and only review proposals that relate to the specific department. This model promotes agency expertise and maximum knowledge on the research topic at hand.

ii. Inter-agency Sharing Agreement Model

The inter-agency sharing agreement model of Georgia allows state agencies to manage one federally registered IRB, across multiple departments. This model can be especially helpful if various departments only need a few proposals reviewed per year, while other agencies need more frequent access to IRBs. Additionally, this model offers the opportunity for state hosting agencies to receive funding from partnering agencies if needed by the hosting department of off-set IRB costs. This model can also assist state governments in which the departments are not under a single overarching agency or cabinet but have multiple departments that could use IRB access. This model can also be beneficial for departments with smaller research staff. However, this model of IRB, while using less state staff, does expand the type of research and expertise needed on the IRB member roster. It also requires the Administrator or Chair to coordinate across multiple departments.

iii. Holistic Multi-Department Model

The holistic multi-department IRB model works well in state agencies that have multiple departments under a singular cabinet. In addition, this model allows state agencies to host a singular IRB for multiple departments that all conduct research. These IRBs allow a single administrator who oversees the research across multiple departments to coordinate data and research requests. In this model, there is no singular hosting department, and no charges to the various departments within the cabinet for submissions. This model also allows the utmost transparency and singular guidelines for individuals accessing state data. With a singular IRB reviewing data requests and research requests, this model cuts down on potential variation between departments and procedures that could arise under the singular agency/department model or inter-agency sharing agreement model. The holistic model also allows fewer state employees to volunteer time while still covering multiple departments for IRB review.

iv. IRB Benefit Research in Child Welfare

With most states having access to at least one federally registered IRB (Figure 1), the process for obtaining an internal state IRB is attainable. However, this analysis found that sixteen states do not have access to an IRB suggesting significant opportunity to expand research capabilities within those states. The majority of state agencies host IRBs within their department of health (Table 1), and while this indicates access to IRBs for public health

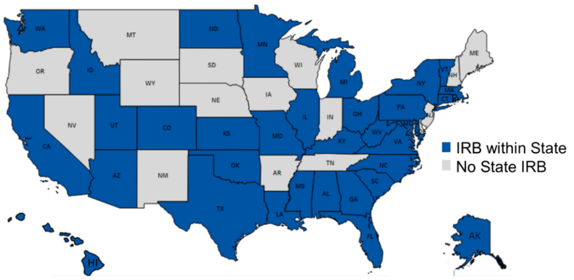

Figure 1: States with an internal Institutional Review Board.

employees, this leaves multiple departments and state researchers without access to IRB review. While child welfare faces the most immediate need for IRB access due to FFPSA, several state departments lack access to IRB. Only three states have IRB access within the Department of Education, and only one state operates an IRB accessible to the Department of Correction (Table 1), both fields in which Human Subjects Research is pivotal to the department and operation. Other state departments that could benefit from IRB oversight are the department of adult and aging services, department of Medicaid and any other human services-based department. With only eleven of thirty-four states hosting IRBs accessible to child welfare (Figure 2) and thirty-four states hosting any IRB (Figure 1), there is capacity for IRB access across departments and state governments.

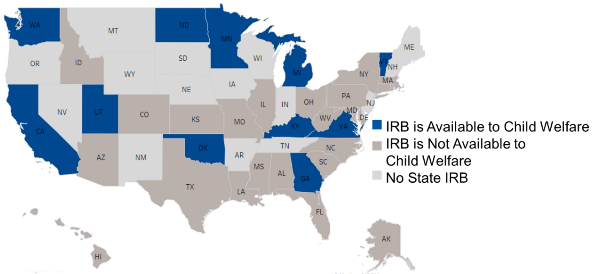

Figure 2: States in which the child welfare agency has access to an Institutional Review Board

v. Protection of Human Subjects and their Personal Information

IRBs are tasked with protecting human subjects involved in research. State governments house massive amounts of information that could be used to study, evaluate, and research policies and programs to better the lives of the constituents they serve, but this information should not be accessed lightly. The amount of information collected in these systems is collected for services, or the betterment of policy and practice, and not research. Thus, it is imperative that researchers within these agencies have access to an IRB to give protections to the human subjects' information, even when not immediately required. Osborne and Luoma argue that there are multiple benefits to having practice-based research reviewed by an IRB, even if not federally required including, ensuring the rights of human subjects are protected, ensuring research methodologies are ethical, alerting researchers to specific state and local laws, managing potential legal liability to protect both researchers and research subjects from misconduct, and allowing for dissemination of findings in academic journals (Osborne and Luoma 2018).

The Belmont report explicitly expresses the need to protect human research subjects based on respect for persons, beneficence, and justice (National Commission for the Protection of Human Subjects of Biomedical and Behavioral Research 1979). These recommendations have been approved by the Common Rule further articulating the need to protect human subjects, and their personal information. It is critical to think about the populations that state agencies serve. Child welfare agencies interact with all three vulnerable populations defined by the Common Rule: children, pregnant women, and incarcerated persons. Access to an IRB to evaluate state child welfare research further protects human subjects, and their personal information.

vi. Expanding Research Capacity Outside of Academia

Not only will access to an IRB within government agencies help government researchers, but they expand the ability to support researchers publishing outside of academia. . By expanding the ability for government scientists to disseminate findings and share results, this further strengthens the field of evidence for any discipline and meets the rigorous requirements of FFPSA for child welfare. In 2003, the Op-Ed of the *Journal of Epidemiology and Community Health* discussed the need to allow state researchers to distribute their research widely, opining that "Government agencies should encourage and facilitate government scientists to publish their findings in peer reviewed journals." (Choi et al. 2003). The need to publish evidence-based evaluations within state agencies is needed in the field of child welfare, and the greater child welfare discipline can benefit from added researchers evaluating and publishing their work.

VI. Recommendation for State to Build Internal IRBs

This analysis revealed states fall into two categories to provide IRB accessibility to child welfare: states without any IRBs and states with IRBs where policies do not support inter-department collaboration. Considering only eleven states have accessible IRBs for child welfare agencies, this analysis reveals the majority of states can implement changes to expand IRB access to allow state child welfare researchers to meet the rigorous demand of FFPSA. Through successfully engaging stakeholders and using other states' published resources, states can implement IRBs without large increases in funding. Federally registering an IRB does not cost the hosting agency additional funds, and many states can use existing employee expertise to oversee the IRB. Due to statutes and federal law, federally registered IRBs must post their policies and procedures as well as contact information governing the IRB. Almost all of the states' IRB policies and procedures were available online and can be used as blueprints for other states making modifications to an existing IRB or creating an IRB.

The key to successful implementation regardless of current IRB capacity is bringing the correct stakeholders and decision makers to the table. An implementation champion of the IRB will be needed who is either familiar or ready to learn the federal regulations governing the IRB and prepared to champion building the policy or procedures. Ideally, this is a scientist/researcher within the state with previous experience submitting IRB procedures. Next the implementation champion must engage the executive leaders of the department, and their head of research/chief scientists to learn about the research needs of the agency and obtain cabinet approval. Once cabinet approval is obtained, the cabinet can take the request to the governor's office for full state approval. Failure to accurately engage these decision makers can cause the implementation to fail. Below we suggest the additional following recommendations depending on the specific category each state falls into:

- For the sixteen states that do not currently have any federally registered IRBs, state administrators should start by assessing the number of departments that conduct research and identifying an implementation champion. Once these departments and individuals have been identified, administrators must evaluate the state department organization chart to identify if the departments fall under a singular cabinet or operate independently. The set-up will determine which model of IRB would be appropriate for the state.
- States in which the departments are separated from each other may wish to explore singular department/agency IRBs or inter-agency sharing agreements depending on the number of researchers within each department and the relationships between the departments.
- For states that have departments under a single cabinet, a holistic multi-department IRB can be created to oversee multiple departments within the state.

After deciding the most functional model for the state, administrators should identify if an IRB administrator position is needed separate from the chair, which would be most likely under a holistic multi-department IRB, or inter-agency sharing agreement IRB. States must consider the availability of the individual already within the state or create a position. Once these major structural decisions are evaluated and considered, state administrators can model their IRB policies and procedures based on existing state IRBs.

Without careful planning and full understanding the organizational structure and research capacity of each agency can cause an IRB to not be built, or non-functional. Without carefully building an IRB that operates in the context of each state, research capacity will not be built, and state researchers will fail to conduct ethical evaluations. The consequences for child welfare are even more dire. Without access to an IRB, state child welfare agencies will be unable to pull federal funding for their prevention programs.

The thirty-four states with at least one IRB are best positioned to evaluate the structure of the IRB and use existing resources to expand capacity to other state departments. Depending on the number of reviews needed by additional agencies, the existing IRB can enter an inter-agency sharing agreement and appoint additional members to the current committee. While the states will need to update both their federal IRB registry and FWA, both of these processes are free and would restart the clock on federal registration.

VII. Conclusion

The majority of states (68%) use internal IRBs to support state research and researchers. However, this analysis found a significant gap in the accessibility of these IRBs to support state child welfare agencies. Only eleven states have an internal IRB that is accessible to the child welfare department. For states to meet the demands of FFPSA, each state must build access to an internal state IRB. The twenty-three states that already have an internal state IRB, which is not accessible to the child welfare agency, can expand their existing IRB to include the child welfare agency. For the sixteen states that do not have any IRBs, they can build an IRB specific to their state by analyzing the organization chart of departments, evaluating agency needs and number of state researchers within each department, and using the vast, free, resources of policy and practice documents located on state websites. Creating and maintaining a state IRB will increase the research capacity of child welfare agencies to meet the demands of FFPSA and contribute to greater capacity of researchers outside academic institutions.

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Elisabeth S. Wilson studied Biology and Sociology at DePauw University where she was introduced to interdisciplinary policy research through her Senior Thesis: *Legislators as Peer Reviewers: How legislators influence scientific research produced by the United States Department of Agriculture (USDA)*. She pursued her MS degree from North Dakota State University studying how agricultural practices impact pollinator nesting behavior. Now, Elisabeth is the Senior Research Analyst for the Indiana Department of Child Services where she works to build research capacity within child welfare and state government. Elisabeth hopes to dedicate her career to expanding research access and informing decision makers on evidence-based decision making.

Heather Hendley graduated with a BA in Psychology and started her journey with the Department of Child Services as a family case manager in 2010. She has been instrumental in building and ultimately leading Indiana’s statewide program for older youth, Collaborative Care. Presently, Heather is the Assistant Deputy Director of Strategic Solutions and Agency Transformation where she manages federal reporting, continuous quality improvement, quality service and assurance, and research and evaluation for the Department. Heather hopes to coordinate efforts across these disciplines to inform large scale changes within the Department to positively impact the lives of children and families.

Rachel D. Russell received degrees in Anthropology, English, and French from Purdue University. She obtained her juris doctor degree from Valparaiso University School of Law. She has served as a paralegal in public defense, clerked at the Lake County Public Defender's Office in Crown Point, Indiana where she assisted with death penalty cases, and externed for Margret G. Robb at the Indiana Court of Appeals. After law school, Rachel became a public health lawyer and deputy general counsel for several years at the Indiana Department of Health. She began her tenure at the Indiana Department of Child Services in 2017 as Deputy General Counsel and Ethics Officer.

Heather H. Kestian has been a licensed attorney in good standing with the Indiana Supreme Court since October 2008. She joined the Indiana Department of Child Services (DCS) in 2008 as a local office attorney where she represented the agency in Child in Need of Services (CHINS), Termination of Parental Rights (TPR) proceedings, and in appellate matters. She has served as an Administrative Law Judge for DCS, a Local Office Director for DCS, and the Collaborative Care Field Director. She currently serves as the Deputy Director for

Strategic Solutions and Agency Transformation (SSAT). She graduated *Cum Laude* from the University of Toledo College of Law in May 2008.

Terry J. Stigdon MSN, RN, was appointed as director of the Indiana Department of Child Services in early 2018. Stigdon has implemented changes aimed at offering the best service to Hoosier children and families. As a result of her efforts the state has seen a decrease in children in residential treatment and foster care. Prior to her appointment, she spent nearly 20 years at Riley Hospital for Children. Her work took her to the pediatric intensive care unit as well as the emergency medicine and trauma center. Stigdon, a Chicago native, holds a bachelor's degree in nursing as well as a master's degree in nursing leadership and management.

Acknowledgements

Thank you to Noelle Russell for her thoughtful review of the manuscript. Thank you to all the IRB coordinators who communicated with us throughout this analysis. Thank you to Peter Serles and Nabanita Nawar for their thoughtful reviews of the manuscript.

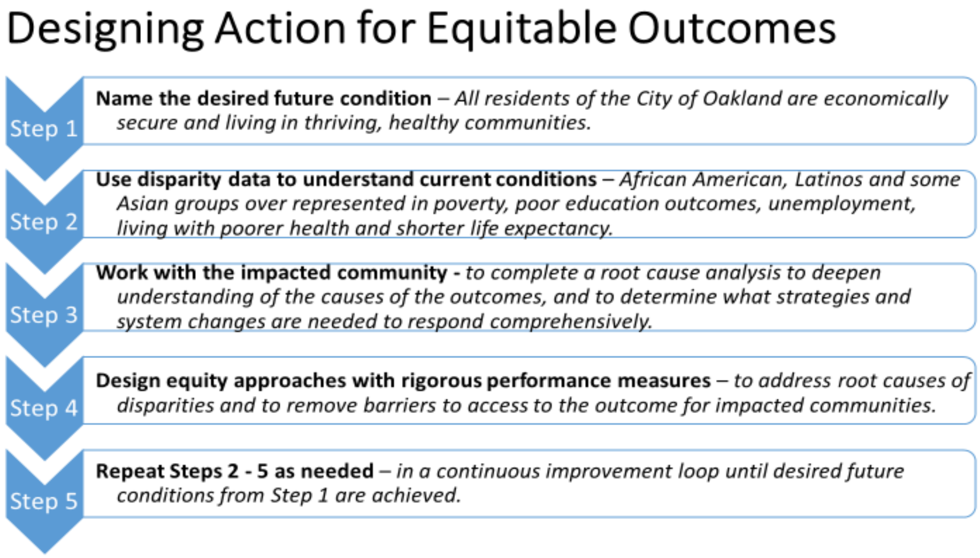
Disclaimer

All authors work for the Indiana Department of Child Services; however, no individual's salary or compensation is dependent on the analysis or publication of the manuscript.

From: **Department of Race and Equity, City of Oakland**
To: **Equitable Data Working Group**
Date: **October 3, 2022**
Re: **Engagement and Accountability RFI (Q1-5)**

1. What are examples of successful collaborations involving equitable data between the Federal government and (a) Tribal, territorial, local, and State governments, or (b) local communities?

The City of Oakland, CA can offer many successful examples of how data plays a crucial role in advancing racial equity. However, it is important to recognize that data alone does not create the institutional changes needed to eliminate racial disparities in the communities served by government agencies. Creating an institutional culture where data is used to advance racial equity and address disparities in access to services and mitigate or remedy pasts harms done by racist policies, practices, and procedures requires the intentional development of a framework, tools, and training that positions staff to successfully manage a racial equity change process within a government institution. The framework supports the creation of internal systems, policies, procedures, and practices, at all levels of the organization to work towards a common vision and goals that, over time, will result in the elimination of racial disparities.



Designing Action for Equitable Outcomes

Step 1 **Name the desired future condition** – *All residents of the City of Oakland are economically secure and living in thriving, healthy communities.*

Step 2 **Use disparity data to understand current conditions** – *African American, Latinos and some Asian groups over represented in poverty, poor education outcomes, unemployment, living with poorer health and shorter life expectancy.*

Step 3 **Work with the impacted community -** *to complete a root cause analysis to deepen understanding of the causes of the outcomes, and to determine what strategies and system changes are needed to respond comprehensively.*

Step 4 **Design equity approaches with rigorous performance measures** – *to address root causes of disparities and to remove barriers to access to the outcome for impacted communities.*

Step 5 **Repeat Steps 2 - 5 as needed** – *in a continuous improvement loop until desired future conditions from Step 1 are achieved.*

Thanks to this framework, the racial equity work in the City of Oakland, CA is: ***"City-wide, Data Driven, and Systemically Focused."***

The City of Oakland is using data and an integrated approach to pursuing equity. The Department of Race and Equity (DRE) was created by a city ordinance in 2015. The creation of DRE reflects the city's recognition and acknowledgment that troubling racial disparities exist and that it is time to provide focus and support for their elimination. In alignment with our framework, DRE supports all City departments and decision makers to address systemic causes of inequities and remove barriers that restrict access to fair services from the city government.

In Oakland's not-so-distant past, housing, policing, employment policies, and community disinvestment, like elsewhere in the U.S., were explicitly racist. The impacts of these past institutional policies and practices are apparent in the current conditions in marginalized communities and can be found embedded in public policies that contribute, often inadvertently, to ongoing race-based disparities.

Three notable examples of our approach to the use of data include the following: (1) the 2018 Oakland Equity Indicators Report, (2) the City of Oakland's Capital Budget Prioritization Process, and (3) the City of Oakland's Three-Year Paving Plan. These examples illustrate how the equity change process can successfully be implemented at different levels of government and how data is used at those different levels to drive equitable outcomes that benefit the communities most impacted by racial disparities.

Example 1: The Oakland Equity Indicators Project and Report

In 2018, the Department of Race and Equity published the Equity Indicators report. The project was the result of a partnership between the Institute for Local Governments at the City University of New York, and the Berkley Goldman School for Public Policy and was funded by the Rockefeller Foundation.

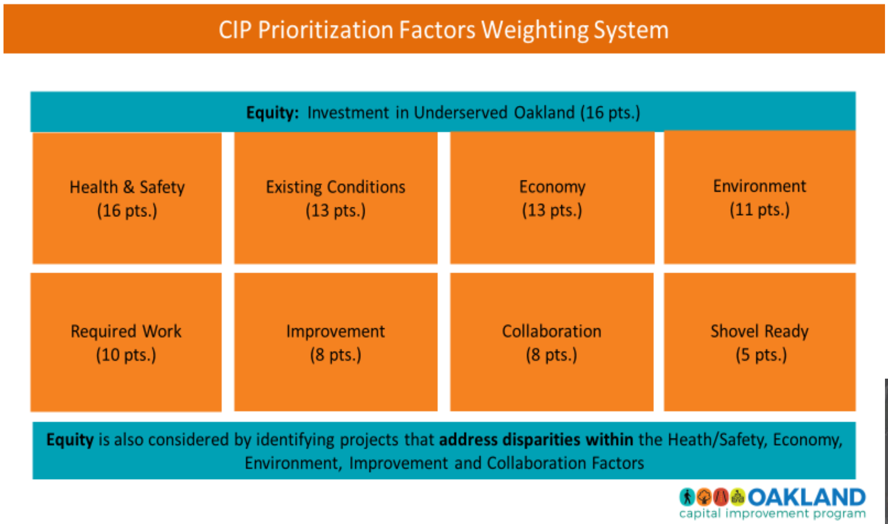
Looking at Census data sets, local program data, and using analytic tools provided by the Census, the report offers a snapshot of racial disparities in Oakland for 72 different indicators of well-being. All indicators found disparities for Black and Latino Populations. To complement this quantitative framework, the Department of Race and Equity also partnered with a coalition of trusted community organizations to begin a process to gather qualitative data from diverse community members in Oakland. This qualitative data provided important context and insights about root causes and potential solutions to the problems illuminated in the Equity Indicators report. Data-informed, transparent decision-making is essential to transformational institutional change that will advance equitable outcomes in our communities of color. The interviews of 500 Oakland residents provided additional data findings which supported the lived experience of Black, Indigenous, Immigrants, refugees, undocumented, and people of color of all genders and levels of ability living in Oakland.

This was the first step in starting to address the impacts of systemic racism in our City and helped city staff and policymakers to understand the current conditions of inequity in Oakland. In addition, the report helped the Department of Race and Equity to facilitate data discussions in different departments and started to create a shift in how data is used to inform program and policy and internal procedure design. Since then, the report has been used by numerous community organizations to hold the city accountable for delivering services and creating policies that address the needs of geographic areas in Oakland most impacted by racial disparities due to past policy decisions that resulted in divestments in those areas.

Example 2: City of Oakland Capital Budget Prioritization Process

Through the conversations with the Departments of Transportation and Public Works about how to address racial disparities in access to City services, it became clear that the City needed to change the capital budgeting process to bring it into alignment with racial equity. DRE worked with department staff and community members to design a prioritization process to help center the needs of divested neighborhoods and advance racial equity.

The prioritization factors were developed in collaboration with community members and grassroots organizations creating a scoring system that centered on racial equity in capital projects. As a result, areas of the City that had not received funding for the repair, creation, and or improvement of facilities started to receive resources and support to meet their needs.



CIP Prioritization Factors Weighting System

Equity: Investment in Underserved Oakland (16 pts.)

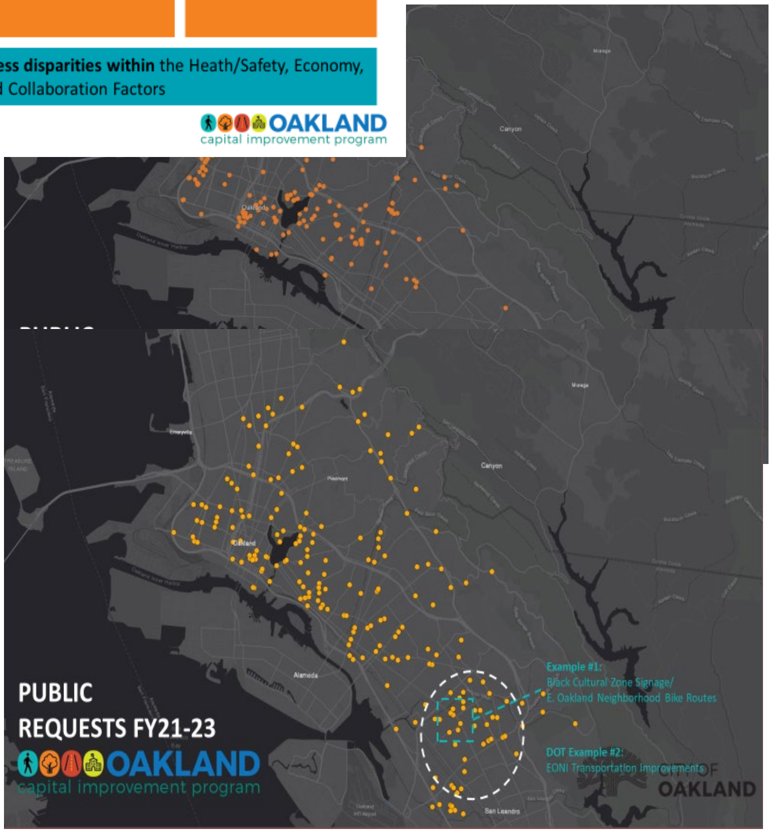
Health & Safety (16 pts.)	Existing Conditions (13 pts.)	Economy (13 pts.)	Environment (11 pts.)
Required Work (10 pts.)	Improvement (8 pts.)	Collaboration (8 pts.)	Shovel Ready (5 pts.)

Equity is also considered by identifying projects that **address disparities within** the Heath/Safety, Economy, Environment, Improvement and Collaboration Factors

OAKLAND
capital improvement program

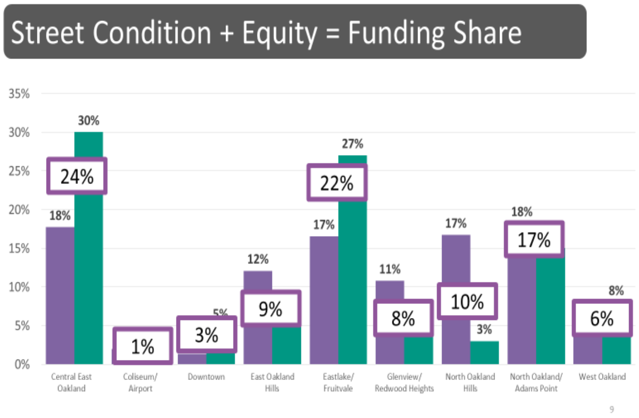
This new way of prioritizing projects also helped us to take a deeper look into how the City engages with communities impacted by racial

Orange dots represent public requests received on our first engagement round. After analyzing the data and realizing we had little engagement in areas with high populations of Black and Latinos the Capital Improvement Program (CIP) workgroup adjusted the engagement process and contracted a grassroots local organization to do focused outreach in these communities.



disparities. Using DRE’s Inclusive Public Engagement Guide, a tool designed to center communities that have a history of disenfranchisement in the public process, Departments were able to increase the participation of impacted community members and explore their project and service needs in ways that made sense to them.

Example 3: Three-Year Paving Plan: Paving Equity into the Streets of Oakland



To develop an equity-based paving plan, Oakland’s Department of Transportation (OakDOT) analyzed:

1. Demographic and road condition data for nine separate areas of Oakland.

2. The population density, income, and racial and ethnic composition of each area, along with the total street mileage including miles in need of repaving and the average condition of streets in that area.

- The analysis allowed the public to have a common baseline of existing conditions and Racial Equity that is made publicly available as part of the OakDOT Geographic Equity Toolbox and visually represented in the Oakland Equity Map.

Before using disparity data and equity tools.

After using disparity data and equity tools.

2. Among examples of existing Federal collaborations with (a) Tribal, territorial, local, and State governments or (b) local communities involving equitable data, what lessons or best practices have been learned from such collaborations*?*

To address structural racism, institutional racism, and unrecognized bias, it is essential to center racial equity in data practice; include community voices and power sharing at every stage of design; and develop trusting relationships among those represented in the data and those in government agencies using the data. To obtain equitable results, questions of racial equity to need to be embedded throughout the data life cycle:

- In planning
- In data collection
- In data access
- In algorithms/use of statistical tools
- In data analysis
- In reporting and dissemination

Measurement must take place at two levels:

1. To develop baselines, set goals, and measure progress towards community goals.
2. To measure the success of specific programmatic and policy changes.

In addition, local government agencies urgently need to be provided a budget to set up data systems and use new technologies, train staff, and offer data grants for community organizations to process and analyze data in partnership with the federal government. Without these resources, local agencies will keep continue to lag and be unable to end systemic racism.

For example, the federal government has an important role to play in setting standards for data sharing and collaboration amongst agencies at different levels of government. At the moment, there are agencies that charge a fee for access or usage of their data at the State and County levels, creating barriers to access for local governments like Oakland. Grassroots organizations that serve the communities most impacted by structural racism do not have the means to buy data sets or conduct the analysis needed to disaggregate data by race and ethnicity, and provided to the public or share with other agencies. At all levels of government from Federal to local, it is imperative that the Census and other Federal agency data are reliable, trustworthy, free, and accessible to states and local governments.

3. What resources, programs, training, or other tools can facilitate increased data sharing between different levels of government (Tribal, territorial, local, State, or Federal) related to equitable data?

Two great resources in this area are the University of Pennsylvania Actionable Intelligence for Social Policy Toolkit for Centering Racial Equity Throughout Data Integration. Their programs offer great resources for government staff to better understand how to center racial equity in data policy and data initiatives.

Regarding training, in our experience, it is crucial for staff to understand the basics of a racial equity change process, its implementation, and how data is used to better understand root causes, and disparities and develop baselines, set outcomes, and measures. In this area, the work of Quisha Brown (Racial Equity Lens Logic Model & Theory of Change: A Step by Step Guide to Help Organizations Become More Confident in Their Ability to Demonstrate Outcomes (2021)) and Marybelle Nzegwu Tobias, author of "Racial Equity Impact Analysis: Eliminating Lead Paint Hazards in Oakland & Alameda County" (2021), will be key to supporting staff in better understanding these processes.

4. What resources, programs, training, or other tools can expand opportunities for historically underrepresented scholars and research institutions to access and use equitable data across levels of government*?*

Many government employees need support to understand how to set goals and measurements using data at the program and operations level. We have found the training offered by Erika Bernabei on racial equity and results in base accountability a basic training need. As well as training on how to use qualitative data for analysis and goals design and success measurements. In this area, the work of CO: Census goes a long way in supporting organizations and staff in local government agencies to translate feedback into actionable goals and metrics.

DRE is also available to offer support in how to develop trainings for City staff to understand a change process to advance equity at the operations level using data to drive equity-centered outcomes and measurements and racial equity frameworks geared to be driven by data and outcomes. The Oakland City Council, for example, recently dedicated $350,000 to support DRE and the City to advance necessary improvements in systems for collecting and processing data to track performance and equity progress (Resolution No. 89249 C.M.S. (June 7, 2022)).

5. What resources, programs, training, or tools can increase opportunities for community-based organizations to use equitable data to hold the government accountable to the American public*?*

The same trainings and opportunities for education in stem and data sciences made available to government agencies should be offered to the public as a means of increasing and building the capacity of grassroots organization to become true partners and collaborators with government agencies. Grants should be offered to support grassroots organizations already doing this work in impacted communities.

City of Los Angeles Response to Advancing Equity with Community Data Partnerships

SUBMITTED BY EVA PEREIRA, CDO OF LOS ANGELES

[redacted]

1. **What are examples of successful collaborations between the Federal government and (a) Tribal, territorial, local, and State governments or (b) local communities involving equitable data?**

   - **CFPB HMDA data:** The CFPB makes data on mortgage lending available to the public. The data is collected as part of the home mortgage disclosure act (HMDA) and is disaggregated by race, which enabled the City of Los Angeles to study racial disparities in mortgage lending. We were able to compare the city vs state vs nation to see how Los Angeles was performing on an important racial equity measure.
   - **NASA and the City of Los Angeles' predicting what we breathe project:** NASA has partnered with the City of Los Angeles to study air quality in the region. This partnership with inform local government about serious air quality issues and will enable the city to respond with useful strategies for reducing air pollutants.
   - **PPP loan data:** Federal PPP data enables cities to conduct their own equity analyses on lending throughout the pandemic. The City of Los Angeles used federal data to understand disparities in lending in the region.
   - **Calenviroscreen:** The State of California provides local governments with authoritative data layers on environmental and pollution burdens by census tracts. This data product is released every two years and is called Calenviroscreen. It's merged with census data to provide useful information on pollution and health burdens by communities in California. This data is incredibly useful to the Mayor's Office.

2. **Among examples of existing Federal collaborations with (a) Tribal, territorial, local, and State governments or (b) local communities involving equitable data, what lessons or best practices have been learned from such collaborations?**
   - Geographic specific information (i.e. data associated with key geographic boundaries like census tracts) is essential for local data equity projects. Providing federal data at standard geographic boundaries like census tracts, makes the data more usable.

- Disaggregating data by race / ethnicity is essential for local data equity projects as well. However, it is important to keep the standard categories used on census forms to enable optimal usability.

3. **What policies, resources, programs, training, or other tools can facilitate increased data sharing between different levels of government (Tribal, territorial, local, State, or Federal) around equitable data?**

- Resources:
    - More authoritative GIS layers maintained by the federal agencies and shared with the public.
    - Consultant-level resources towards re-aligning the current systems with industry-leading software and processes. For example, we've found that many departments are inundated with maintaining current work and there is very little additional time to dedicate towards building new datasets outside of the urgently needed information.
- Programs:
    - More Citywide and Statewide data collaboratives / exchanges to enable the sharing of information and best practices.
- Trainings / Materials:
    - CDO handbook that attempts to standardize the roles and responsibilities of a CDO and outline best practices

2022

Advancing Equity with Data Partnerships

NEW HAMPSHIRE

COMPILED BY: SCHREIBER, ELLYN - DHHS AFFILIATE

New Hampshire Early Childhood Teams September 22, 2022
Advancing Equity with Community Data Partnerships

1. What are examples of successful collaborations between the Federal government and (a) Tribal, territorial, local, and State governments or (b) local communities involving equitable data?

    - Access to interactive child care mapping
    - Mapping of family voice/engagement in Regional Early Childhood System(Regional)
    - Community Project: Mapping out internal data sets and sharing with communities, e.g. child maltreatment rates, elevated blood lead levels in children, cash assistance, SNAP, hospital Discharge reasons
    - Special Education: Addressing Disproportionality, (race, disability), utilized TA discipline
    - HS and EHS, equity data available to public, and programs have child specific data e.g.: race, ethnicity, language, eligibility, % of children with disability
    - PDG funded interactive Mapping includes capacity for including income, language, employment across regions
    - ESS data integration mapping, identifying disproportionality, (race and ethnicity)

2. Among examples of existing Federal collaborations with (a) Tribal, territorial, local, and State governments or (b) local communities involving equitable data, what lessons or best practices have been learned from such collaborations?

    - Lessons learned from COVID about how to use data in a timely manner to target approach or intervention

    - Common Education Data standards, allows translation in data integration

    - Importance of training about how questions are asked, thinking about how, and then prioritizing the importance of data collecting and having a clear idea of how data can be used.

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- Size matters, can't compare very small to very large, when interpreting, must consider size/volume
- Having data that automatically updates
- Must have clear reason for collecting and goal for the collection prior to collecting, and articulate with or before request
- Collecting what is needed, not everything

3. What policies, resources, programs, training, or other tools can facilitate increased data sharing between different levels of government (Tribal, territorial, local, State, or Federal) around equitable data?

- Training-Knowledge of software, how to extract, input data, manipulate
- Training of privacy laws and what it means for data that you are working with
- Need for dedicated staff for maintenance of data and data system
- Data dictionary
- Guidelines for creating a data agreement, and what needs to be included

4. What policies, resources, programs, training, or other tools can expand opportunities for historically underrepresented scholars and research institutions to access and use equitable data across levels of government?

- Access to data information in multiple languages and accessible formats
- Very clear processes and procedures about how data can be accessed and how to do it
- Outreach and readily accessible information about this so people can easily find this out
- Disability supports, (vision, hearing, etc.) multiple accessible formats

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- Ways of getting data to people that is not reliant on technology

5. What policies, resources, programs, training, or tools can increase opportunities for community-based organizations to use equitable data to hold government accountable to the American public?

    - HUD community partners enter into shared data system, giving them access to data, includes equity data, data informs future, priorities determined based on disproportionality
    - Data not available by specific area, (e.g. geographic data) - create federal and state data system that allows you customize the "slice", (user/community organization can choose how it is sliced), data needs to be collected in a way that will allow this

6. What policies, resources, programs, training, or tools can make equitable data more accessible and useable for members of the public?

    - Need to maintain privacy rules, e.g. cell size suppression to protect privacy
    - Built in data dictionary, use tutorial
    - FAQs
    - Public facing Tip/tools guidance
    - Guidance about limitations of data
    - Cleary identified data governance including contact information for questions or data issues

7. In which agencies, programs, regions, or communities are there unmet needs, broken processes, or problems around participation and accountability that could be remedied through stronger collaborations and transparency around equitable data?

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- In **all** agencies, programs, regions, or communities there are there unmet needs, broken processes, or problems around participation and accountability could be remedied through stronger collaborations and transparency around equitable data
- Gaps in need because our definition of data is so limited that we are not collecting all relevant data, (need broader but detailed definition)
- Data security concerns while important can create lengthy time delays and interfere with timely sharing
- Federal rules can prohibit sharing, which can create or feed mistrust
- Need for education around what equity data means and how it cannot be used, (with a goal of minimizing misuse of data)

AISP

3 October 2022
Re: Request for information; Equitable data engagement and accountability

To the Office of Science and Technology Policy:

Actionable Intelligence for Social Policy (AISP), based at the University of Pennsylvania, works with state and local governments to connect agency partners so data can be shared securely and used collaboratively to improve outcomes. The AISP Network currently includes 23 states, 9 counties, and 4 large cities that are actively sharing and linking cross-agency data, and we convene regularly to share learnings and best practices. For more than a decade, we have supported and observed significant growth, impact, and innovation in this field, including a more explicit emphasis on equity in data use — and more requests from governments seeking to engage community members and partners in their data sharing efforts.

In response to this growing demand, AISP has developed new tools, training, and technical assistance. Since 2019 we have led a diverse workgroup of civic data partners to co-create strategies and identify best practices to center racial equity and community voice in data integration efforts. This group collaboratively developed A Toolkit for Centering Racial Equity Throughout Data Integration (May 2020). In the Toolkit, we put forward a shared vision for a new kind of data infrastructure — one that seeks to share power and knowledge with those who need systems change the most — and offer strategies to begin the work as well as concrete examples of promising and problematic practice.

Now, we are facilitating our inaugural Equity in Practice Learning Community (EiPLC), which is our next step toward supporting sites in planning and implementing promising practices in centering racial equity in data access and use. The EiPLC offers training, technical support, and peer learning opportunities to state and local data integration efforts as they work to share and build power with community through more equitable data access and use. The six participating sites — Baltimore, MD; Broward County, FL; Charlotte-Mecklenburg, NC; Connecticut; King County, WA; and Oregon — are building, testing, and adapting new models for incorporating community voice in key decisions about cross-sector data use at the state or local level. More information is available on our website: https://aisp.upenn.edu/eiplc/

Through the development of the Toolkit and our Learning Community, we have affirmed that community participation should be understood as an on-going and iterative process that supports trust-building with impacted people and populations. Importantly, we have seen that meaningful participation requires that collaborators are resourced to do the work. Agency and partner staff need dedicated time and training, and compensation for community members should be established early on in project budgets.

We have also found that this work can feel overwhelming in it's depth and breadth, so it is helpful to orient this work around the data life cycle to determine where process changes can be made. We encourage the federal government to do the same, considering how collaboration and equity can be encouraged at each stage: planning, data collection, data access, use of algorithms and statistical tools, data analysis, and reporting and dissemination.

Below we offer state and local examples of promising, equity-oriented engagement practices at each stage of the data life cycle for your consideration:

- **Planning:** Utilize Participatory Action Research models to center the expertise of people with lived experience on a given topic and offer training and sustained engagement to this group from the project outset (See the Hartford Opportunity Youth Collaborative)
- **Data collection:** Work directly with clients (people in the data) and staff (people who collect the data) to develop equity-oriented data collection standards. The process and the outcomes can address concerns, gain trust and buy-in, and better align values across groups. (See Allegheny County, PA DHS in *A Toolkit for Centering Racial Equity Throughout Data Integration* [*Toolkit*], p. 54)
- **Data access:** Host easily accessible and high-quality information about what data are collected, stored, and maintained within the data system. This can help close knowledge gaps between the public, agency analysts, and researchers. For example, clear process around request forms and approvals provide context for how agencies, residents, and providers can access data based on their user type and tools like data use dictionaries provide context around what data are and are not available, and why (See Kentucky Center for Statistics in *Toolkit*, p. 24)
- **Use of algorithms/statistical tools:** Involve community members in conversations about new tools or systems by working with activists and data advocates to develop accessible language and formatting for engagement with a broad audience. Materials should clearly communicate risks and benefits of algorithms and statistical tools (See Automating.NYC website in *Toolkit*, p. 27)
- **Data analysis**: Disaggregate data to analyze intersectional experiences by race, class, gender, and other identities. Consider how consent policies influence who is represented in a data set for analysis (see King County DCHS Data Insight Series)
- **Reporting & dissemination:** Report data in an actionable — and findable — format to improve the lives of those represented in the data, and provide public access to aggregate data to help drive toward change. Include stories as a complement to quantitative findings to better contextualize the lived experiences behind the numbers (See Charlotte-Mecklenburg Housing & Homelessness Data Dashboard)

The ethical sharing and use of data is achieved when strong and transparent governance is at the foundation of all collaboration. Most efforts are largely funded with taxpayer dollars, so clear communication among partners about what data are being shared and for what purpose is essential to accountability. Demonstrating and communicating the value of integrated data to residents, agencies, and collaborators also builds social license. Policies, protocols, and documentation of data use — as well as any specific projects the effort is engaged in — should be readily available to the public in understandable and accessible formats.

While some of these practices highlighted above may be more feasible at the local level, many practices (e.g. creating metadata standards and creating accessible modes of communicating and sharing data) apply equally in the federal context and in collaborations across levels of government. In addition, the federal government has a key role to play in terms of developing standards and resourcing state and local grantees to test and refine these practices.

We're grateful for the opportunity to contribute our thoughts to the Office of Science and Technology Policy and the Office of Management and Budget, whose emphasis on equitable engagement is encouraging and urgently needed, and we appreciate the broad set of voices being brought to the conversation through this RFI. We are excited for the work ahead.

We write on behalf of the Asian Pacific Institute on Gender-Based Violence (API-GBV) to respond to the Office of Science and Technology Policy (OSTP)'s Request for Information, FR Doc # 2022-19007, 87 Fed, Reg 54289 (Sept. 2, 2022). We applaud the Biden-Harris Administration's executive order 13985 on equity and the President's Vision for Equitable Data.

Thank you for the opportunity to provide input regarding equitable data engagement and accountability.

API-GBV is a national resource center on domestic violence, sexual violence, trafficking, and other forms of gender-based violence in Asian and Pacific Islander and immigrant communities. API-GBV works in partnership with various national networks of advocates, community-based service programs, national and state organizations, legal, health, and mental health professionals, researchers, policy advocates, and activists from social justice organizations to better address the needs of Asian, Asian American, and Pacific Islander (AAPI) and immigrant victims. In addition, as a Department Justice (OVW & OVC) and Health and Human Services (FVPSA) funded technical assistance provider, API-GBV analyzes critical issues, promotes culturally relevant evidence-informed intervention and prevention, provides consultation, technical assistance, and training; develops resources, conducts and disseminates research and impacts systems change in our work with federal agencies, state and local governments, state and local human services and housing agencies, courts, law enforcement, and prosecutors.

Please consider the following responses to the questions posed.

First, there needs to be ***updating federal race and ethnic data standards, and collection of government wide standards for demographic data beyond existing categories,*** including language, disability, gender identity, and sexual orientation. For example, for community-based organizations in the AAPI community, report data that separates Asian, Native Hawaiian and Other Pacific Islander categories, as well as a Middle Eastern and North African category is vital for implementation of improved data initiatives.

There have been numerous lessons learned during the COVID-19 pandemic, during which the racial and ethnic disparate impacts have been frequently acknowledged, agencies such as the Centers for Disease Control and Prevention continue to report data combining the separate Asian and Native Hawaiian and Other Pacific Islander categories, and often fail to report any data about Asians, Native Hawaiian and Other Pacific Islanders, and American Indians and Alaska Natives, lumping them into an "Other" category. *See*, https://www.cdc.gov/mmwr/volumes/70/wr/pdfs/mm7015e3-H.pdf .

Disaggregation by more specific race and ethnicity categories is essential to understanding inequities and disparities and advancing equity. We urge OSTP to support even more granular disaggregation than the above listed categories when appropriate, and to continue to work with state and local governments to support additional disaggregation where there are more diverse racial and ethnic subpopulations. For example, the COVID-19 pandemic has demonstrated the importance of collecting, analyzing, and publicly reporting more granular disaggregated race and ethnicity data. Disaggregated data have been vital to understand the disproportionate impact of COVID-19 on Bangladeshi in New York, Filipino nurses, and the Marshallese in Arkansas.

In addition, the collection and reporting of data about the primary and preferred languages that individuals speak, read, and write when communicating with federal, state, and local agencies is critical. For example, the ***collection of demographic data should be done in ways that provide meaningful language access***. Without basic language access in basic data collection efforts, including access for individuals with visual, hearing, and other communications barriers, there will be inaccurate data about inequities and barriers to access and utilization of those federal programs and services. For example, though statistics show that Asian Americans in the U.S. are faring relatively well through the COVID-19 pandemic, the data fails to include the most vulnerable Asian-Americans, such as those who have limited English proficiency, who often don't participate in such surveys. See, https://www.scientificamerican.com/article/its-a-myth-that-asian-americans-are-doing-well-in-the-pandemic/?

Unfortunately, various surveys that government agencies rely on to develop policy and programs are hampered by this shortcoming. One example of lessons learned from existing collaborations is from the Centers for Disease Control and Prevention, that supports standardized telephone surveys conducted in ***English and Spanish,*** but fail to meaningfully survey those whose primary language is not English or Spanish. For example, the ***Behavioral Risk Factor Surveillance System.*** The **Behavioral Risk Factor Surveillance System (BRFSS)** is an annual national system of health-related telephone surveys that collect state data about U.S. residents regarding their health-related risk behaviors, chronic health conditions, and use of preventive services. BRFSS collects data in all 50 states as well as the District of Columbia and three U.S. territories. Though BRFSS completes more than 400,000 adult interviews each year, making it the largest continuously conducted health survey system in the world, the data collected does not reflect information from communities with more recent immigration, and with greater numbers of individuals who are limited English proficient.

OSTP should draw upon existing models for developing whole of government standards for identifying and meeting language access needs, as well as conducting surveys in languages beyond English and Spanish. For example, the Federal Emergency Management Agency has a language access plan that provides individual assistance materials in 20 languages and alternate formats, including Braille and large print. See, U.S. Department of Homeland Security Federal Emergency Management Agency, Language Access Plan, 2016, https://www.dhs.gov/sites/default/files/publications/FEMA%20Language%20Access%20

Plan.pdf. The Office of the National Coordinator for Health Information Technology within HHS also use standards with full disaggregation of primary and preferred language data. See, International Organization for Standardization, Language Codes 639, http://www.iso.org/iso/home/standards/language_codes.htm.

Furthermore, minimal data about individuals in the U.S Territories also continues to be a challenge. Any national data collection surveys should include data from individuals in the U.S. territories in order to better address the longstanding disparities that exist among residents in territorial communities.

OSTP should also promote the ***Strengthening of Privacy Practices and Transparency.***To improve participation in data collection and accuracy in the data, the federal government must build trust among the people from whom data is collected. The federal government should work to ensure that participants understand the purpose of the data collection; including ***how individuals can opt out of sharing data*** that is not required, what the data will be used for, how information will be shared and with whom, how the relevant agenc(ies) will protect the data against disclosure of personally identifying information, what remedies individuals have if their confidentiality or privacy has been violated, and what recourse individuals have for breaches or misuse of their data. For survivors of domestic violence, sexual assault, and stalking, these considerations are vital, so that they are not put at further risk of harm and trauma, particularly in light of increased electronic and data sharing. Researchers and others collecting data must also take care to ensure that the questions used to collect data are racially and culturally sensitive.

For example, OSTP should promote ***expanding the use of alternative identifiers or allow applicants to omit identifiers,*** rather than seeking SSN's wherever possible, to help protect the safety and privacy of survivors fleeing domestic violence and stalking, as well as to limit the chilling impact for applicants who have ITIN's. For example, ***HUD's HMIS Data Standards,*** 69 FR 45888 (July 30, 2004), available at https://www.govinfo.gov/content/pkg/FR-2004-07-30/pdf/04-17097.pdf which seek the collection of Social Security Numbers, along with other extensive personal identifying information, should be modified and met with less intrusive requirements to reduce the risk of harm to survivors, as well as decrease the chilling impact on others who lack SSN's.

In addition, requests from federal agencies to verify applicant's immigration or citizenship status have been misinterpreted by some state or local agencies to require submission of immigration documents or SSNs in situations such information is not required. This in turn causes additional confusion and latitude for state agencies to set more stringent documentation requirements than necessary. Agencies should use guidance such as the HHS/USDA issued "Tri-Agency Guidance" in 2000 and additional guidance related to CHIP in 2001 and SNAP in 2011 to help reduce the invasive, chilling effect of immigration status-related questions on benefits applications.

Again, thank you for the opportunity to provide input, and please feel free to contact me with any questions or concerns.

ASIAN PACIFIC INSTITUTE ON GENDER-BASED VIOLENCE
Grace Huang
Director of Policy
Pronouns: She/Her/她/Ella
E: [redacted] | **T:** [redacted]
W: [redacted] | **A:** Seattle Office

Hello,

My name is Angel Algarin and I am an Assistant Professor at Arizona State University's Edson College of Nursing and Health Innovation. As a social epidemiologist interested in HIV prevention research, I had the opportunity to work with the Florida Department of Health to analyze data from the National HIV Behavioral Surveillance Survey (a survey conducted in various cities amongst the United States among at risk populations). While analyzing the data at the city level was helpful, my analyses could have been more robust if I were able to leverage the full national NHBS dataset. However, the time and work that it takes to request and access these data make it extremely difficult. I would like to formally suggest that processes of sharing health data collected by federal agencies with the community and researchers be streamlined to allow more rapid access to investigators and community members who need these data to evaluate and inform their work. This streamlining could include building a central data request portal and disseminating information into the community on how to use the portal to gain access to the data they need.

Thank you!

Sincerely,

Angel B Algarin PhD, MPH
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October 3, 2022

ATTN: National Science and Technology Council Subcommittee on Equitable Data
White House Office of Science and Technology Policy
Eisenhower Executive Office Building
[redacted]
Washington, D.C. 20504
Submitted by email to [redacted]

Re: Request for Information; Equitable Data Engagement and Accountability

Dear Director Nelson:

Thank you for the opportunity to respond to the Office of the Science and Technology Policy's Request for Information on Equitable Data Engagement and Accountability.

Benefits Data Trust (BDT) is a national nonprofit that improves health and financial security by harnessing the power of data, technology, and policy to provide dignified and equitable access to assistance. Together with a national network of government agencies and partners, we efficiently connect people today to programs that pay for food, healthcare, and more while helping to modernize benefits access for tomorrow. Since 2005, BDT has assisted people in submitting over one million public benefits applications and secured more than $9 billion in benefits for households across the country, helping to reduce hunger and poverty and build pathways to economic mobility.

We bring more than 15 years of experience in using data and technology to target outreach and awareness campaigns to connect people to essential benefits and services such as the Supplemental Nutrition Assistance Program (SNAP), the Special Supplemental Nutrition Program for Women, Infants, and Children (WIC) and Medicaid, informing public policy strategies, and incorporating human-centered design to ensure services are informed by – and responsive to – clients' needs. We welcome the opportunity to be part of the conversation improving access to public benefits.

In our response, we address federal actions that can promote access to public benefits, including (1) Providing permission and guidance to states in leveraging data to engage in cross-program outreach and enrollment; (2) Providing resources for states to easily verify eligibility data; and (3) Supporting health care plans and providers with access to information about enrollment in public benefits. Such actions have the power to ease access to benefits and reduce the frustration of individuals seeking assistance.

Thank you for your consideration.

Rachel Gershon, Senior Policy Manager, [redacted]

Public benefits like SNAP, WIC, and Medicaid are powerful tools to address personal deprivation, strengthen the economy, and encourage economic growth. Assistance reduces hunger, lifts people out of poverty, and substantially decreases mortality rates.[1] And yet, for years, public benefits policy has prioritized preventing fraud and abuse over promoting efficiency, effectiveness, or equity. This has exacerbated rather than reduced racial and other inequities. As a result, benefits are hard to access and use, with more than $80 billion in assistance going untapped annually, and millions of children, older adults, veterans, and families needlessly going hungry.[2] Government agencies collect the same information and documentation repeatedly and enforce archaic rules that prevent eligible people from receiving assistance.

Given advances in data and technology, the Biden administration has the opportunity to leverage equitable data and advance *true* program integrity that prevents fraud and abuse *and* ensures that eligible people receive assistance efficiently and equitably**.** As noted in the White House National Strategy on Hunger, Nutrition, and Health (National Hunger Strategy"), states should engage in "cross-enrollment of eligible people across SNAP, Medicaid, and other federal programs."[3] In order to engage in cross-program outreach and cross-enrollment activities, states and localities have voiced to us a need for guidance. **Notably, coordinated permission and guidance at the federal level regarding how to leverage data (with appropriate consent) would empower states, localities, and community-based organizations to ensure better access to public benefits for their communities.** In addition to building upon the National Hunger Strategy, these recommendations fit well with President Biden's Executive Order on Transforming Federal Customer Experience and Service Delivery to Rebuild Trust in Government, which aims to meet Americans experiencing key life events with equitable access to assistance.

1. What are examples of successful collaborations involving equitable data between the Federal government and (a) Tribal, territorial, local, and State governments, or (b) local communities?

Below are examples of successful collaboration by federal and state government entities to improve access to public benefits.

A. Efforts to leverage data to conduct effective outreach. As more people know about the assistance available to them, more will be able to access them. States and the administration have engaged in innovative ways to let people know which benefits are available to them, especially using enrollment data for benefits with similar eligibility criteria. For example:

- **Using Pell Grant data to increase access to EBB and ACP.** The Education Department informed Pell Grant recipients about the Emergency Broadband Benefit (EBB) and is emailing over six million Pell Grant recipients this award year to let them know that they are eligible for the Affordable Connectivity Program (ACP) and how to sign up.[4]
- **Using other data sources to increase access to ACP.** The Social Security Administration, Department of Education, Department of Veterans Affairs, and Department of Housing and Urban Development are delivering outreach for the ACP.[5]
- **Using SNAP and Medicaid data to increase access to WIC.** BDT partners with several states, using SNAP, Medicaid, and other administrative data to provide data-driven outreach to individuals likely eligible for WIC through text messaging, with evidence of increased WIC certification.[6] Several other state WIC agencies have used existing data to identify individuals likely eligible for WIC, notified those individuals, and helped them apply.[7] The United States Department of Agriculture (USDA) is currently

implementing new WIC funds from the American Rescue Plan to increase outreach efforts, and BDT looks forward to how data-driven outreach can be leveraged.

- **Using Medicaid data to increase access to SNAP.** A peer-reviewed study by economists at the Abdul Latif Jameel Poverty Action Lab and BDT found that targeted outreach and telephonic application assistance *tripled* enrollment in SNAP among Medicaid enrollees aged sixty and older. This intervention was observed to address equity considerations, with increased enrollment for Black individuals, individuals with non-English primary languages, and older adults.[8]
- **Using data to connect students to assistance.** The Department of Education sent a Dear Colleague Letter to all public and private higher education institutions informing them that they can use Free Application for Federal Student Aid (FAFSA®) data to communicate with students about other public benefit programs that they may be eligible for, such as SNAP and ACP. The letter encourages colleges to coordinate with campus stakeholders to inform their campus community of these benefits.[9] And, as announced last week in the National Hunger Strategy, "USDA and [the Department of Education] will establish a Memorandum of Understanding (MOU) to conduct joint outreach to Pell Grant recipients and others to inform them of their potential eligibility for SNAP benefits."[10]

B. Other efforts to facilitate enrollment and maintenance of coverage

- **Using already-verified information to facilitate enrollment in health care assistance programs.** The administration leverages the Federal Data Services Hub to assist states with Medicaid, Advanced Premium Tax Credit, and Basic Health Program eligibility verification via secure, verified information.
- **Using already-verified information to facilitate enrollment in phone and internet assistance.** The administration leverages the National Verifier to assist with Lifeline and ACP eligibility verification via secure, verified information.[11]
- **Engaging in cross-program enrollment.** There are a number of pathways for states to use already-verified information to engage in cross-program enrollment, including *ex parte* renewal, Express Lane eligibility, and the Combined Application Project.[12] The Centers for Medicare and Medicaid Services, in particular, has been leveraging cross-program enrollment to address access in Medicaid (including *ex parte* guidance in anticipation of the end of the Public Health Emergency) and Medicare Savings Programs (with the pending enrollment processes Notice of Proposed Rule-making signaling the use of Low-Income Subsidy information to streamline Medicare Savings Program enrollment).[13] New Mexico just launched a new program to automatically connect eligible families with WIC when they apply for SNAP, Medicaid, or Temporary Assistance for Needy Families (TANF).[14]

C. Efforts to provide the states and the public with up-to-date program information

- **Providing the public up-to-date program information.** The Centers for Medicare and Medicaid Services (CMS) hosts a dynamic set of tools to share waiver and state plan amendments documentation that informs states and the public of current Medicaid policy.[15] USDA offers a website of state-by-state COVID-19 waiver document and waiver approvals for SNAP.[16] Access to data oncurrent program parameters allows researchers, evaluators, and the public to consider how those rules affect access to public benefits for individuals and the equitable administration of those benefits.

2. Among examples of existing Federal collaborations with (a) Tribal, territorial, local, and State governments or (b) local communities involving equitable data, *what lessons or best practices have been learned from such collaborations*?

In the course of using data to engage in application assistance, BDT has a number of lessons learned for using data to ensure equitable access.

A. Use data to engage in a coordinated, comprehensive, "no wrong door" approach to benefits access. In order to ensure that people can effectively get the benefits information they need, it is crucial that state and federal governments offer multiple access points – whether online, over the phone, in-person at government offices, or in-person at sites in the community where people already frequent.

B. Consider how siloed policy and administration at the governmental level can amplify barriers for the individual. For instance, separate applications for different benefits with similar eligibility requirements, requiring submission of the same verifications to different agencies, uncoordinated renewal timelines, and siloed policy, administration, and compliance requirements broadly increase burdens on a population already experiencing chronic scarcity. It also puts pressure on the human services workforce with added complexity.

C. Consider how program integrity standards and program evaluation activities may hamper access initiatives. Initiatives to use data to improve access may run into barriers if incentives are not aligned on the program integrity side of program administration. Current program integrity measures disincentivize administering agencies from pursuing solutions that reduce burdens and barriers to public benefits access, by focusing financial penalties and significant efforts to keeping ineligible people off benefits.

D. Incorporating clear consent language and increasing an individual's ownership of data can help provide guardrails in data-sharing processes. Building in consent for how individuals want their data shared, and how they want to be contacted, can improve systems for maintaining benefits.

E. Include stakeholders who are participants, eligible non-participants, and community-based organizations that involve benefit design, implementation, and evaluation. Persons with lived experience with benefits have access to valuable data about how systems work, and how they can be better designed.

3. What resources, programs, training, or other tools can facilitate increased data sharing between different levels of government (Tribal, territorial, local, State, or Federal) related to equitable data?

Leveraging data to improve access to benefits holds promise, but it can be challenging for state and local governments to understand what is allowed. BDT has published resources to assist with this process, including: (1) A Medicaid churn toolkit for states to engage in data-informed practice to keeping eligible people enrolled[17]; (2) A WIC coverage toolkit for states to leverage data from Medicaid and SNAP to increase enrollment[18]; and (3) A SNAP texting guidebook to help county and state government staff address costly churn by leveraging text messaging.[19]

In addition, last week, the White House Conference on Hunger, Nutrition, and Health announced BDT's commitment to "publish a new toolkit in early 2023 to help states and higher education institutions identify and enroll eligible college students in public benefit programs like SNAP, Medicaid, and the new Affordable Connectivity Program"[20]

7. In which agencies, programs, regions, or communities *are there unmet needs, broken processes, or problems related to participation and accountability* that could be remedied through stronger collaborations and transparency around equitable data?

Please find below our set of recommendations for remedying unmet needs in the public benefits space using stronger collaborations and transparence around equitable data.

A. Make it easier for individuals to understand their public benefit options. Despite meeting the eligibility criteria for multiple public benefit programs, individuals often connect to only a subset of programs for which they are eligible. Cross-benefit outreach and enrollment assistance can be a particularly successful strategy for states to connect individuals with needed benefits. We recommend that the Biden administration build on the National Hunger Strategy to provide funding and guidance to support successful outreach and enrollment activities. In particular, the administration should consider:

- **Publishing guidance for states to feel more comfortable engaging in cross-benefit outreach activities and enrollment activities.** Leveraging data that government agencies already have on hand can unlock opportunities to increase enrollment across benefit programs, but many agencies grapple with data security and privacy concerns that can make them hesitant to take advantage of these opportunities. For example, specific guidance on data-sharing between benefit programs to facilitate outreach and enrollment can help states reach across silos to help eligible individuals access benefits. When states express hesitance for how eligibility could be streamlined across two programs, joint guidance from both federal agencies overseeing those benefits would help spur positive changes.
- **Creating dedicated (or braided) funding that facilitates cross-benefit outreach and enrollment activities.** Even when funding is available to government agencies and community-based organizations to promote benefits access, it is typically focused on one (or just a few) benefits, causing efforts to become siloed. Dedicated and coordinated funding can help state agencies fund cross-benefit outreach.

B. Make it easier to verify eligibility. Verifying documentation is another area where an individual can face major barriers in accessing and maintaining benefits. States and localities have engaged in creative solutions for allowing documents to be uploaded using multiple methods. For example, Minnesota WIC's policies allow documentation obtained by phone to satisfy income, residence, and identification requirements.[21] The federal government could do more to help states verify eligibility using existing data sources such as the Federal Data Services hub and the National Verifier/Lifeline.

- **Leverage federal data sources to streamline verification processes.** Federal data sources such as the Federal Data Services Hub and the National Verifier should be expanded to help states more easily verify documents and reduce the frustration of applying for and maintaining benefits.[22] They offer secure, verified information that states can use. We can improve the system by allowing more benefits to utilize these tools. For example, state agencies can use the Federal Data Services Hub to verify Medicaid eligibility but are not allowed to use that same information to verify SNAP eligibility. States should be allowed to leverage the Federal Data Services Hub to verify eligibility. The National Verifier could be leveraged to expand beyond its existing programs to reduce the burden of multiple verifications on states and individuals.

C. Support health care plans and providers with access to information about enrollment in public benefits. In our work with health plans, we hear that they often lack sufficient and timely access to data on what public benefits their members are not enrolled in. Sharing such information (with the member's consent) can improve population health and promote health equity. For example:

- Knowledge of a member's enrollment status in public benefits is helpful for determining opportunities to connect that member with assistance.
- Information about upcoming renewal requirements can be helpful in reminding members to keep their contact information up to date with state systems and offering targeted assistance for people who need help renewing their benefit.
- Knowing which members have been recently disenrolled from public benefits can help plans and providers identify who is at risk of losing access to basic assistance.

We are glad to see that the Office of the National Coordinator for Health Information Technology (ONC) and its partners are working on making social drivers of health needs and interventions part of a standardized and well-adopted part of Health Information Systems, including electronic health records. We are also glad to see the Trusted Exchange Framework Common Agreement (TEFCA) includes government benefits as a data element that can be shared and look forward to its implementation and further opportunities to guide the process.

We recommend that, in the process of including public benefits information into health information systems, care is taken to consider which information would be most helpful for plans and providers. For example, data on upcoming renewals and recent dis-enrollments may be particularly helpful for identifying members with application assistance needs. Routinely updating information is also important, as members can come on and off public benefits frequently.

D. Research. Understanding the power of public benefits, and the best way to improve them, relies on research. We recommend that the administration consider:

- Encouraging states to publish data that can be used to analyze how well a benefit is taken up among eligible individuals, including numbers of applications, denial rates, denial reasons, disenrollment rates, and disenrollment reasons, disaggregated by demographic factors important for equity.
- Funding research to understand (1) issues related to equity and access to public benefits; and (2) the relationship of public benefits to economic, health, and education (especially higher education) outcomes.
- Funding quantitative, qualitative, and mixed-methods research that includes individuals with lived experience in research design and planning.
- Providing guidance to states regarding engaging in equity research, including considerations for disaggregating data, defining equity, and measuring equity.

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[1] Brian P Lee, Jennifer L Dodge, and Noral A. Terrault. Medicaid Expansion and Variability in Mortality in the USA: A National, Observational Cohort Study. The Lancet Public Health 7:1 (December 2, 2021) (Linking Medicaid expansion to decreased mortality). Signe-Mary McKernan, Caroline Ratcliffe, and Breno Braga. The Effect of the US Safety Net on Material Hardship Over Two Decades. Journal of Public Economics 197 (May 2021) (Increased participation in TANF, SNAP, Medicaid, and the Children's Health Insurance Program (CHIP) decreases hunger and other material hardship).

[2] The figure is based on BDT estimates of the dollar amount of benefits that eligible individuals are not enrolled in based on the most recent government data publicly available.

[3] White House. Biden-Harris Administration National Strategy on Hunger, Nutrition, and Health (September 2022)

[4] U.S. Department of Education. Department of Education Launches Outreach Campaign to Millions of K-12 Students and Federal Pell Grant Recipients Now Eligible for Monthly Discounts on Broadband Internet Service (May 12, 2021). White House. Fact Sheet: Vice President Harris Marks Important New Milestone in Administration's Efforts to Cut Costs for American Families (July 21, 2022). The White House. Biden-Harris Administration Making "Back to School" Drive to Help Students and Families Get Free High-Speed Internet (September 15, 2022).

[5] White House. Fact Sheet: Vice President Harris Marks Important New Milestone in Administration's Efforts to Cut Costs for American Families (July 21, 2022).

[6] Maneely, J. and Neuberger, Z. Benefits Data Trust and Center on Budget and Policy Priorities. Using Data Matching and Targeted Outreach to Enroll Families with Young Children in WIC (2022).

[7] Center on Budget and Policy Priorities and Benefits Data Trust. Assessing Your WIC Certification Practices (2022).

[8] Amy Finkelstein and Matthew J. Notowidigdo. Take-Up and Targeting: Experimental Evidence from SNAP. The Quarterly Journal of Economics. 134(3):1505-1556 (August 2019)

[9] United States Department of Education. Biden-Harris Administration Takes Action to Support Students' Basic Needs and Mitigate the Spread of COVID-19 at Colleges and Universities (January 20, 2022)

[10] White House. Biden-Harris Administration National Strategy on Hunger, Nutrition, and Health (September 2022)

[11] For more information on the federal data services hub and the national verifier, see Sonal Ambegaokar, Zoë Neuberger, and Dorothy Rosenbaum. Opportunities to Streamline Enrollment Across Public Benefit Programs. Center on Budget and Policy Priorities and Social Interest Solutions (November 2, 2017)

[12] see Sonal Ambegaokar, Zoë Neuberger, and Dorothy Rosenbaum. Opportunities to Streamline Enrollment Across Public Benefit Programs. Center on Budget and Policy Priorities and Social Interest Solutions (November 2, 2017)

[13] Centers for Medicare and Medicaid. State Health Official Letter RE: Promoting Continuity of Coverage and Distributing Eligibility and Enrollment Workload in Medicaid, the Children's Health Insurance Program (CHIP), and Basic Health Program (BHP) Upon Conclusion of the COVID-19 Public Health Emergency (March 3, 2022); Centers for Medicare and Medicaid. Fact Sheet: Streamlining Eligibility & Enrollment Notice of Proposed Rulemaking (August 31, 2022).

[14] New Mexico first in nation to connect Human Services Department and Department of Health WIC services to combat child hunger (June 9, 2022)

[15] See CMS Waiver List and Medicaid State Plan Amendments

[16] See SNAP: COVID-19 Waivers by State

[17] Jamila McLean, BDT. Medicaid Churn Toolkit.

[18] Center on Budget and Policy Priorities and Benefits Data Trust. Increasing WIC Coverage Through Cross-Program Data Matching and Targeted Outreach (2022)

[19] Katie Sullivan, Sara Soka, and Keith Barnes. Using Text Message Outreach to Reduce SNAP Churn (2021)

[20] The Biden-Harris Administration Announces More than $8 Billion in New Commitments as Part of Call to Action for White House Conference on Hunger, Nutrition, and Health (September 28, 2022)

[21] Center on Budget and Policy Priorities and Benefits Data Trust. Assessing Your WIC Certification Practices (2022).

Advancing Equity with Community Data Partnerships: We Need to Hear from You

https://www.whitehouse.gov/ostp/news-updates/2022/09/06/advancing-equity-with-community-data-partnerships-we-need-to-hear-from-you/

Response due 10/3/2022 5 pm et

This response to the OSTP Equitable Data RFI was Authored by Robert Gradeck at the University of Pittsburgh's Western Pennsylvania Regional Data Center from feedback provided by colleagues with the Black Equity Coalition (BEC) in Allegheny County, Pennsylvania. Mr. Gradeck is a partner in the Data Justice Working Group of the BEC. Email: [redacted]

The Western Pennsylvania Regional Data Center is a collaborative open data partnership between the University, Allegheny County, and the City of Pittsburgh. It . Staff from the Regional Data Center maintain a community open data infrastructure, work with publishing partners to establish open data pipelines, and provide services, data tools, education, and support to data publishers and data users in the broader community through its role as a civic data intermediary.

The Black Equity Coalition (BEC) supports the creation of equitable systems to affirm the dignity of every human being through collaborations, networks, and policymaking.Originally focused on responding to COVID-19, the Coalition quickly realized that the pandemic's disproportionate impact on the health, well-being, and economic stability of people of color highlighted the need to address institutional racism and structural impediments that continue to plague Black, undervalued and underserved communities.

Questions and responses

1. What are examples of successful collaborations between the Federal government and (a) Tribal, territorial, local, and State governments or (b) local communities involving equitable data?

N/A in our role

2. Among examples of existing Federal collaborations with (a) Tribal, territorial, local, and State governments or (b) local communities involving equitable data, what lessons or best practices have been learned from such collaborations?

- The establishment of data standards that center equity can be a way to build better practices in state and local governments. Mandating the adoption of federal standards when reporting data to the Federal government can allow for progress and comparable data even where state and local agencies are reluctant to change. The Federal government can mandate adoption of data classification systems that accurately represent people's identity and allow for disaggregated, intersectional reporting. They can also develop standards for capturing data on race and ethnicity, gender identity, and disability status. If processes had been in place at the start of the pandemic, we may have been better-able to measure the disparity in infection and vaccine access in a more-timely and more-accurate fashion through the Black Equity Coalition. These standards can be formal (as with crime reporting), or voluntary (as was the case through the White House Police Data Initiative).

3. What policies, resources, programs, training, or other tools can facilitate increased data sharing between different levels of government (Tribal, territorial, local, State, or Federal) around equitable data?

- The Federal government can mandate improvements to data practices by state and local agencies, and should provide funding for compliance, along with technical assistance to support adoption of these standards. It's vital that these standards be developed in partnership with state and local governments and members of many different communities so that they reflect the values, identities, and concerns of community members.

- Federal staff can also engage with private-sector software firms and open source ecosystems to ensure that products used by state and local governments are compliant with Federal standards and reduce friction around data sharing.

- We are excited about the potential of data collaboratives to make software affordable and embrace opportunities to make our data more-equitable. The Federal government can support the development and maintenance of these systems, and incentivize their developers to incorporate principles of data equity and data justice into the products. These systems were summarized in a recent report by Waldo Jaquith and Robin

Carnahan prior to their appointment to the U.S. General Services Administration in 2021 (https://softwarecollaborative.org/landscape-report.html).

- Collaborations between Federal agencies and local governments can be developed and strengthened when Federal agencies engage with communities of practice involving local governments. Our partners in the City of Pittsburgh and Allegheny County are engaged with the Civic Analytics Network, GovLab, and Metrolab. Smaller governments are connected through locally-managed networks such as councils of government and CONNECT, a municipally-focused initiative based at the University of Pittsburgh.

- Federal agencies can also strengthen collaborations by providing technical assistance to state and local governments in data sharing, data collection, data management, analytics, privacy, and data use. Federal staff have developed a considerable amount of expertise in equitable data all across the data lifecycle, and state and local governments would benefit from a relationship. This federal-state-local collaboration already happens through the decennial Census' Complete Count Committees, and can enhance data equity.

- Federal agencies can also continue to encourage state and local agencies to adopt transparency as a core value and open data as a key practice. Government agencies at all levels should be encouraged to use open data as a primary mechanism for publishing and sharing non-sensitive data.

- Partnerships across governments can be encouraged in program design and incentivized through funding opportunities.

4. What policies, resources, programs, training, or other tools can expand opportunities for historically underrepresented scholars and research institutions to access and use equitable data across levels of government?

- Funding for student internships, and fellowships can help to provide opportunities for underrepresented scholars to work with accessible data in government.

- Dedicated funding for early-career researchers and scholars can also help to provide opportunities to be engaged in equitable data partnerships.

- Targeted funding opportunities enable researchers to work at the intersection of data and community.

- Providing career incentives for faculty to engage in community partnerships can also have an impact, and community partnerships should be given weight in promotion and tenure processes.

5. What policies, resources, programs, training, or tools can increase opportunities for community-based organizations to use equitable data to hold government accountable to the American public?

- Federal agencies should institutionalize a meaningful participatory role for community members in data governance processes. Establishment of an inclusive framework would shift power to community members, and enable them to have control over what data is collected, and how it is managed and used. In doing this, the Federal government can serve as a model for state and local jurisdictions.

- The Federal government is in a position to provide dedicated financial support to enable community data intermediaries to work with community partners and community members. The role of data intermediaries is vital in helping people find and use data to improve communities. The Regional Data Center serves as the Pittsburgh partner in the National Neighborhood Indicators Partnership (NNIP). We and our partners in the NNIP peer learning community often struggle to find dedicated support to provide direct technical assistance to community organizations in the use of data, and often are unable to meet community demand for our services due to a lack of dedicated funding.

- Public and academic libraries can also play vital roles in helping people use data. Federal governments can also support libraries as key institutions in civic data ecosystems. Through the Civic Switchboard project (funded by the Institute of Museum and Library Services), we explored how to support libraries to build roles in their civic data ecosystems (https://civic-switchboard.github.io/).

- Capacity-building and funding support for data literacy is also needed. In our community, we are launching a peer learning workshop series for data stewards and community leaders to emphasize the importance of thinking critically about creating, applying, and managing data and technology in our society. We'll encourage participants to identify how data and technology are used to reinforce systems of oppression so that they can shift power to people that are too often marginalized in our society. In these workshops, participants will learn to ask questions about data and technology, reflect on how their actions and decisions impact people and communities, and begin to institutionalize the values of equity, fairness, and justice into the data and technology practices and infrastructures of their organizations.

- Algorithmic transparency initiatives have grown across the world, and the Federal government is in a position to be more transparent in the ways that it uses algorithmic systems to make decisions. At the University, Pitt Cyber managed the Pittsburgh Task Force on Public Algorithms to establish best practices and guidance for municipalities looking to create systems of algorithmic accountability. https://www.cyber.pitt.edu/algorithms

6. What policies, resources, programs, training, or tools can make equitable data more accessible and useable for members of the public?

- Open data should continue to be a priority of the Federal government. There is room for improvement in improving the methods and standards by which Federal data is shared, and we encourage continued focus on the use of data to inform federal policymaking efforts.

- State and Federal agencies are in a position to encourage local communities to collaborate on open data. The Regional Data Center operates a shared infrastructure in our region, and other communities should be encouraged to explore collaborative open data initiatives.

- The Federal government can devote additional resources for the creation of contextual data documentation. This would build additional confidence and trust in data, and enable people to use data more-responsibly. Datasheets or data guides/read-me's are some formats that have been used to capture added context.

- Efforts to improve broadband access and affordability in underserved and low-adoption communities should continue so that more people have the bandwidth to access important community information.

- Dedicated federal staff in each agency can serve as data navigators and data ambassadors to help people in local partnerships find federal data that is relevant to their work. It can sometimes be tough knowing who to talk with about data at a Federal level.

- Tools for accessing data should be designed with accessibility in mind so that people who don't speak English or those with different abilities can all have access to data.

- Federal agencies should also enhance current data catalogs and make them publicly-available so that people can determine how well particular datasets meet equity and justice principles. These catalogs can also be used to identify datasets that state and local governments are required to report to the Federal government.

7. In which agencies, programs, regions, or communities are there unmet needs, broken processes, or problems around participation and accountability that could be remedied through stronger collaborations and transparency around equitable data?

- People that are engaged in data work within the Federal government should be members of communities that are underrepresented and undervalued in data. This will strengthen the quality of equity-focused work at the Federal level, and build trust with local communities.

- Clear, transparent, accessible, and uniform processes should be established enabling community members to provide feedback about data to Federal agencies.

- Researchers using data from particular communities should make their findings available in open-access publications.

- In data projects and initiatives, community partnerships should be developed at the earliest stages, and community members should play meaningful roles and share power with public-sector agencies and researchers in the design of initiatives and research projects.

- Data that is disaggregated and intersectional should be made available if possible to inform community partnerships.

- Invest in building ongoing partnerships and relationships with community coalitions that extend beyond individual projects. We have a great data-focused coalition here in Pittsburgh with the Black Equity Coalition and would love to partner with Federal agencies.

- This work can also focus on helping community organizations shift power so that processes and practices can reflect community values and create community benefits.

Comments submitted as an individual

1. What are examples of successful collaborations involving equitable data between the Federal government and (a) Tribal, territorial, local, and State governments, or (b) local communities?

The most recent and compelling example from a health perspective is the All of Us study (https://allofus.nih.gov/). With it's goal of 1million participants with an over-sampling of marginalized identities (e.g., race, ethnicity, rurality, sexual and gender minority status), this is a clear example of a program designed to ensure marginalized populations are included and represented. Similar efforts to understand the experience of all Americans from a variety of perspectives (https://health.gov/healthypeople/priority-areas/social-determinants-health) will require active engagement with community leaders. The All of Us study wisely partnered with community-led organizations (e.g., the PRIDE Study) to faciliate LGBTQI+ involvement (https://www.joinallofus.org/lgbt)

2. Among examples of existing Federal collaborations with (a) Tribal, territorial, local, and State governments or (b) local communities involving equitable data, what lessons or best practices have been learned from such collaborations ?

Community-led remains the most robust method of ensuring community trust and involvement in efforts. This means providing resources to community-led organizations (https://jamanetwork.com/journals/jama-health-forum/fullarticle/2775211). As Assistant Commissioner of the Bureau of HIV/AIDS Prevention and Control, New York City Department of Health and Mental Hygiene, Dr. Oni Blackstock demonstrated the value of organizational capacity building grants specific to Black MSM-led and trans/NBNC-led grassroots organizations, microgrants to trans-led organizations, and the need to change the structure of our funding to contracted providers to ensure that they are reaching Black and Latinx MSM and trans women

3. What resources, programs, training, or other tools can facilitate increased data sharing between different levels of government (Tribal, territorial, local, State, or Federal) related to equitable data ?
There need to be accepted standards for data collection, documentation, and security. There similarly needs to be funding to support each of these steps; these are not one-and-done efforts.

4. What resources, programs, training, or other tools can expand opportunities for historically underrepresented scholars and research institutions to access and use equitable data across levels of government ?

There need to be larger repositories of various data sources with clear and easy guidance to access various levels of data. The All of Us study is another good example of this via their tiered access. However, the preference that researchers be part of academic institutions limits the possibility for community-led organizations to explore numerous data sources germane to their missions. There need to be additional vetting procedures to ensure community-led organizations are involved and able to access data.

5. What resources, programs, training, or tools can increase opportunities for community-based

organizations to use equitable data to hold government accountable to the American public ?

We need additional tools to understand the historical and every-day experience of discrimination. THese will help facilitate understanding of the downstream effects of various national, state, and institutional policies as well as interpersonal experiences that affect the health and well-being of everyone, particularly marginalized populations. We continue to use demographics (e.g., race, ethnicity, disability status, sexual identity, gender identity) as proxies of the experiences in every-day life when they are in fact poor proxies. Further, researchers and policy-makers have proven incapable of moving beyond identity to the root cause of adverse outcomes and inequities experienced by marginalized communities; people continue to be blamed for their poor outcomes because the data show differences by identities.

We need more robust and in-depth programs and trainings on exploring health equity and inequity and how better to measure these issues.

6. What resources, programs, training, or tools can make equitable data more accessible and useable for members of the public? are there unmet needs, broken processes, or problems related to participation and accountability

Sexual orientation and gender identity data continue to be inadequately collected across various surveys and surveillance systems. There have been numerous studies and calls for better SOGI data collection to even get an appropriate count of LGBTQI+ persons in the US:

https://www.nejm.org/doi/full/10.1056/NEJMp2032447

https://ajph.aphapublications.org/doi/abs/10.2105/AJPH.2020.305722

https://isgmh.northwestern.edu/2020/08/13/public-health-priorities-for-lgbtq-equity-during-covid-19-and-beyond/
We must have comprehensive and robust SOGI data collection across all platforms and systems to meet the needs of these marginalized populations.

<>http://www.carlstreed.com/<>
Thank you for your time and consideration of these critical issues,
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Comments submitted as an individual

CLEAN AIR
TASK FORCE

October 3, 2022

The White House Office of Science and Technology Policy
Eisenhower Executive Building
[redacted] NW
Washington, D.C. 20504

Submitted via email to [redacted]

Re: Recommendations in response to Request For Information: Equitable Data Engagement and Accountability, 87 FR 54269

Clean Air Task Force ("CATF") is pleased to provide responses to the Office of Science and Technology Policy's Request for Information on how Federal agencies can better support collaboration with other levels of government, civil society, and the research community around the production and use of equitable data. CATF is a global nonprofit organization working to safeguard against the worst impacts of climate change by catalyzing the rapid development and deployment of low-carbon energy and other climate-protecting technologies.

Our response to this RFI is informed by research conducted for CATF's Climate Equity Project, which seeks to determine how the clean energy transition can contribute to justice and equity, especially for disenfranchised and underserved communities, while achieving our mid-century climate goals. Part of this research focuses on the methodologies deployed at the Federal, state, and community levels to evaluate environmental impacts on communities and to develop parameters for defining "environmental justice" communities. CATF's analysis intersects with an ongoing dialogue among environmental justice scholars and organizers for decades as they have challenged norms around who collects authoritative environmental data and the processes whereby it is collected. The environmental justice community has raised questions about the nature of environmental data and whether it is equitable: What counts as data? What data is collected? How is it collected? Is it made accessible and usable to the public? Whose interests do the data serve?[1]

With the Biden-Harris Administration having declared a "whole-of-government" approach to environmental justice through the Justice40 initiative, it is an opportune moment to investigate such questions and the ways in which data shape environmental governance processes, particularly for disenfranchised and underserved communities. Justice40 does not explicitly mention data accessibility or usability, though the recommendations from the White House Environmental Justice Advisory Council reference community data input extensively and could signal a future push to incorporate it.[2] As such, the comments provided here focus specifically on

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[1] Dawn Walker et al., *Practicing Environmental Data Justice: From DataRescue to Data Together*, GEO: GEOGRAPHY AND ENVIRONMENT 4 (2018) https://rgs-ibg.onlinelibrary.wiley.com/doi/epdf/10.1002/geo2.61.

[2] Shalanda Young et al., *The Path to Achieving Justice 40*, THE WHITE HOUSE: EXECUTIVE OFFICE OF THE PRESIDENT: COUNCIL ON ENVIRONMENTAL QUALITY: BLOGS (July 20, 2021) https://www.whitehouse.gov/ceq/news-updates/2021/07/20/the-path-to-achieving-justice40/.

community-level environmental data and offer recommendations to make community-based environmental data collection and usability more equitable.

RFI Question 1. What are *examples of successful collaborations* involving equitable data between the Federal government and (a) Tribal, territorial, local, and State governments, or (b) local communities?

One of the landmark methods of collaboration involving environmental data is EPA's Environmental Information Exchange Network ("EN" or "Exchange Network"). Launched in 2002, this online forum is "an inter-governmental, collaborative partnership of EPA, states, territories, and tribes to foster better environmental management and decision-making through increased access to timely, high quality environmental information."[3] Using the Exchange Network, states, territories, tribes, universities, not-for-profit organizations, and others can share data with EPA and other partners securely online. This platform strives to support better environmental decisions through the improved exchange of, and access to, environmental data and information. To promote the continued growth of the EN, EPA makes grant funding available for eligible states, federally recognized tribes, and U.S. territories under the Exchange Network Grant Program in support of continued sharing of environmental data.

Partners range from state environmental agencies like the Alaska Department of Environmental Conservation and the Oklahoma Department of Environmental Quality to tribal groups like the Hualapai Tribe and the Navajo Nation. There are even some county-level partners, like the Snohomish County Department of Public Works. As of September 2022, there are 108 partners in the EN.[4]

Though the Environmental Information Exchange Network is an established framework within which collaborative knowledge sharing could contribute to equitable access to environmental data, it is somewhat limited in its scope and number of partners, so it is arguably not a "successful" collaboration yet. Having said that, the EN provides a strong example of what environmental agencies and scientists should aim to do: make environmental data accessible and easy to use.

There exist very few examples of Federal collaborations involving equitable environmental data. Nonetheless, the Strong Heart Study ("SHS") - the largest epidemiologic study of American Indian health in the United States conducted by the US National Institutes of Health ("NIH") – is exemplary for its respect of Indigenous Data Sovereignty or "the right of a nation to govern the collection, ownership, and application of its own data...deriv[ing] from tribes' inherent right to

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[3] UNITED STATES ENVIRONMENTAL PROTECTION AGENCY, *Learn about the Environmental Information Exchange Network*, https://www.epa.gov/exchangenetwork/learn-about-environmental-information-exchange-network (last visited Sept. 29, 2022).

[4] 18 of these are planned partnerships and not yet operational. View current partners map at ENVIRONMENTAL INFORMATION EXCHANGE NETWORK, PARTNER PROFILES, https://exchangenetwork.net/map-nodes/ (last visited Sept. 29, 2022).

govern their peoples, lands, and resources."[5] Investigators associated with the SHS subscribe to the doctrine that research requires full partnership and ongoing consultation with tribal communities. This collaboration between the NIH and the tribal communities demonstrates the effectiveness of a community-based participatory research approach which allows for the studied community to codesign data collection practices, establish safeguards for community protection, and inform best practices for data sharing within the community.

RFI Question 2. Among examples of existing Federal collaborations with (a) Tribal, territorial, local, and State governments or (b) local communities involving equitable data, what lessons or best practices have been learned from such collaborations?

Drawing on best practices demonstrated by the community-based participatory research approach, research should include relevant population groups in data collection exercises, including planning, data collection dissemination, and analysis of data. The data collection process should include means for free, active, and meaningful participation of relevant stakeholders, in particular the most disenfranchised and underserved populations. Following the collection process, any analysis of said data should be 'returned' to the community and shared in a culturally appropriate way.[6]

When it comes to data collection, communities of interest should be self-defining and should have the option to disclose or withhold information about their personal characteristics. Historically, there have been instances of misuse of data collected by state offices when the principle of 'do no harm' was disregarded. Data collection, analysis, and subsequent publication should not create or reinforce existing discrimination, bias, or stereotypes exercised against population groups.[7] Moreover, data disclosed to collectors must be protected and kept private so as to ensure the confidentiality of all participating individuals. Prior to data collection, it should also be made clear that participant responses are aggregated and thus completely anonymous, and no shared information or opinions will be attributable to a single individual without prior consent.

Data collectors should provide clear, openly accessible information about their operations, including research design and data collection methodology. Data collected by state agencies should be openly accessible to the public, as should metadata and paradata, which describe the data and the process by which it was collected.[8] To facilitate full accessibility and trust among disenfranchised and underserved communities, all data should be made available taking into consideration different types of physical and mental ability, language, literacy levels, and cultural backgrounds.

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[5] Cynthia Triplett et al., *Codesigning a community-based participatory research project to assess tribal perspectives on privacy and health data sharing: A report from the Strong Heart Study*, 29 JOURNAL OF THE AMERICAN MEDICAL INFORMATICS ASSOCIATION 1120, 1121 (2022).

[6] OFFICE OF THE UNITED NATIONS HIGH COMMISSIONER FOR HUMAN RIGHTS, A HUMAN RIGHTS-BASED APPROACH TO DATA 4 (2018) https://www.ohchr.org/sites/default/files/Documents/Issues/HRIndicators/GuidanceNoteonApproachtoData.pdf.

[7] *Id.*, at 12.

[8] *Id.*, at 15.

RFI Question 6. What resources, programs, training, or tools can make equitable data more accessible and useable for members of the public?

In order to make data truly accessible, it is vital to consider the capacity of a community to engage with and use the data. As one Urban Institute report put it, "A community with data capacity is one where people can access and use data to inform efforts to understand and improve outcomes where they live."[9] Some communities are not equipped with strong data capacity. "People of color," the report describes, "and those with low incomes have had few opportunities to access data or build skills to use data to advocate for change in their communities."[10] In order to equip disenfranchised and underserved communities to use data effectively in advocacy, planning, and policymaking, it is essential to provide them with tools and training to enable them to do so.

One program that has been effective in equipping communities nationwide to access and utilize data is the National Neighborhood Indicators Partnership ("NNIP"). In 2016, NNIP and Microsoft's Civic Technology Engagement Group launched a project to expand training on community data and technology for government and nonprofit staff members. It includes a brief summary of the training landscape and action steps for various stakeholders, a guide for organizations interested in providing training, and a fact sheet summarizing results from a survey on current content and practices.[11] The central principle of the NNIP is that any data capacity training should focus on the experiences of the people and groups affected by the data. By training communities to utilize data relevant to them, such a training program can equip communities to tell their stories and advocate for necessary change.

RFI Question 7. In which agencies, programs, regions, or communities are there unmet needs, broken processes, or problems related to participation and accountability that could be remedied through stronger collaborations and transparency around equitable data?

There currently exists a significant gap in available datasets where relevant, disaggregated data on race and ethnicity is lacking. Denice Ross, chief data scientist in the White House Office of Science and Technology Policy, said that policymakers, researchers, and companies should avoid taking existing data for granted, since "using only the data we have can mask important aspects of our society."[12] Indeed, lack of accurate data and data collection methods for disenfranchised and underserved communities has led to a growing data divide in which high-quality data on a variety of issues often does not reflect the experiences or needs of vulnerable or underrepresented populations. When it comes to collecting environmental data, current data sets do not accurately reflect the environmental realities facing these communities today.

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[9] LEAH HENDEY ET AL., THE URBAN INSTITUTE, INVESTING IN DATA CAPACITY FOR COMMUNITY CHANGE 1 (2020).

[10] *Id.*

[11] NATIONAL NEIGHBORHOOD INDICATORS PARTNERSHIP, EXPANDING TRAINING ON DATA AND TECHNOLOGY TO IMPROVE COMMUNITIES, https://www.neighborhoodindicators.org/activities/projects/expanding-training-data-and-technology-improve-communities (last visited Sept. 29, 2022).

[12] Gillian Diebold, *How Can the United States Address the Data Divide*?, CENTER FOR DATA INNOVATION, at 0:04:00 (Aug. 30, 2022) https://datainnovation.org/2022/08/how-can-the-united-states-address-the-data-divide/.

Other Helpful Resources:

Principles for Advancing Equitable Data Practice, Urban Institute

Guidelines for Equitable Open Data in Detroit, Detroit Digital Justice Coalition

Local Data as an Equity Tool How Data Intermediaries and Backbone Organizations Use Data to Improve Service Provision and Center Community Voices

Webinar: It’s a Process, Not a Product: Building Equitable Data Infrastructure

Data Sovereignty in Community-Based Environmental Monitoring: Toward Equitable Environmental Data Governance

The Future for Community Use of Data to Advance Equity

Data Usability: The Forgotten Segment of Environmental Data Workflows

Respectfully Submitted,

Clean Air Task Force

Request for Information; Equitable Data Engagement and Accountability

Disaster Technologies Incorporated (doing business as Disaster Tech) is Public Benefit Corporation with a mission to use data and technology for saving lives, protecting the environment, and building community resilience before, during, and after disasters. Government produced data is essential to our tech to serve communities in disaster management capacities; our motto is that we serve those who serve. Quality, high fidelity data, included disaggregated data, allows Disaster Tech to provide valuable, actionable insights from models and analytics to uncover disaster risks in the local community, related to social-economic vulnerabilities and inequities. Government data that is poorly managed, biased, or inaccessible amplifies disaster risk, as it limits our ability with the community to discover the greatest risks and where best to make investments for risk mitigation, to resolve inequities in the communities with acute vulnerability to systemic, structural disaster risks. Like climate change, disaster risk is human-driven, and similarly, poor data governance is a human-driven problem.

Here are our initial answers to the RFI questions:

1. *What are examples of successful collaborations between the Federal government and (a) Tribal, territorial, local, and State governments or (b) local communities involving equitable data?* The National Climate Assessment (https://nca2018.globalchange.gov/chapter/15/) included an entire chapter that was specific to addressing Tribes and Indigenous Peoples risks posed by climate change. The US Climate Resilience Toolkit, published by NOAA, provided a rural capacity map (https://toolkit.climate.gov/tool/rural-capacity-map) to illustrate where human capacity may be needed in rural areas to implement and manage climate adaptation and mitigation strategies. This tool helps a variety of users better understand local climate change risks and develop a planning framework.

4. *What policies, resources, programs, training, or other tools can expand opportunities for historically underrepresented scholars and research institutions to access and use equitable data across levels of government?* Incentivizing the pursuit of knowledge by creating specific programs within various funding agencies that explicitly desire to examine equitable data. A new type of reporting standard will likely be needed to measure equitable data. Unleash American's brain trust on the problem and have them report out as credible information sources.

5. *What policies, resources, programs, training, or tools can increase opportunities for community-based organizations to use equitable data to hold government accountable to the American public?* Knowledge and transparency of information are the two best strategies. Providing some flagging information that identified equity-specific or equity-focused funding (and relevant percentages) on USAspending.gov. Develop performance metrics that are able to normalize funding by appropriate equity definitions.

6. *What policies, resources, programs, training, or tools can make equitable data more accessible and usable for members of the public? There's often a significant distance between data and knowledge.* Data without context and understanding is without meaning and of little use to users/stakeholders. Educational programs that do more than just pipe data are needed to report on the context, develop insights and build public knowledge. More effective simplification of public grant reporting (or better communication) would improve public understanding. Providing a framework, technology-enabling

decision tools, and open access to information would help take complex topics and simplify them for the public.

7. *In which agencies, programs, regions, or communities are there unmet needs, broken processes, or problems around participation and accountability that could be remedied through stronger collaborations and transparency around equitable data?* More funds should be available for transparent grant evaluations, data storage and management, and other initiatives that complement federal investments without reducing the overall funding for implementing programs. Random assignment of equity-focused evaluators to projects that are selected for funding is an option that might work to increase data availability and transparency. Instead of relying on uneven statutory requirements for program evaluations, require a percentage of all investments to include formative and summative evaluations and separately fund a mechanism to ensure that projects selected for funding are sampled fairly and assigned an evaluator that is fully funded to support the project's data and performance. A database similar to the US. Dept of Education’s "What Works Clearinghouse" and make reports and raw data available for use and transparency.

   Disaster Tech is a climate tech company focused on building resilience to natural disasters. Developing resilience involves numerous phases of data synthesis and analysis that should include equity as an important feature. Impact-based risk assessment is often missing for extreme weather and climate impacts to critical infrastructure, often due to missing data. One such area that suffers from this is power system vulnerabilities. There is no centralized aggregation and normalizing of power outage information to inform emergency managers during disaster response and inform scientists to make better predictive models ahead of storms.

   Across the federal government, there is poor data management on critical infrastructure data, with known examples of data inconsistencies or where multiple agencies are duplicating efforts (at times with shared understanding between agencies that there is overlap or duplication). As an example, the US DOE Energy Information Administration should be the authoritative source via eia.gov Open Data portal for energy infrastructure and system related data (as per the Federal Power Act and Energy Policy Act), such as locations of power systems or oil and gas infrastructure. A citizen scientist or researcher can compare, for example, power substation geospatial location data from eia.gov versus what DHS Homeland Infrastructure Field Level Data (HIFLD) provides (in ESRI proprietary shapefile format); by overlaying both geospatial data points on a map, discrepancies between location data are spatially seen, for example where one substation location from EIA does not match the location data from DHS.

   It begs the question: how many other discrepancies are hidden in federal data, and how many data sets managed by different federal agencies have varying degrees of data quality, integrity, or authoritativeness? If a goal of a government data provider is to broker trust with the community that it serves, then the data sets must be trustworthy. Lack of transparency (and continued poor transparency) with Covid data further eroded public trust in public health agencies such as CDC. If models that are meant to discover disaster risk or measure power system fragility are based on this federal data, does it follow the statement: garbage in garbage out? At a minimum, federal agencies in the overall interagency data strategy should be identified as the lead, and that agency identified should be responsible for ensuring the authoritative trust and stewardship of the data and its consumers: the public, private companies, institutions of higher education, SLTT, and international partners.

Please email any responses to our RFI submission to [redacted] Thank you for the opportunity to participate in this public feedback session.

Best regards,

Sean Griffin, CEO Disaster Tech, former policy director, White House National Security Council staff

Dr. Madiha Jafri, Chief Technology Officer, Disaster Tech

Dr. Jason Shafer, Chief Science Officer, Disaster Tech

Environmental Defense Fund

Response to the Request for Information: Equitable Data Engagement and Accountability

Document Citation: 87 FR 54269

Submitted: October 3, 2022

Environmental Defense Fund (EDF) appreciates the opportunity to respond to the Request for Information on how Federal agencies can better support collaboration with other levels of government, civil society, and the research community around the production and use of equitable data.

Environmental justice is critical to successfully enhancing the health and well-being of all Americans. Everyone deserves a safe and clean environment. OSTP can play a key role ensuring data and analysis inspires and enables the work to eliminate disparate environmental health outcomes based on race, ethnicity, and income.

Environmental Defense Fund is a national, non-profit environmental organization dedicated to using science, economics, and law to build a vital Earth – for everyone. EDF's Healthy Communities program strives to make air, water, food, and household products safer through cutting-edge research, wide-ranging partnerships, and a focus on strengthening laws and policies that protect health.

Key Recommendations

In these comments, we provide recommendations based on gaps we have identified in data and analysis production and access. Three key recommendations warrant special attention:

1. OSTP should make access and analysis of fine spatial resolution health data a priority action. As we detail below, fine scale data is needed to fully characterize health inequities.
2. OSTP should coordinate within and across federal agencies to improve access to and analysis of fine resolution air and water data and pollutant source data.
3. OSTP should also coordinate within and across federal agencies to advance cumulative impact assessment of chemical and non-chemical, including climate-related, environmental stressors, to enable targeted services.

We encourage OSTP to consider our recommendations, as well as feedback provided by environmental justice community groups who disproportionately experience the health impacts associated with climate change, air and water pollution chemical exposures, and other environmental and social stressors, in finalizing its approach.

1. Research and Data Collection, Analysis, and Utilization

A. OSTP should enable spatially resolved health data access and integration.

Recommendation: We urge OSTP to address the urgent need to provide access to spatially resolved health data for design, implementation, monitoring and evaluation of policies.

The lack of investment in development and access to high resolution baseline disease rates poses a structural barrier to identification of communities that are hotspots of air pollution health burdens and limits targeted solutions, policies, actions and financing to address these inequities.

We recommend that OSTP convene NIH, HRSA, CMS, and CDC to determine barriers and opportunities for making census tract and finer spatial resolution health data available for environmental and climate justice evaluations.

Comment: Air pollution has a disproportionate burden on communities of color and low wealth. Studies have shown that historically racist policies such as redlining and citing of highways and polluting facilities have resulted in racial/ethnic minority and other disadvantaged populations living in areas with a disproportionately higher number of emitting facilities[1,2] and facing higher exposure burden in comparison with White American populations. In addition, policies and actions to reduce air pollution are generally concentrated in wealthier and less diverse populations, resulting in widening disparities.[3,4] Yet the issues of air pollution–related health impact inequities extend beyond exposure alone. Many of the same racist policies, institutional practices, and poor cultural representations have caused disinvestment in racial/ethnic minority communities, resulting in differential quality and distribution of housing, transportation, economic opportunity, education, food, access to health care, and beyond. All of these inequities manifest in health disparities, higher underlying mortality rates, and greater susceptibility to pollution-caused disease.[5,6]

While there have been steps taken in the right direction, we recommend a *greatly expanded effort to focus on spatially resolved health data required to characterize and monitor changes in inequities that are environmentally mediated*.

To support the variety of census-tract based environmental justice initiatives, OSTP must address the lack of publicly available health data at the census-tract scale and the cost and time involved in accessing restricted datasets. Designing, implementing, and assessing the effectiveness of policies requires monitoring environmentally-related disease rates during and following implementation. Federal and numerous state policies and programs are developing census tract-based tools to define disadvantaged communities for resource allocation (e.g., Justice40, New York CLCPA, Washington, New Jersey, etc.), yet relevant health data at this spatial resolution is rarely available. OSTP can do more to help address health data gaps and access issues due to privacy and identifiability concerns. OSTP can work with HHS and its operating divisions to build upon existing databases (e.g., CDC WONDER and H-CUP) utilizing data analytic methods and statistical models appropriate for small area health analysis.

Health Impact Assessments[7] (HIAs) are increasingly being used to assess current environmental health inequities and estimate benefits of proposed policies at the federal, state and local level. HIAs require baseline health status data (for example: incidence of disease outcomes, rates of hospitalizations or emergency room visits). Oftentimes county-level data is used, despite large magnitudes of health disparities in urban areas and research that has shown aggregation to the county likely underestimates exposure and health inequities.[8,9,10]

Numerous projects EDF scientists have led demonstrate the need for spatially resolved health data. Most HIAs rely on publicly available rates of disease outcomes (mortality rates, emergency room visit rates or hospitalization rates) from H-CUP or CDC WONDER. These are often only available at the county scale. In our study we compared the magnitude, spatial patterns and racial ethnic distribution of estimated air quality impacts when using county scale health data from CDC WONDER and locally developed census block group (CBG) mortality data from the Alameda County Public Health Dept. The analysis found that CBG baseline disease rates yielded 15% and 13% higher spatially aggregated estimates of pollutant-attributable mortality rates compared with the application of county baseline disease rates. Differences were even more evident at the city level. For example, for just Oakland, CBG baseline disease rates yielded 52%, 67%, and 57% higher NO_2, black carbon (BC), and $PM_{2.5}$-attributable mortality rates compared with the application of county baseline disease rates.

Applying CBG baseline disease rates also revealed neighborhoods with high pollutant-attributable mortality rates that were masked when using county-level disease rates. The magnitude of the spatial disparities was also larger when utilizing CBG baseline disease rates: neighborhood–level pollutant-attributable rates varied by factors of 29, 12, and 14 for NO_2, BC, and $PM_{2.5}$ across Alameda County, whereas applying county baseline disease rates yielded lower spatial differences (6, 4, and 3 times, respectively).

Additionally, we found that using CBG instead of county baseline disease rates resulted in a larger percentage of pollutant-attributable cases for CBGs with >50% minority population in Alameda County. Within Oakland, CBGs with the highest percentage of minorities and highest estimated NO_2-attributable mortality rates were in West Oakland near I-880, a high-traffic–volume truck route, and in Chinatown, in the southeastern part of Downtown Oakland. *Overall, inequities in air pollutant attributable health outcomes were underestimated when using the lower spatial resolution health data that is currently publicly available.*

The Bay area study also found that over 5,000 new childhood asthma cases were attributed to traffic related air pollution.[11] This is an average of 1 in 5 cases across the region and up to 1 in 2 cases in some areas. But because there exist no fine scale measures of asthma incidence for children, we were unable to accurately identify air pollution asthma incidence hotspots that take into consideration health disparities. In fact, there is only a single childhood asthma incidence rate available at a state level, which masks the large differences in asthma incidence across communities, neighborhoods, cities and counties across the state.

EDF's recent report on the distribution of $PM_{2.5}$ related health burdens under current and alternative National Ambient Air Quality Standard provides a case study in New Jersey demonstrating the additional value of high-resolution baseline health data in characterizing health burden inequities.[12] The scientists developed and utilized fine scale race and ethnicity stratified rates of pediatric asthma emergency department (ED) visits at the zipcode level. H-CUP normally only has either county level or Zip 3 level data. Comparing the patterns of both baseline disease rates and estimated $PM_{2.5}$-attributable childhood asthma ED visits the report finds:

- Zip 3 level data does not capture the full spatial disparities in childhood asthma ED visits and misses hotspots across the state that are captured by the fine scale zipcode level data.
- This limits the ability to identify the locations of neighborhoods bearing higher burdens of air pollution attributable childhood asthma emergency room visits.
- Coarse scale incidence rates overstate air pollution- asthma ED visits for white populations by 30% and understate incidence for other races by up to 90%.

EXHIBIT 4-2. BASELINE INCIDENCE FOR ASTHMA ED VISITS IN NEW JERSEY AT ZIP CODE AND ZIP3 SCALES

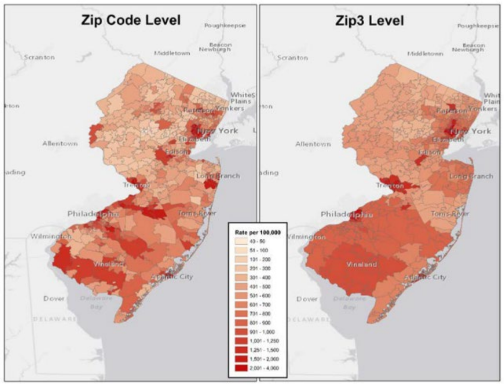
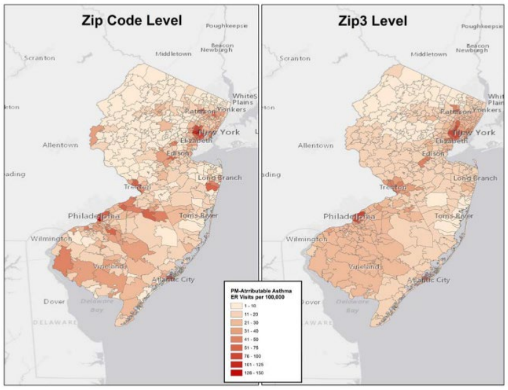


EXHIBIT 4-3. PM-ATTRIBUTABLE ASTHMA ED VISITS IN NEW JERSEY AT ZIP CODE AND ZIP3 SCALES



These studies specifically highlight the need for fine-scale mortality, asthma ED visit, and childhood asthma incidence rate data for air quality health equity analyses and the need for increased investment in race/ethnicity vulnerability assessments across exposure health outcomes.

The National Syndromic Surveillance Program (NSSP) at CDC may serve as a template for addressing identifiability and data analytic challenges. The NSSP has supported development of standardized methods for access, data processing and standardization of healthcare visit data, through support of the Biosense and underlying ESSENCE platforms, and working with state and local health departments to develop best practices in data sharing. The other program we would like to highlight is the HHS emPOWER Program Platform[13] that uses CMS data to identify and protect the health of at-risk Medicare beneficiaries, who rely on electricity-dependent health care services, during climate change related weather emergencies and disasters.

One important limitation of syndromic surveillance is zip code as the smallest spatial unit of analysis. While some states have programs to access processed emergency department visit data at higher spatial resolution outside of their syndromic surveillance programs, the process is not consistent across states, limiting national level analyses. Medicare and Medicaid claims data through CMS is another comprehensive health data source that could be leveraged for development of higher resolution health data for monitoring and evaluating inequities as environmental justice policies are implemented. The cost and time associated with accessing CMS data is prohibitive for many academic researchers and isn't even possible for other organizations without an Institutional Review Board and significant monetary resources. While the National Center for Health Statistics (NCHS) provides access to yearly mortality and birth data, the finest spatial resolution available is at the county level, and race/ethnicity or income subsetting often results in suppression of data for many counties. We were able to work around this to develop higher spatial resolution data by aggregating data over a longer duration of time (e.g., allow census-tract level data when a 5-year period is chosen as the temporal aggregation). But most counties and states do not even have the raw data available at the resolution to enable independent scientists to carry out such analyses.

These barriers to utilizing fine spatial scale health data, particularly those relevant to environmental justice analyses of air pollution and climate policies, must be addressed to more fully characterize and monitor environmentally-mediated inequities in health.

2. Source Data Collection, Analysis, and Utilization

A. OSTP should enable spatially resolved source data access and integration.

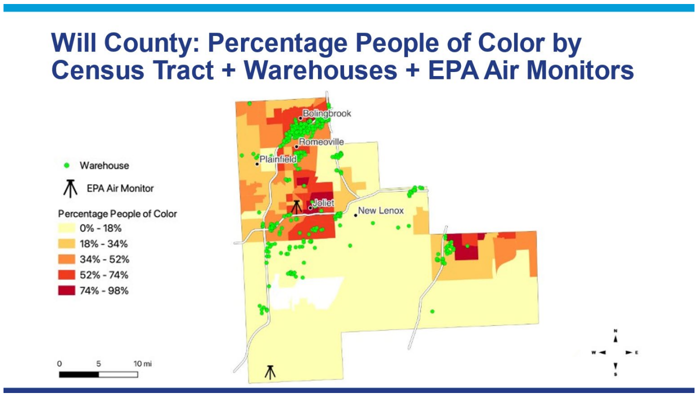
Recommendation: We urge OSTP to dramatically expand access to and analysis of data on sources of environmental exposures. While certain large sources are required to report emissions, other potential sources are not easily understood. In particular, the location and nature of trucks and truck-attracting businesses such as warehouses and waste management facilities are not available at an adequate spatial or temporal resolution to enable accurate attribution of pollution to these sources. The result is difficulty assessing, designing and implementing pollution mitigation policies.

Comment: Transport constitutes a large and growing share of emissions. Lack of data on truck locations and activities impedes accurate assessment of the status quo and accurate comparison of alternatives.

- In Oakland and other cities, EDF and partners analyzed the impact of NO2 on new diagnoses of children's asthma. In the neighborhoods with the most traffic-related pollution, more than 1 in 3 cases of children's asthma are caused by pollution. Even with high resolution data from satellite-informed land use regression models of NO2 these analyses were unable to fully reflect local pollution hotspots due to lack of detailed data on truck activity.
- Scientists at EDF, Harvard Chan School of Public Health and University of North Carolina, using state of the art fine scale air quality modelling and health impact assessment methods, found that electrification of medium- and heavy-duty diesel vehicles will have significant benefits in New York City at a census tract scale.[14] The analysis found that up to 68 percent of childhood asthma ED visits reduced will be accrued in census tracts with >85 percent minority populations if full electrification takes place by 2040. The ability to represent how a policy will reduce health inequities was only possible, in part, because of unique truck traffic data for New York City accessed through

the New York Metropolitan Transportation Council. Even so, this kind of travel demand model does not capture traffic ending or beginning at warehouses or other truck attracting facilities.

- EDF's Proximity Mapping integrates social, demographic and health information for people living within half a mile of a truck-attracting facility such as a warehouse. As a result, the tool can visualize the disproportionate proximity of low-wealth communities and Black, Asian-American, Latino and Indigenous communities to areas where trucks gather. In Illinois, for example, the dataset shows almost 2 million people living within a half mile of an identified warehouse, 138,000 of whom are children under five. Warehouse neighbors are twice as likely to be Hispanic or Latino as the state average. This analysis was only possible due to purchasing a license to a commercial database providing locations of warehouses.


Will County: Percentage People of Color by Census Tract + Warehouses + EPA Air Monitors

OSTP should work with agencies to produce granular source data and make it accessible, so that understanding where trucks operate does not require teams of scientists and access to unique or private data:

- **DOT:** OSTP should investigate ways to improve access to:
    - Distribution of traffic volume (annual average daily traffic) by vehicle class at resolution finer than county scales (e.g., link level)
    - Location and count of trucks – including local roads, right up to facility gates
    - Age of trucks by location – since age has significant impact on emissions profiles
    - Ownership and secured creditors of trucks – who has an interest in the status quo
    - Location of truck-attracting facilities such as warehouses and waste management facilities, with expected truck counts at facility gates
    - OSTP should facilitate the development of best practices for distributional air pollution health impact assessments as a component of transportation policy analyses

- **EPA**: OSTP should investigate ways to integrate granular truck and truck-attracting facility data into EPA-developed mapping tools such as EJScreen.

- **OSHA:** OSTP should work with OSHA to build occupational health data collection, analysis, and research capabilities regarding worker exposure to truck emissions.

3. Insights on cumulative impacts

A. OSTP should coordinate within and across federal agencies to advance cumulative impact assessment of chemical and non-chemical, including climate-related, environmental stressors.

Recommendation: We urge OSTP to coordinate within and across federal agencies to prioritize assessing the cumulative impact of multiple social determinants of health (also referred to as chemical and non-chemical stressors), with a focus on how non-chemical and climate-related stressors may modify the impact of environmental chemical exposures.

Comment: A cumulative impact assessment explores how social determinants of health, such as from the built, natural, and social environments, interact to cause or exacerbate adverse health outcomes.[15] This type of comprehensive assessment might consider that certain communities lack access to nutritious food and are exposed to higher levels of PM2.5 due to their proximity to major roads. Ultimately, cumulative impact assessments reflect people's real-world experiences, which is a key step in addressing or changing these factors to promote environmental and climate justice.

For example, it is now recognized that obesity is a multi-factorial disease and environmental chemicals such as phthalates or brominated flame retardants, often intentionally added to everyday consumer products, can alter the development and function of adipose tissue and other organs, which ultimately disrupts a body's normal metabolism.[16] Thus, these obesogenic chemicals can determine how much food is needed to maintain homeostasis and thereby increase an individual's susceptibility to obesity. Obesogenic chemicals contribute to increased rates of obesity; therefore, failing to consider them in combination with other factors, such as access to healthful foods, may likely fail to address the high rates of obesity in this country.

Many public health agencies have available data resources and research and regulatory priorities that are relevant to cumulative impact assessments. For example, many agencies have strategic plans to address health disparities and promote environmental justice specifically, such as the National Institute of Environmental Health Sciences (NIEHS).[17] In addition to NIEHS, we recommend that OSTP coordinate with different agencies with have jurisdiction over public health and assess the toxicity or hazards posed by chemicals in the environment and workplace. Examples of these agencies include but are not limited to the National Center of Health Statistics (NCHS), the National Center for Environmental Health (NCEH), the Agency for Toxic Substances and Disease Registry (ATSDR), and the Food and Drug Administration (FDA). There is a unique opportunity for OSTP to play a convening role and ensure that agencies are able to achieve their mandates and make the best use of their own data and analytic capacities, as well as best practices from outside the federal government.

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Environmental Defense Fund appreciates OSTP's consideration of these comments. Please contact Aileen Nowlan, Policy Director, Global Clean Air [redacted] with any questions.

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[17] NIEHS. (Access 2022, June 13). *2018-2023 Strategic Plan, Advancing Environmental Health Sciences Improving Health*. NIH. https://www.niehs.nih.gov/about/strategicplan/strategicplan20182023_508.pdf

October 3, 2022

I was glad to see this RFI on Equitable Data Engagement and Accountability from OSTP.

I led the data analytics team at the Massachusetts Bay Transportation Authority (MBTA) and thought a lot about how to make transit data more accessible to the public beyond releasing open data. In response to questions 4 - 6 I think an important component is data holders (agencies) providing more context for their datasets.

For example, when we completed a federally required passenger survey to collect demographic data for our routes and station usage we released an online tool to allow people to visualize and download the data. I also started public facing datablog for my team to talk about the details of how we used data and provide the public with additional analysis. We also used a layering principle for our public facing dashboard so people could easily get the level of detail or explanation they wanted.

As a Leadership in Government fellow for Open Society Foundations I made a website designed to help community organizations better engage with transit agencies on the data they use. The site Transit Data Primer explains which datasets can answer which types of questions, explains a few analysis concepts, and discusses the limitations and potential errors in quantitative data. I think this model could be applied in other fields, especially the concepts around what makes an analysis “wrong”. A common disconnect between government agency use of data and community organizations is when the questions people are asking don’t match the datasets available. This is why a key goal of this project was to give community members language around what questions to ask about data analysis.

I am happy to discuss this tool more.

Laurel Paget-Seekins

September 20, 2022

NSTC Subcommittee on Equitable Data
Office of Science and Technology Policy
Eisenhower Executive Office Building
[redacted]
Washington, DC 20504

RE: Comments in Response to FR Document 2022-19007, Request for Information on Equitable Data Engagement and Accountability

Thank you for the opportunity to submit comments regarding the Office of Science and Technology Policy request for information on Equitable Data Engagement and Accountability, published in the Federal Register on September 2, 2022. These comments are jointly submitted by the National Council of Asian Pacific Americans (NCAPA) and AAPI Data.

The National Council of Asian Pacific Americans (NCAPA) is a coalition of 38 national Asian American (AA) and Native Hawaiian and Pacific Islander (NHPI) organizations around the country. Based in Washington D.C., NCAPA serves to represent the interests of the greater AA and NHPI communities, the fastest growing racial group in the nation, and to provide a national voice for Asian American and Native Hawaiian and Pacific Islander issues.

AAPI Data is a nationally recognized publisher of demographic data and policy research on Asian Americans and Pacific Islanders, with hundreds of news mentions in national and local outlets. Based at the University of California, Riverside, our reputation is built on data and research that is accurate, compelling, and timely. In addition to our news impact, community organizations, government agencies, and decisionmakers regularly reach out to us, to better understand key aspects of AAPI communities.

Data equity is a top priority for Asian American, Native Hawaiian, and Pacific Islander (AA and NHPI) communities across nearly every issue area. We are a highly diverse group of communities with over 50 ethnic groups, speaking over 100 languages.[1] However, this diversity is rarely represented in federal data collection, which collects data on our communities in the aggregate, creating severe challenges for racial and ethnic groups within our communities whose urgent needs are obscured in this process. Therefore, increasing the availability of disaggregated data for AA and NHPI communities remains at the core of our data equity advocacy efforts.

As our communities continue to press for disaggregated data, it is increasingly important to engage in other important aspects of data equity such as timeliness, accessibility, human-centered design, community inclusion, and integration of subject-matter expertise and population expertise among community organizations and researchers alike. As NCAPA and AAPI Data outlined in our recent report, *2022 Asian American, Native Hawaiian, and Pacific Islander (AA and NHPI) Roadmap for Data Equity in Federal Agencies*, these recommendations that stem from this "data disaggregation plus" approach will be outlined in this public comment.[2] The report is enclosed with this public comment.

Our recommendations are to:

1) Update the federal minimum standard for data collection across all relevant agencies that expand upon the categories used in the 2020 Census and American Community Survey, to include smaller AA and NHPI populations. This process must include as wide a range of voices from these communities as possible and comprehensive engagement including guidance on how to provide comments and sufficient time to help under-resourced community organizations to properly prepare their input.
2) Ensure the inclusion of community and scientific expert voices in all stages of federal statistical data collection, including its design and development, collection, compilation, processing, analysis, dissemination, and preservation.
3) Include community members and researchers in evaluating and changing data criteria and data systems, particularly for data dissemination and outreach. Data equity can only truly be achieved when all members of the public are able to access and understand the data available from the federal government.
4) Work closely with community groups and researchers to identify case studies and pilot programs specific to AA and NHPI communities that will build on the knowledge base and methodologies to increase data equity and data collection and disaggregation.

Increase Availability of Disaggregated Data By Updating Federal Minimum Standards for Data Collection

In 1997, recognizing the inadequacies of the then-current single aggregate race and ethnicity category of "Asian and Pacific Islander," the OMB separated it into "Asian" and "Native Hawaiian and Other Pacific Islander." The 2020 Census, on the other hand, utilized the evidence-based format of a "Combined Question for Race and Ethnicity with Detailed Checkboxes and Write-in Areas" because Census Bureau's

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[1] https://www.ncapaonline.org/wp-content/uploads/2020/05/NCAPA_PolicyPlatform_2020.pdf

[2] https://aapidata.com/wp-content/uploads/2022/05/AANHPI-DataEquityReport-May-2022.pdf

research demonstrated that this format yielded the most accurate responses. For Asian Americans, the format lists 7 checkboxes (Chinese, Filipino, Asian Indian, Vietnamese, Korean, Japanese, and Other Asian), followed by a write-in section for respondents to enter other Asian identities (e.g. Pakistani, Cambodian, Laotian, and Hmong). For Native Hawaiians and Other Pacific Islanders, the format lists 4 checkboxes (Native Hawaiian, Samoan, Chamorro, and Other Pacific Islander), followed by a write-in section for respondents to enter other NHPI identities (e.g. Tongan, Fijian, and Marshallese).[3]

There are some efforts by specific federal agencies that serve as examples of data disaggregation collection efforts that are already underway: The Health Center Program Uniform Data System (UDS) and Federally Qualified Health Centers may serve as appropriate candidates to house a data disaggregation pilot program as they already collect AA and NHPI subpopulation data on the ground but aggregate data when reporting publicly. UDS currently only reports data for topline Asian, Native Hawaiian, and Other Pacific Islander categories, and does not allow for health centers to report more granular subpopulation data. The Consumer Financial Protection Bureau (CFPB)'s collection of Home Mortgage Disclosure Act (HMDA) data may also serve as an excellent model for federal agencies in implementing disaggregated data practices. HMDA data have included detailed race and ethnicity categories starting with the 2018 data.

Certain other federal agencies, such as the Department of Health and Human Services (HHS), have also gone beyond the minimum standards provided by the OMB and offer an example for what improved data disaggregation and data equity standards currently look like in practice. The HHS's preferred means of collecting race and ethnicity data is self-identification and asking separate questions for ethnicity first and then race. For Asian Americans, the HHS uses 7 categories (Asian Indian, Chinese, Filipino, Japanese, Korean, Vietnamese, and Other Asian). For Native Hawaiians and Other Pacific Islanders, the HHS uses 4 categories (Native Hawaiian, Guamanian or Chamorro, Samoan, and Other Pacific Islander).[4]

However, most agencies and offices, with the exception of the few listed above, do not disaggregate AANHPI data. The current aggregate options are particularly inadequate to capture our communities' needs – disaggregated data across datasets and programs of the various federal agencies is long overdue, and sorely needed in order to to meet the needs of AANHPI communities.

Health

The global COVID-19 pandemic has exposed disparities and unaddressed systematic inequities throughout the country and within our communities, with communities of color frequently bearing the brunt of the virus's health toll. For AA and NHPI communities, COVID-19 is yet another stark reminder that data disaggregation can be a matter of life or death. Aggregate health data does not paint an accurate or complete picture of COVID-19 impacts on AA and NHPI communities. The Centers for Disease Control (CDC), has reported that as of June 17, 2021, Asian Americans had 0.7 times as many COVID-19 cases as white Americans and were on par with white Americans in terms of hospitalization

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[3] https://www2.census.gov/about/training-workshops/2020/2020-02-19-pop-presentation.pdf

[4] https://aspe.hhs.gov/basic-report/hhs-implementation-guidance-data-collection-standards-race-ethnicity-sex-primary-language-and-disability-status

and death rates.[5] However, the CDC's public-facing information does not disaggregate Asian American data and does not include data on Native Hawaiians and Pacific Islanders. The COVID-19-Associated Hospitalization Surveillance Network, from where the CDC draws its data on hospitalization rates, furthermore, *aggregates* AA and NHPI data into a single category.[6]

The passage of the Affordable Care Act enabled noticeable gains among Asian Americans in terms of obtaining health insurance. However, while aggregated data suggest that Asian Americans have the lowest uninsured rate of any racial or ethnic group, these numbers do not tell the full picture without disaggregated data.[7] In 2015, of the top 10 highest uninsured groups in the US, 5 are Asian Americans (Pakistanis at 20.9%, Koreans at 20.5%, Cambodians at 18.9%, Vietnamese at 18.5%, Bangladeshis at 18.2%) and 2 are Native Hawaiian and Pacific Islanders (Micronesians at 18.3% and Samoans at 16.7%).[8]

There is urgent need for the CDC and those offices within Health and Human Services (HHS) that have yet to disaggregate AANHPI data to do so.

Education

While aggregate data report that Asian Americans surpass all other racial groups in educational attainment, disaggregated data reveals a much more nuanced picture. Although 50% of Asian Americans in general hold a bachelor's degree, disaggregated data demonstrate that less than 20% of Cambodian, Hmong, Laotian, and Bhutanese groups have even attended college.[9] Among Native Hawaiians and Pacific Islanders, 57.9% of Samoans, 56.8% of Tongans, 53% of Native Hawaiians, and 49.3% of Guamanians or Chamorros have not attended college.[10] Furthermore, Marshallese and Samoan adults are less likely to hold a bachelor's degree than any other racial group.[11] Based on data from 2018, AANAPISIs enroll one out of every 3 AA and NHPI students at four-year institutions and over half of all AA and NHPI students at two-year institutions. Despite this, AANAPISIs are severely underfunded and receive the least funding per capita of all Minority Serving Institutions.[12]

It is therefore critical that the Department of Education collect and release disaggregated data for AANHPI students, in order to facilitate educational equity. Similarly, noting that the threat of violence and harassment for Asian Americans have seen the largest rise during the COVID-19 pandemic,[13] it is

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[5] https://www.cdc.gov/coronavirus/2019-ncov/covid-data/investigations-discovery/hospitalization-death-by-race-ethnicity.html

[6] https://www.cdc.gov/coronavirus/2019-ncov/covid-data/covid-net/purpose-methods.html

[7] https://www.commonwealthfund.org/publications/issue-briefs/2020/jul/gap-closed-aca-impact-asian-american-coverage

[8] https://www.searac.org/wp-content/uploads/2018/04/2015_ACA_policy_brief_v13_final.pdf

[9] https://www.pewresearch.org/fact-tank/2017/09/08/key-facts-about-asian-americans/
https://aapidata.com/infographic-education-aa-nhpi/

[10] https://apiascholars.org/wp-content/uploads/2019/12/NHPI_Report.pdf

[11] https://www.advancingjustice-la.org/sites/default/files/A_Community_of_Contrasts_NHPI_US_2014.pdf

[12] https://www.ncapaonline.org/wp-content/uploads/2020/10/NCAPA-AANAPISI-Brief.pdf

[13] https://www2.ed.gov/about/offices/list/ocr/docs/20210608-impacts-of-covid19.pdf

necessary to properly assess its impact on students via the Department of Education's Civil Rights Data Collection (CRDC); additional reports measuring the impact of COVID-19 should be made accessible, similar to ED OCR's recent report, *Education in a Pandemic: The Disparate Impacts of COVID-19 on America's Student*s.

Housing and Economy

Income distribution among Asian Americans is the most unequal out of all racial and ethnic groups; Asian Americans in the 10th percentile make 10.7 times as much as Asian Americans in the 90th percentile.[14] Although the median annual household income of Asian Americans in 2019 was $85,800, this figure included incomes ranging from $44,000 per year for Burmese American households to $110,000 per year for Indian American households.[15] Similarly, among Native Hawaiian and Pacific Islander, the average household incomes for Guamians and Fijians in 2015 were slightly above the US median income average of $56,516, but "Other Micronesians" households made about $30,000 per year.[16]

12.3 percent of Asian Americans live below the federal poverty level but disaggregation shows the wide range masked by this single number, with 6.8 percent of Filipino Americans to 39.4 percent of Burmese Americans living in poverty.[17] NHPI communities experience poverty rates 20% higher than the national average but are often combined with AA groups, obscuring this significant and important difference.[18]

Homeownership among AA and NHPIs also reveals that while as an aggregate group, 58 percent of AA and NHPIs are homeowners, rates of homeownership vary widely with 25 percent of Samoan, 28 percent of Burmese, and 28 percent of Tongan Americans being homeowners, while 62 percent of Filipinos, 62 percent of Chinese Americans, 64 percent of Vietnamese, 64 percent of Japanese, and 68 percent of Taiwanese Americans are homeowners.[19] Among low-to-moderate income AA and NHPI households, 37 percent of Asian households and 22 percent of NHPI households owned homes compared to 53 percent of low-to-moderate income white households.[20]

Aggregated data on economic indicators like homeownership, credit score, and household income are unreliable for adequately identifying AA and NHPI needs. For example, Asian Indian and Chinese borrowers are often welcomed by banks and offered low interest rates and closing fees, while other AA

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[14] https://www.pewresearch.org/social-trends/2018/07/12/income-inequality-in-the-u-s-is-rising-most-rapidly-among-asians/

[15] https://www.pewresearch.org/fact-tank/2021/04/29/key-facts-about-asian-americans/

[16] https://equitablegrowth.org/how-data-disaggregation-matters-for-asian-americans-and-pacific-islanders/

[17] https://www.urban.org/urban-wire/asian-americans-are-falling-through-cracks-data-representation-and-social-services

[18] https://www2.ed.gov/about/inits/list/asian-americans-initiative/what-you-should-know.pdf

[19] https://nationalequityatlas.org/homeownership_korean_ancestry

[20] https://www.nationalcapacd.org/wp-content/uploads/2021/03/NationalCAPACD_HousingCounselingReport_final_031221.pdf

and NHPI groups such as Native Hawaiians, Filipinos, and Vietnamese often find themselves with higher-cost loans offered by mortgage companies.[21]

There is an urgent need for disaggregated data from all agencies collecting or providing data related to housing, earnings, wages, labor, banking, and other financial services. As mentioned earlier, Consumer Financial Protection Bureau's Home Mortgage Disclosure Act (HMDA) data has made great improvements in this direction and should be considered a model advancement in data equity that can be adopted by other agencies working with consumer financial data.

Immigration

Approximately 57% Asian Americans were born in another country, and Asian Americans are projected to become the nation's largest immigrant group by 2050. Predictably, immigration histories and patterns differ among the many Asian American ethnic groups and also frequently inform communities' unique needs and conditions. For example, only 27% of Japanese Americans are immigrants because significant waves of Japanese immigration occurred in the 19th century as laborers moved to Hawaiian plantations. By contrast, 85% of Bhutanese Americans are foreign born as many arrived recently as refugees.[22] Southeast Asian refugees from Vietnam, Cambodia, and Laos constitute the largest group to be resettled in American history. Immigration is also a complex issue for Pacific Islanders as many NHPIs are U.S. citizens but others are foreign-born or hold different types of immigration statuses. Some Pacific Islanders are considered US nationals because they come from US territories, and others are considered migrants and lawfully present non-citizens from Compact of Free Association (COFA) countries, which includes the Republic of the Marshall Islands (RFI), the Federated States of Micronesia (FSM), and the Republic of Palau. Other Pacific Islanders are foreign nationals and must apply for legal permanent resident status. Others still are undocumented.[23]

Disaggregated data on undocumented AA and NHPI can provide clarity about the needs of these particularly vulnerable immigrants in our communities. Of the estimated 1.7 million undocumented Asian Americans, 26 percent are Indian, 22 percent are Chinese, 14 percent are Filipino, 10 percent are South Korean, 7 percent are Vietnamese, 3 percent are Pakistani, and another disaggregated 17 percent are from other Asian countries.[24] Disaggregated data on undocumented Pacific Islanders is more difficult to find, creating roadblocks for community advocacy, but California data on deported Pacific Islanders can offer a glimpse into the disparities and urgent needs of NHPIs. Between 2001 and 2011, approximately 1,200 NHPI residents were deported from California to the Pacific Islands with approximately 80 percent of the people deported being sent to Fiji. Another 15 percent were deported to Tonga and 4 percent were deported to Samoa.[25]

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[21] https://ncrc.org/mortgage-lending-in-the-asian-american-and-pacific-islander-community/
[22] https://www.pewresearch.org/fact-tank/2021/04/29/key-facts-about-asian-americans/
[23] https://advancingjustice-la.org/sites/default/files/A_Community_Of_Contrasts_NHPI_CA_2014.pdf
[24] https://aapidata.com/undocumented/
[25] https://advancingjustice-la.org/sites/default/files/A_Community_Of_Contrasts_NHPI_CA_2014.pdf

Additionally, examining visa backlogs based on country can reveal which specific AA and NHPI communities are most impacted by waitlists, delays, and backlogs that have plagued our family-based immigration system for years. In FY 2021, immigrants from the Philippines, India, China, Vietnam, Bangladesh, and Pakistan make up the second, third, fourth, fifth, and seventh, and eighth largest numbers of backlogs respectively.[26]

Without disaggregated data on AA and NHPI communities on immigration and documentations status from Department of Homeland Security (DHS) and United States Customs and Immigrations Services (USCIS), these nuances of AANHPI community members immigration histories and related needs go undocumented and unmet.

Language Access

In 2019, 67.8 million people in the U.S. reported speaking a language other than English at home, and more than 25.5 million people—nine percent of the U.S. population—are LEP. Approximately 32 percent of AA and NHPIs in the U.S. are foreign born and more than 6 million AA and more than 100,000 NHPIs are limited English proficient. The federal government has recognized the importance of language access for LEP individuals. Federal law and regulations, including Title IV of the Civil Rights Act of 1964, Section 1557 of the Affordable Care Act, and Executive Order 13166 issued in 2000, establish civil rights obligations for the government to provide language access protections for LEP persons. The Stafford Act requires FEMA to “identify in coordination with State and local governments, population groups with limited English proficiency and take into account such groups in planning for an emergency or major disaster.” The HHS Office of Minority Health created National Standards for Culturally and Linguistically Appropriate Services in Health Care as a guide for health care providers; and of the 14 standards, there are four that relate directly to language access.

These standards should be applied, where practicable, across the federal government, including language access in efforts to advance data equity for AANHPI communities. NCAPA recommends that all resources and materials developed by government agencies are translated into at least the 19 languages identified in the FEMA Language Access Plan. Data collection, analysis, and report should additionally include preferred language in addition to disaggregating by race and ethnicity.

Include Community Voices in Data Equity Process

To ensure the inclusion of community and scientific expert voices in all stages of federal statistical data collection, we will highlight some best practices and current challenges that can be addressed.

CreateAdvisory Committees and Stakeholder Engagement

The Census Bureau has created a number of institutional structures that create and support the ongoing engagement of community and scientific expertise. The Census Scientific Advisory Committee and

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[26] https://travel.state.gov/content/dam/visas/Statistics/Immigrant-Statistics/WaitingList/WaitingListItem_2020_vF.pdf

National Advisory Committee provide a formal and regular process for external stakeholders to engage with Census Bureau staff around all Census Bureau data collection and processing efforts.[27] A similar structure for data equity and at other federal statistical agencies would help to build trust and familiarity among community organizations, researchers, and federal statistical agencies.

The Census Bureau also has programs that create opportunities for federal agency statistical staff and end users to interact on a regular basis. Examples include the Census Information Center,[28] State Data Center,[29] and Federal-State Cooperative for Population Estimates[30] programs at the Census Bureau. These programs provide the Census Bureau and stakeholders opportunities to learn about each others' work and to find areas to cooperate to make the Census Bureau data products more responsive to external data needs. We particularly single out the Census Information Center (CIC) network and encourage the Census Bureau to expand the network to include more geographic and demographic coverage. The CIC network aims to promote the use of Census Bureau data products and services among underserved communities, such as communities of color, rural communities, senior citizens, and children. There are currently 10 Asian American-serving CICs and one Native Hawaiian-serving CIC. The CICs provide vital feedback on Census data products and tools and provide examples of how Census Bureau data is used to help the communities they serve. The CICs also promote data accessibility and training to their communities.

Provide Sufficient Time and Support for Stakeholder Input

An additional advantage of the Census Bureau's stakeholder outreach is that the engagement gives external stakeholders the expertise of communicating with the Census Bureau including learning about the internal jargon and processes, so that comments and feedback that are provided can be most effective.

Without this level of pre-existing knowledge, public comment periods, like the 30-day comment period for this RFI, are often not sufficient to enable deep engagement with underserved community organizations. Most AA and NHPI community organizations are under-resourced and staff time is at a premium. Placing the burden on community organizations to come up with best practices and examples of successful engagement in isolation and with minimal guidance will inevitably result in low levels of engagement. For this RFI in particular, we recommend that if OSTP has not received significant input from AA and NHPI community organizations that a follow-up RFI accompanied by a substantial outreach effort to engage community organizations. By providing substantial guidance and with sufficient lead-time for community organizations to marshal their limited staff resources, OSTP will gain deeper insights into the challenges of data equity for not just AA and NHPI communities but other under-resourced communities as well. Future data equity related public comment opportunities must include robust outreach and engagement plans that include detailed guidance and timelines, opportunities to

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[27] https://www.census.gov/about/cac.html

[28] https://www.census.gov/about/partners/cic.html

[29] https://www.census.gov/about/partners/sdc.html

[30] https://www.census.gov/programs-surveys/popest/about/fscpe.html

interact with federal agencies, and sufficient time for community organizations to respond. For maximum impact, these outreach efforts should take place well-before the formal comment period begins and should be part of an ongoing engagement process, for example, through advisory committees or stakeholder engagement programs outlined in the previous section.

A successful outreach example was supplied by an NCAPA member, EPIC, a community organization that advances social justice by engaging Native Hawaiian & Pacific Islanders in culture-centered advocacy, leadership development, and research. Office of Educational Technology at the Department of Education developed guidance to help local and state leaders reach and achieve digital equity in education. The office reached out to EPIC and other Native and Indigenous groups for feedback on their guidance. With EPIC, the office hosted a call with the wider Pacific Islander community to identify gaps and challenges that the community faces and to listen and follow the lead of the community. Ultimately, the guidance recommended continuous engagement of the community both to build awareness among federal agency staff on Pacific Islander concerns and also to build visibility of the federal government and its activities among community members. Through these interactions, the Office of Educational Technoloyg was able to leverage trusted messengers to support their work.

Include AA and NHPI Issues in Equity Action Plans

In January 2021, Executive Order 13985, Advancing Racial Equity and Support for Underserved Communities through the Federal Government, tasked federal agencies with creating Equity Action Plans to assess department policies and identify barriers to equity and solutions for mitigating gaps. In an internal analysis of select federal agencies' Equity Action Plans, we found that several identified barriers that prevented closing gaps in equity. These barriers included a lack of equity assessments; lack of data or lack of analysis of collected data; infrastructure gaps, including in technology, personnel, and tools; and important policies that hinder data collection. Below, we provide a summary of some of these challenges as identified by the select agencies (*see Table 1*).

Table 1. EO 13985-Related data equity challenges identified by select federal agencies

Federal agency	**Challenges identified**
Department of Education	Onerous data requirements of FAFSA applications[31]
Department of Homeland Security	Lack of data to make conclusions about disparities[32]
Department of Labor	Missing and incomplete demographic data in Workforce Training data; insufficient analysis of existing Workforce Training data[33]

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[31] https://www2.ed.gov/documents/equity/2022-equity-plan.pdf

[32] https://assets.performance.gov/cx/equity-action-plans/2022/EO%2013985_DHS_Equity%20Action%20Plan_2022.pdf

[33] https://www.dol.gov/sites/dolgov/files/general/equity/DOL-Equity-Action-Plan.pdf

Department of Treasury	Challenges in imputing demographic data; algorithmic bias[34]
Health and Human Services	Lack of data to identify inequities, including for Medicare and Medicaid[35]
Small Business Administration	Over-reliance on credit score (a barrier for small business owners with lack of banking/debt history); LenderMatch (matching platform for underserved borrowers) and Community Advantage Pilot (loan program to meet credit and technical assistance needs of underserved small businesses) do not optimize marketplace to match Community Financial Institutions (CFIs) and underserved borrowers[36]
Social Security Administration	Policy change in 1987 causing sharp decline in race and ethnicity demographic data[37]

It is worth noting that some agencies in our analysis did not engage in discussing challenges in these plans, including the Consumer Financial Protection Bureau (CFPB), Department of Commerce, Department of Justice, and the Federal Emergency Management Agency (FEMA).

To close data equity gaps, federal agencies across the board need to carry out equity assessments in full and develop plans that are accountable by including detailed short- and long-term indicators that can be tracked by the agencies and reported upon. Further, plans should aim to improve data quality by closing structural gaps in data collection and analysis, by aiming to disaggregate data.

Increase Data Dissemination and Outreach for AA and NHPI Communities

The last mile of data dissemination and outreach remains a significant hurdle to achieving data equity. For equitable data to be more accessible to members of the public, federal agencies must develop tools and training for data dissemination that are user-friendly and easy to access. For example, the new improvements to the Data.census.gov website, which is the primary data dissemination tool for Census Bureau data products, have brought some user-friendly and natural language search features when searching for geography-based data. For example, a natural language search on Data.Census.Gov for poverty in Texas will call up both a highlighted statistic on the poverty rate for Texas and quick access to a user-friendly profile of key statistics for Texas based on ACS data. However, these improvements need to be extended to race and ethnicity data, particularly for underserved and smaller AA and NHPI

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[34] https://assets.performance.gov/cx/equity-action-plans/2022/EO%2013985_USDT_Equity%20Action%20Plan_2022.pdf
[35] https://www.hhs.gov/sites/default/files/hhs-equity-action-plan.pdf
[36] https://assets.performance.gov/cx/equity-action-plans/2022/EO%2013985_SBA_Equity%20Action%20Plan_2022.pdf
[37] https://assets.performance.gov/cx/equity-action-plans/2022/EO%2013985_SSA_Equity%20Action%20Plan_2022.pdf

communities. Current natural language searches on Data.Census.Gov for race and ethnicity data lead to a list of tables for users to go through on their own to find the exact data they are looking for and often the first few tables listed are not the relevant tables. This last mile of delivery of data remains a major challenge to increasing accessibility of data for underserved populations and the burden is falling on underresourced community organizations or to academic institutions to fill the gap. An example of a community-led response to this last mile gap is AAPI Data's work to provide tools to access government data at aapidata.com.

Use Case Studies and Pilot Programs to Expand Availability of Data for AA and NHPI Communities

Case studies and pilot programs have been an important pathway to expanding the data available for AA and NHPI communities, particularly around the issue of health disparities. These case studies and pilot program demonstrate the importance and viability of various methods to increase availability of disaggregated data including increasing sample size, aggregating across multiple years, oversampling of specific small populations of interest in survey design, combining data sets across agencies, and using of administrative data and survey data to construct disaggregated datasets. Advocacy by NCAPA member organizations, including the Asian & Pacific Islander American Health Forum, resulted in the NCHS to oversample Asian Americans in both the National Health Interview Survey (NHIS) and the National Health and Nutrition Examination Survey (NHANES), the NHIS since 2006 and the NHANES since 2011.[38] For Native Hawaiians and Pacific Islanders, the National Center for Health Statistics (NCHS) conducted the first ever Native Hawaiian and Pacific Islander National Health Interview Survey (NHPI NHIS), a survey of 3,000 NHPI households using the 2014 NHIS survey instrument. Public use data from this survey was released in March 2017.[39]

Conclusion

Aggregated data masks wide disparities and urgent needs within Asian American, Native Hawaiian, and Pacific Islander communities that go undiscovered, unheard, and unchecked. A lack of disaggregated data across federal agencies presents an insurmountable barrier for advancing equity, including data equity, for AANHPI communities. We strongly urge OSTP to make data disaggregation a top priority for achieving data equity for AANHPI communities, and begin the necessary work of disaggregation across federal agencies.

In closing, we would also like to register the dismay and frustration of our communities in being asked to provide the same evidence for data equity for our communities as we have for several decades. It is concerning that the federal government needs further convincing of the pressing need for disaggregated data for AANHPI communities in almost all areas. In particular, placing the onus to provide evidence

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[38] Ponce, N.A., Bautista, R., Sondik, E.J., Rice, D., Bau, I., Ro, M.J., & Tseng, W. (2015). Championing Partnerships for Data Equity. Journal of Health Care for the Poor and Underserved, 26(2), 6-15. https://doi.org/10.1353/hpu.2015.0058

[39] National Center for Health Statistics. (2022). Native Hawaiian and Pacific Islander (NHPI) National Health Interview Survey (NHIS). Retrieved from https://www.cdc.gov/nchs/nhis/nhpi.html

upon communities, when the federal government commands limitless resources in comparison, further exacerbates the inequity our communities face as our organizations struggle to meet our communities' needs with already constrained resources.

Sincerely,

Gregg Orton
National Director
National Council of Asian Pacific Americans

Karthick Ramakrishnan
Founder and Director
AAPI Data

Delivery
Associates

October 3, 2022

Denise Ross
US Chief Data Scientist
White House Office of Science and Technology Policy

RE: Docket 2022-19007, *Engagement and Accountability RFI*

Delivery Associates (DA) works with governments and social impact organizations to achieve ambitious goals and create equitable public value. We bring expertise in helping deliver community benefitting programs through strategy, capacity building, data systems, and analytics, as well as facilitation and stakeholder engagement. We have experience supporting clients who are at different stages of using equitable data to improve outcomes and reduce disparities. For example:

With States:

- Supporting Hawaii Community Colleges to increase disadvantaged communities to access post-secondary training.
- Supporting the Texas Higher Education Coordinating Board to review its current capacity and produce a strategic plan for its post-secondary training programs, including implementation plans on equitably reaching displaced workers statewide.
- Developing the Rhode Island Preschool Implementation plan to expand access to high-quality pre-K to all of RI's 4-year-olds, with a focus on families and workers of color.
- Guiding the Puerto Rico Department of Education on how to address poor student outcomes in one of its most disadvantaged districts through a combination of academic interventions and internal management and human resource changes.

With localities:

- Setting our equity vision and goals as co-leaders of the American Cities Climate Challenge, which supported 25 of the largest US cities.
- Supporting the City of Tulsa in its ARP allocations, including designing an RFP process for community groups aligned with City Equity Indicators and resulting in increased investment in BIPOC communities in Tulsa.
- Working with two jurisdictions to embed "equitable outcome teams" in the Senior Executives Office
- Supporting the cities of Knoxville, Paterson, Pittsburgh, Youngstown and more in the development of public-facing data portals and dashboards that improve accountability for service delivery.

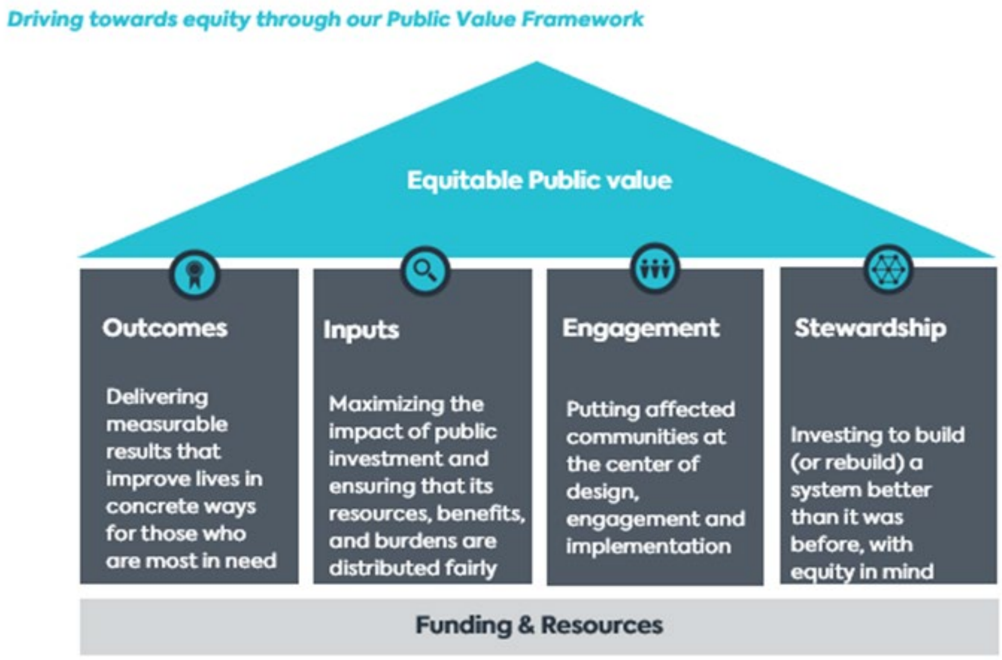
With non-profits and research organizations:

- Collaborating with Results for America to help embed racial equity in their state and federal standards for use of evidence in program design/implementation.
- Supporting education foundations and non-profits to use equitable data on school subgroup performance to direct investments based on evidence

Our response covers questions 1, 2, 3, 6 and 7, related to collaborations within and between levels of government, making data available for the public and CBOs, and current challenges and unmet needs.

Executive Summary

Delivery Associates works with governments around the country (and the world) to create equitable public value. Core to our approach is a focus on well-measured outcomes, because efforts at equity can too often miss the mark when not grounded in data about the populations who have been historically disadvantaged. We use our Equitable Public Value Framework to ground our work (Figure 1), and disaggregated and equitable data is essential to all elements of this framework: from understanding whether disparities are being reduced to measuring whether government is investing equitably.



Our response brings together lessons and specific examples from our work with US cities, states, and the Federal government. In answering questions 1,2, 3, 6 and 7, three primary lessons emerge for how equitable data can be more easily shared and used to drive equitable outcomes:

1. Though seemingly simple, **making disaggregated data more easily accessible** or **creating clear standards** for others to do so is essential to enabling collaborations grounded in equitable data across the board.
2. The same interventions and collaborations that support public access and use (open data, data dashboards etc.) can also improve sharing within and between levels of government or with CBOs.
3. The biggest challenges or untapped opportunities appear where the Federal government **doesn't provide enough clarity** around equity concepts, or where equitable **data is in silos** in ways that prevent others from acting on them.

The responses below are not intended to be an exhaustive inventory of all examples or a comprehensive assessment, but rather a few highlighted points based on DA's experience.

Questions 1 and 2: Successful collaborations between the Federal government and other governments around equitable data

Successful collaborations between the Federal government and states or local governments focused on equitable data stem from the Federal government's regulatory authority as well as its unparalleled ability to convene.

First, the Federal government has successfully used **regulations and rulemaking** to encourage and enable collaboration between different levels of government and communities. The ability to set universal standards that encourage consistent and comparable data collection can be a major force for changing how local governments and other entities understand and differentiate the impact of policies and programs on their residents. For example:

- The US Department of the Treasury's rule governing Covid-19 relief funds requires that ARPA funds be allocated using an equity framework. Each jurisdiction that receives funding is required to submit periodic reports to the Treasury Department (and post them on a public-facing web page) describing how their activities promote equity, including specific equity goals and targets. This type of guidance is almost certain to nudge governments to disaggregate data further than they might otherwise have done, and provides Treasury with a wealth of data.
- Federal education law (i.e., Every Student Succeeds Act (ESSA) / Elementary and Secondary Education Act (ESEA) requires states to produce comparable annual datasets on a range of school performance indicators and to report the data for sub-populations including race/ethnicity, family income status, disability status and language proficiency. Indicators include student achievement on test scores and grades, graduation rates, attendance, and more. DA has leveraged education data required under these federal laws to develop a database comparing school performance across 10 states that adjusts for school characteristics to gather insight on the impact of specific interventions and investments by our clients. For example, this database is being used by a large US philanthropy to measure and track the aggregate impact of their investments and make decisions about where to adjust investments based on evidence.

Second, the Federal government can use its **convening power** to engage directly with states and localities to focus on policy areas where equity objectives are not being met to encourage adoption of best practices and support localities in overcoming challenges.

- For example, the White House convened a local government working group focused on the Child Tax Credit o share data and best practices that helped to increase uptake of the Child Tax Credit - a program with immense potential that is too often under-utilized. This involved 1) sharing CTC application data by zip code for participating cities — in a dashboard developed by Code for America; 2) regular knowledge and best-practice sharing calls among cities, counties, community partners and the White House. This initiative has helped cities better track program performance in their cities and share ideas on how to increase uptake.

Question 3: Policies, resources, programs, training, or other tools to facilitate increased data sharing between levels of government

Our experience supporting local governments in program implementation has shown that many of the tools that support data sharing between governments are similar to those that support sharing with CBOs and members of the public, although higher capacity governments will have capacity for more complex data sharing arrangements for sensitive or potentially personally identifiable data.

Perhaps the greatest tool to increase data sharing is simply to **make data public**. The Federal government, states, and localities are of course replete with examples of data shared publicly. However, it bears repeating, as local and state government staff are often stressed for time and capacity to navigate more complicated sharing arrangements. For example, data standards and requirements for machine readable data formatting (compatible with APIs) could significantly increase data sharing between levels of government and with the public and allow third party organizations to add capacity by leveraging and integrating disparate sources to glean useful insights. There is precedent for federal rulemaking in this space including the Transparency in Coverage (TiC) rule released by HHS and Labor in 2020 regarding health pricing, that has required health insurers to release prices for plans and other services as machine readable files so that consumers, researchers, employers and others can access and use them efficiently.

In areas where the Federal government may not have access to equitable data or wants to encourage states or localities to collect it, establishing both **flexible criteria and clear equity principles** for federal funding programs can encourage local governments to be creative. For example, the City of Tulsa used part of its ARPA funding allocation to support CBOs leading equitable community development projects. The RfP for CBOs specifically asked applicants to state which of Tulsa's equity indicators their project will address. The city's ARPA working group created data trainings to help under-resourced CBOs from disadvantaged neighborhoods to have a better chance of success. Finally, CBOs are required to report demographic data of those who benefited from their work, so Tulsa's reports back to Treasury include equitable data specific to the local context.

Particularly for smaller cities with limited staff capacity and experience applying for federal funding, **guidance to navigate federal data sources** can elevate the quality of grant applications and encourage the long-term use of this data. As part of the Bloomberg Local Infrastructure Hub, we are currently working with subject matter experts, the US Conference of Mayors, and the National League of Cities to orient potential applicants to the relevant public resources to quantify the need in their communities for federal aid. Guidance on using FEMA's flood maps is currently helping dozens of cities develop a detailed view of flood risk, highlighting where Flood Mitigation Assistance funding could reduce the threat to local disadvantaged communities.

Question 6: how to make equitable data more accessible and useable for members of the public?

In recent years, we have seen a strong push for governments, researchers, and others to release data via open data portals or similar initiatives. However, for members of the public who may have limited time or expertise in the underlying topic or in navigating advanced data systems, data needs to be shared in ways that are intuitive and understandable.

From our experience working with governments interested in improving transparency and accountability with the public, we have seen that designing and building public-facing data tools or dashboards that focus on the key indicators that are most relevant to the public can be one of the most powerful tools. However, given the number that are built and sit (relatively) unused, a few of the attributes we have found to be important in the dashboard design include:

- **Tied to resident needs**: Public-facing dashboards should focus questions and data that speaks to what the public cares about. This should include disaggregations by relevant dimensions or a focus on issues where disparities are well known to exist. Providing links to resources can also help the public use data to inform their choices.
- **Clean visuals:** Graphs and tables should be labeled clearly and avoid jargon or acronyms that may not be universally understood.
- **Clear explanations:** Features that allow residents to ask questions and include FAQs can help residents understand data and how it is relevant, along with plain-worded explanations of what the data means.
- **Downloadable data:** The best public-facing dashboards will make the public curious to know more and will provide access to underlying information in .csv format or similar.
- **Accessible:** Dashboards should be readily accessible to the public: this includes adhering to ADA standards for accessibility for people with disabilities, as well as including translations in the primary language spoken by community members.

A few examples of cities who have developed simple and clear dashboards that provide information to the public include:

- **Paterson, NJ:** created an information hub with the Coalition for Opioid Assessment and Response that displays the breakdown of opioid overdoses by age, residency type, location and gender. The dashboard helped the city focus its preventive outreach by showing that 20% of all cases occurred in two percent of the city area, and has helped dispel myths about who tends to overdose. The dashboard also includes information about harm reduction, directing the public to relevant resources.
- **Knoxville, TN:** developed a public facing dashboard intended to reduce evictions and utility shut-offs. The dashboard shows estimates of the current unmet need using 211 data, and participation levels in local assistance programs, broken down by race, ethnicity, and income. As a result of this initiative, the city was - for the first time - able to track the level of assistance being distributed to each zip code in the city. In addition, they were able to gather new information for housing instability and assistance and establish a working group to discuss strategic actions to improve grant and benefit distribution to residents.

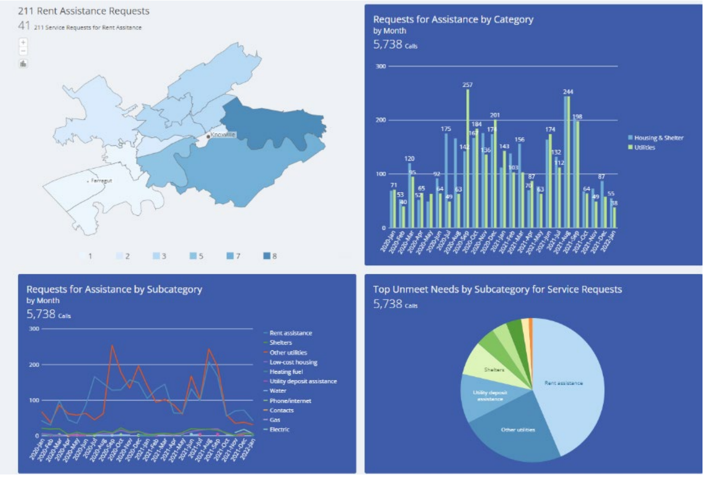


Figure 1. Knoxville Dashboard

- **Pittsburgh, PA:** has recently launched a dashboard intended to help the public understand the city's budget and how it aligns with citywide priorities, which includes equity. While just emerging, this dashboard allows interested residents to clearly visualize how spending is distributed by function and by priority to understand how the budget reflects their priorities.

While these examples are all public-facing, they are also being used by CBOs and governments themselves in order to prioritize resources to those most in need and coordinate responses.

Finally, while making data publicly available is a crucial first step, we have also seen the power of more collaborative approaches to working with the public to test and interpret equity data, such as through the Greenlink Equity Maps and their associated Process Guide for City-Community Collaboration, which spells out a process that can facilitate deeper engagement and understanding on all sides.

Question 7: Unmet needs and problems that could be remedied through improved collaboration on equitable data

In some areas, a **lack of consistent definitions for complex** equitable data concepts can hamper even interested and motivated governments, CBOs, and the public from making progress.

For example, the administration has made a pathbreaking commitment with the **Justice 40 initiative**. However, broad guidance results in high variability across definitions of what makes for a Disadvantaged Community (DAC), making it more challenging for states and localities to fully align with the intent of the initiative. This also causes delays as communities try to determine eligibility and suitability of projects. Recent Federal data tools (e.g. the Climate and Economic Justice Screening Tool) make a big difference, but have been released while funding has already been dispersed and plans are already approved.

Complicated and siloed data, particularly related to child welfare, also prevents governments and advocates from identifying and serving beneficiaries, particularly those who are most disadvantaged.

- States have historically struggled to produce an accurate count of children enrolled in early childhood care programs. Roughly one third of states (18) have established early childhood integrated data systems (ECIDS), which allow them to link individual-level data across the different programs and agencies that administer early childhood care. Yet just seven link information from Head Start– a federal program that specifically intended to serve low-income families– because current law requires states to negotiate data sharing agreements with each individual Head Start provider. Without a complete picture of who programs like this are serving, federal and state leaders have no way to assess access to critical resources for underserved communities.
- In our work on the Expanded Child Tax Credit Learning and Delivery Agenda, delivered to the White House Coordinator for the American Rescue Plan and a coalition of philanthropic organizations, the team found that key datasets on tax filers (demographics, locations, etc.) were fragmented across different agencies, and inaccessible between agencies and state governments. Access to these datasets allow for policymakers to implement programs that allow for more equitable access to social benefits programs (i.e., in this case the expanded Child Tax Credit). With respect to data, we recommended:

1. Establishing data sharing agreements (DSAs) between benefits agencies and across state departments (e.g. including tax/revenue) at all levels of government to facilitate real-time access and usability of rosters/ databases for benefits-related outreach activities.
2. Where there are no existing DSAs and/or there is insufficient time to establish a new agreement, benefits or revenue agencies can conduct outreach to clients below a particular income level to promote a baseline level of communication that does not need data access.
3. Create a consistent data collection and reporting mechanism, including analytics tools and API, that can be accessed by state and local governments to disaggregate anonymized demographic information about benefits recipients and inform future outreach.
4. Set up an inter-agency benefits delivery working group. The aim of this group is to coordinate benefits delivery across different departments; specific to data, develop implementation plans, data strategy, and set routines.

ICLEI USA Response to RFI on Equitable Data Engagement and Accountability

Dear Subcommittee Members,

Thank you for consideration of ICLEI USA's responses to the questions below. Responses are in italics.

II. Key Questions for Input

A. Vision

i. The vision for the Environmental Justice Scorecard is as a robust and comprehensive assessment of the Federal Government's efforts to address current and historic environmental injustice, including the Justice40 Initiative.

ii. Question

1. Does this vision reflect the needs and priorities of communities that face environmental injustices?

The Environmental Justice Scorecard will not be reflective of efforts to address current and historical environmental justice without considering race.

It will never be possible to accurately "measure" or categorize community disadvantage from afar via an index; that being said, with the reality being that the federal government uses such tools for funding purposes, every effort should be made to identify and prioritize environmental justice communities for funding opportunities. This will not be possible if the role of racism in unequal distribution of environmental burdens is ignored.

B. Framework

i. In the first version of the Environmental Justice Scorecard, Federal Government activities will be organized in three reporting categories.

1. *Reducing Burdens and Harms in Communities:* This category would measure the regulatory, enforcement, and other actions taken to reduce harms and environmental injustices.

2. *Benefits to Communities:* This category would measure the Administration's progress on implementation of the Justice40 Initiative, among other environmental justice efforts.

3. *Centering Justice in Decision Making:* This category would capture measures taken to reform agency decision making to incorporate the perspectives, priorities, and lived experiences of environmental justice communities.

ii. Questions

1. Do these categories broadly reflect the needs, priorities, and impacts that communities are facing from environmental injustices?

2. For the first version of the Environmental Justice Scorecard, what processes and markers of progress should be reflected in each of these categories?

-The Scorecard offers an excellent opportunity for the United States to show leadership in the UN 2030 Agenda for Sustainable Development. With the core tenet of "leaving no one behind", the Sustainable Development Goals (SDGs) were formulated with concerted U.S. contribution to embed social equity considerations throughout. Despite this, the U.S. has at times abdicated leadership in this arena but can stand up the importance of data-driven processes for EJ by bringing the scorecard forward as a good practice for SDG tracking. The Scorecard outputs should contribute to Voluntary National Review to the UN ECOSOC. Incorporating or at minimum, being mindful of complementarity, between the SDG indicators will be important, particularly for SDGs 1, 3, 7, 8, and 11.

- Collecting utility emissions data would be a helpful area: having IRP info collected in a standardized format, particularly around hourly emissions and supply sources will help stakeholders better fill in those gaps (do 24/7 the right way). It will also help highlight persistent EJ issues by showing which fossil resources remain active as well as just transition needs but showing which will close.

- Similarly, all utilities and balancing entities should be required to post real-time and historic emissions data.

3. In the long term, what are the desired outcomes that could be included in each of these categories?

C. Engagement

i. Please provide recommendations on how to improve engagement with, and around, the Environmental Justice Scorecard. In particular, what are ways to improve sharing information about the Environmental Justice Scorecard?

-Throughout 2023, a worldwide Global Stocktake of the Paris Agreement will take place through a series of "local stocktake" events at the city / community level. Hosted in hundreds of cities, these stocktakes will answer 3 questions: To what degree is our community's CAP currently supporting the U.S. climate goals? Where do we want to be? How do we get there in an environmentally just way? Particularly for Question 3, the EJ Scorecard offers a standardized way to collect and collate information already requested under this stocktaking exercise. This provides a unique opportunity for engagement. The Paris stocktake is mandated every 5 years and will provide a recurring chance to collect information. Communities' insights will be shared with the UNCCC and can also be shared with CEQ.

-*Work with community partners to co-create equity-driven and vetted climate indicators for Cities to report, and a dashboard with metrics that can be automatically or easily updated. This project would include two phases. The first would be a full equity-focused and community-driven process to identify meaningful metrics/indicators, the criteria they should meet (e.g. easy to gather, center equity, meaningful, tells a larger story, includes resilience impacts). The second* *phase would be to develop an accessible public dashboard/tool that could be tested and launched. The metrics could use available data as much as possible (e.g. Google EIE, census, air quality, health, energy usage). This would help Cities advance towards CAP 2.0, going beyond greenhouse gas inventory reporting.*

Many cities have been working to identify a set of equitable public climate and resilience indicators/metrics that can provide meaningful insights into a community's progress in advancing climate and resilience goals. The intent would be to provide a larger context to climate work beyond quantifying greenhouse gas emissions reductions, which is just one piece of the story. In order to achieve this, we would like to co-create a set of equitable metrics/indicators with community organizations, to understand what meaningful information the community wants to better understand, monitor, and hold local governments accountable to.

ii. For a future website, what are some usability and accessibility features that should be considered for an online platform?

I will respond with a suggestion that addresses questions 5, 6, & 7.

As a participant in a new initiative led by The Cleveland Foundation and another 20 community-based foundations in this region, I am especially delighted to see this initiative. We have very wide racial disparities in our region across a wide range of dimensions--income, health, education, transportation access, food access, water and land quality, greenspace, and so forth. Hence, my interest in your efforts to make relevant data accessible to a full range of community groups who can benefit from a detailed understanding of the challenges and opportunities in their areas of influence.

My comments are directed in the opposite direction. Instead of suggesting additional specific data collaborations to help overcome inequities, I suggest one very important and complementary solution--regional and county dashboards that provide a 360 view of the societal, economic, and natural environments in which they found themselves. Instead of a solitary focus on individual trees, I emphasize a parallel focus on the forest. Building on the work of Johan Rockstrom (Director of the Potsdam Institute for Climate Impact Research), Kate Raworth (Oxford University) and the UN SDG framework (see SDSN and Jeffrey Sachs), I'm developing a dashboard of 60+ indicators, organized into 15 categories, balanced across the triple bottom line of people, profit, and planet. It has a simple, easy to understand, visual interface. The indicators mostly consist of a broad array of stats drawn across the full spectrum of government organizations and data sources.

Here's my point. Not much progress will be made on dissolving inequities without informing and educating the majority culture. More precisely, we need to develop a sustainability mindset and literacy for influence leaders at all levels and across all demographic groups and economic sectors (think ministers, doctors, city & county council members, program administrators, corporate social responsibility directors, econ analysts, etc). As well expressed in the book Factfulness (Hans Rosling), even leaders in relevant positions (eg, World Bank program managers) are woefully ignorant of basic facts about the groups they serve.

I propose that one important outcome of your work should be a readily accessible and understandable dashboard that provides a 360 view of the social, economic and environmental facts and trends in which social and economic programs operate. While experts in specific areas (public health, education, economic development, etc) are well informed within their respective silos, they tend to be poorly prepared to understand basic facts and trends in other areas with whom they must collaborate. A systems view is sadly lacking. The one I'm working on contains data on all 3,143 counties of the US.

The benefits of this systems-view are many, and include:

- A 360 county view across all 3 sectors of economy, society, and environment that helps develop a 'sustainability mindset'
- Helps leaders 'connect the dots' by providing an integrated and dynamic systems view of their region.

- Provides a consistent, evidence-based framework to stimulate discussion and innovation across and among different sectors of work.
- Readily translates into the SDG framework to connect a community to state, national, and global efforts, best practices, and resources.
- Provides broad exposure to a wide variety of data sources, so that those requiring additional data become aware of where to look.
- Provides statistical benchmarks to other counties within the state and nation, the state average, and the national average, to establish answers to the initial question of 'Where are we now?'.
- Provides trend data to show where progress has been made (or not).
- Provides the data needed to support triage and efforts to prioritize their efforts.

I recommend two initiatives.

1. Support the development and implementation of this systems-view data dashboard and its display in our region (with national roll-out to follow).
2. Support a data super-center and hub that can be used for more detailed data access by area researchers, analysts, and program administrators; and for efforts to educate community leaders about where and how to access relevant data.

For this second initiative, I'll note that Kent State has been under discussion with the Census Bureau as a possible site of Census Bureau data site to stimulate useful research. What I'm suggesting is to expand that proposal to become a data integrator site that also provides ready access to other databases such as from the CDC, Dept of Labor, Bureau of Economic Analysis, DOE, EPA, USIA, USDA, etc. Support for a major data hub and its concomitant research activity at a major university could quickly become a model for nation-wide implementation. Take the issue of climate change. The science tells us that we need to accomplish a 50% reduction in carbon emissions within the next 8 years. The speed and scale to achieve this necessary goal requires accurate data across a comprehensive array of community factors.

A useful model for the type of integrated data and research center that I'm proposing is the Indian Institute for Human Settlements, and the work of Aromar Revi. He is a passionate and articulate proponent of the usefulness of a multidisciplinary and community practice engaged hub to adapt and invent the tools and resources required to transform society to meet the needs of a sustainable world.

Best wishes for your work,
David

David DuBois, PhD
Adjunct Faculty, Management & Information Systems

4 QUALITY EDUCATION
11 SUSTAINABLE CITIES AND COMMUNITIES
17 PARTNERSHIPS FOR THE GOALS

What resources, programs, training, or other tools *can expand opportunities for historically underrepresented scholars and research institutions to access and use equitable data across levels of government* ?

Aloha from Hawaii!

Dear committee

As an ethnic minority female living in the Pacific islands, I feel that there is an under representation of public data collected here in Hawaii.

While the population size is not as large as ones found in the mainland, we are able to use the data findings here in Hawaii as a generalization of the Asian & Pacific Islanders (AAPI) population at large in the U.S. Most datasets used as AAPI proxy are from Taiwan or China but we know that there are biased findings based on culture, education, etc. Asians in Hawaii are also more diversified as they include Southeast Asians, East Asians and South Asians. Furthermore, datasets collected by the Fed Reserve or other large organizations seem to be oversampling white households. Minority households such as Asians are overlooked, especially with the subsets of Southeast Asians and South Asians.

Therefore, having studies conducted on the population in the Hawaiian islands would contribute towards greater understanding of the Asian population in the U.S. which has been a rising power/influence in politics, finance, health, etc.

Given the opportunity, I would like to be trained on the resources that would enable me to embark on such a study and collect data from Hawaii as a way of creating equitable data.

Yours truly
Lena Gan
PhD student
Kansas State University
Dept of Personal Financial Planning/Family & Consumer Sciences
Justin Hall
[redacted]

October 1, 2022

Mark Y. Czarnolewski, Ph.D., LLC (Unaffiliated)

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[redacted]

[redacted]

INTRODUCTION

The present document is a response to the Office of Science and Technology Programs Request for Information ((RFI) *Advancing Equity with Community Data Partnerships: We Need to Hear from You (September 6, 2022) By Denice Ross, U.S. Chief Data Scientist in the Office of Science and Technology Policy and Alex Hertel-Fernandez, Senior Equity Fellow in the Office of Information and Regulatory Affairs*

The enclosed responses focus on public health information that is in the public domain and may be referred by researchers or the public for monitoring purposes and in times of emergency for responses to Questions 5, 6 and 7. The response to Question 4 focuses on collaborative communication tools used by the National Cancer Institute (NCI) and National Institute of Standards and Technology (NIST) to promote health communication, and suggests ways the information can be adapted by researchers.

Thank you for this forum which allows the public to submit ideas and suggestions to OSTP. The suggestions and ideas in this document are being offered with the understanding of their limited application. However, when considered as part of the other responses, they may provide some unique contribution to the use of data by different interest groups.

Responses to Office of Science and Technology Programs Request for Information (RFI)

1.What are *examples of successful collaborations* involving equitable data between the Federal government and (a) Tribal, territorial, local, and State governments, or (b) local communities?

2. Among examples of existing Federal collaborations with (a) Tribal, territorial, local, and State governments or (b) local communities involving equitable data, *what lessons or best practices have been learned from such collaborations* ?

3. What resources, programs, training, or other tools *can facilitate increased data sharing between different levels of government (Tribal, territorial, local, State, or Federal) related to equitable data* ?

4. What resources, programs, training, or other tools *can expand opportunities for historically underrepresented scholars and research institutions to access and use equitable data across levels of government* ?

Visuals provide tools as one part of a collaborative communication effort by the National Cancer Institute's (NCI) use of "patient personas" (Goldberg, et al., 2011). Personas help picture those people who will use the NCI system to educate and guide the public. Personas incorporate demographic data, qualitative data, attitudes and typical scenarios into a portrait of a type of user. For NCI, the map of consumer personas considers both technology and health literacy, as well as the differing needs of various points along the cancer journey. *Such tools can expand opportunities for historically underrepresented scholars and research institutions to access and use equitable data across levels of government*.

Visual tools present information and help in the directing of behavior. Such tools have become more pervasive in the health fields. As Schneiderman, et al. (2013) states, "Information visualization and visual analytics processes offer algorithms, interactive designs, and analytic processes that support exploration, monitoring, insight discovery, professional collaboration, and comprehensible presentations to patients, clinicians, policymakers and the general public." (p.58).

Schneiderman, et al. (2013) focuses on the use of various technologies with different degrees of sophistication to collect and eventually present information to three audiences: the individual, clinician and policy makers (often including data analytic specialists, such as statisticians or epidemiologists). Goldberg, et al. (2011) describe usability and accessibility in consumer health informatics. They define user-centered design (UCD) as a process that begins with an understanding of the context of use and incorporates evaluation of design solutions as a way to modify the design until it meets the needs of users. Those needs include usability and business goals. In UCD, the people who use the system for information must be seen as individuals in the context that they use the system.

For example, Subject Matter Experts (SMEs) can articulate and prioritize dominant concerns of marginalized communities, such as trusting the message (or messenger) or ensuring that community members attain access to critical resources that enable self-efficacy behaviors, such as getting access to vaccines, masks and social services (e.g. Lisa Fitzpatrick, MD, April 6, 2021). This can be extended to developing personas that include different demographic groups. The SMEs can adapt messaging based on statistical models that identify disproportionate impacts on minorities (Figueroa et al., 2020).

Personas can also include different age groups. For example, the Census Bureau (https://www.census.gov › data › tables › 2020 › demo › families › cps-2020.html) provides details of Family/Nonfamily households which asks whether households included family members or not , with discrete age categories going from under 1, under 6-11, 12-17, 18-64 to 65 or older. Each age group is associated with different medical conditions, with potential representation as different personas.

5. What resources, programs, training, or tools *can increase opportunities for community-based organizations to use equitable data to hold government accountable to the American public* ?

- Czarnolewski (2019) focuses on accessing readily available public information (e.g., Government reports, peer-reviewed journals, media, etc.) to help identify and amass relevant information to help guide interventions, such as medical and psychological interventions in Puerto Rico. He focused on End Stage Renal Disease (ESRD) (Burrows, et al. 2014; 2017) and diabetes (Cumba-Aviles and Saez-Santiago, 2016; Geis, et al., 2012; Tierney, et al., 2013) information available to the public. The numbers he computed highlight the practicality in quickly retrieving data that can help guide aggressive search and rescue to help ensure health stabilization and maintenance in times of crises, such as Hurricane Maria and its aftermath (Ghosh, et al., 2018.)

6. What resources, programs, training, or tools *can make equitable data more accessible and useable* for members of the public?

Vulnerable Populations on a national level

- Nationally, deaths from, in order: heart disease, chronic low respiratory, cerebrovascular, Alzheimer's, diabetes and influenza/pneumonia diseases are among those most likely found among those >=65 (DHHS/CDC, 2017); *therefore, the conditions in the aftermath of natural disasters like Maria increase the probability of endangering an already vulnerable population (Czarnolewski, 2019).* This concern is borne out by the fact that *86.1% of all deaths in the September and October post Hurricane Maria were >=60 (*Cruz-Cano & Mead, 2019).

- References for rates of diabetes, for example, for different demographic groups can be searched on the American Diabetes Association website (American Diabetes Association (Mar 22, 2018). *Statistics about diabetes*. www.diabetes.org

- Data bases with information on hemodialysis units can be obtained for those who have access to the website operated by the University of Michigan Kidney Epidemiology and Cost Center that is produced under contract with the Centers of Medicare and Medicaid. (https://www.dialysisdata.org) Questions may be submitted to [redacted].

- The Census Bureau's *America's Families and Living Arrangements: 2020* survey can provide additional useful information (https://www.census.gov › data › tables › 2020 › demo › families › cps-2020.html)
  One question provides details of Family/Nonfamily households which asks whether households included family members or not, with discrete age categories going from under 1, under 6-11, 12-17, 18-64 to 65 or older. Such detail would suggest likely needs to deliver to each age group (DHHS, CDC, 2017) in natural disasters. The DHHS, CDC (2017) report presents predominant medical conditions for different age groups.

Vulnerable Populations in a specific example, Hurricane Maria:

- Robles, et al. (Dec 9 2017) report that the Center for Investigative Journalism published its own estimate that nearly 1,000 plus more people than usual died in the months of September and October. Records from Puerto Rico's government show that some of the leading categories of causes of death in September were, in order: diabetes, Alzheimer's/Parkinson's, emphysema/other breathing disorders, sepsis and pneumonia.

- Cruz-Cano and Mead (2019) list the number of excess deaths by top five diseases for September and October in Puerto Rico as (a) heart disease, (b) other, (c) diabetes, (d) Alzheimer's and (e) septicemia, with a total of 1,205 deaths -- *86.1% of all deaths were >=60.* Robles, et al. (Dec 9 2017) note that "the highest surge was in deaths from sepsis — a complication of severe infection — which jumped 50 percent over last year. That change is notable and could be explained by delayed medical treatment or poor conditions in homes and hospitals."

- Will similar patterns emerge in a repeated hurricane in Puerto Rico; will similar patterns emerge in natural disasters in other states; what are the necessary supplies to prevent similar patterns of (injury or) death?

7. In which agencies, programs, regions, or communities *are there unmet needs, broken processes, or problems related to participation and accountability* that could be remedied through stronger collaborations and transparency around equitable data?

Using Puerto Rico post Hurricane Maria provides a good example of a region requiring stronger collaboration (Czarnolewski, 2019) (This information may be updated for the recent Hurricane Ian in 2022):

- The CDC publishes rates of diseases for each state (including U.S. territories, such as Puerto Rico). These publications of disease rates are published in the *Morbidity and Mortality Weekly Reports (MMWR).* End Stage Renal Disease (ESRD) requires dialysis or a kidney transplant for survival and diabetes accounts for 44% of ESRD patients (Burrows, et al., 2017).

- The general population's estimated rates of diabetes on Puerto Rico are: Cumba-Aviles and Saez-Santiago (2016) reporting rates of 13.3 to 16.4%, Geis, et al. (2012) reporting 12.7% and Tierney, et al. (2013) reporting 13.3% or 14.3%.
- Senior citizens in Puerto Rico have higher rates of diabetes than the Puerto Rican population, as a whole, with estimated rates of 37.1% (Salas, et al. 2016). *Because diabetes is comorbid with many diseases (Burrows, et al., 2017; Puerto Rico Chronic Disease Action Plan 2014-2020) and senior citizens comprise the largest number of deaths for diabetes and a number of diabetes' comorbid diseases than other age groups (DHHS/CDC, 2017), the much higher rate of diabetes among senior citizens requires a special focus.*

- Tierney, et al (2013, Table 3) provide diabetes prevalence estimates within each county in Puerto Rico. In general, *low* prevalence counties are concentrated on the eastern half of Puerto Rico and *high* prevalence counties on the western half. The western half tends to have a *higher* percentage in poverty, a higher average household size, a *lower* percentage of those >=25 years who completed high school, and *lower* median household income. *Perhaps, analogous patterns of economic demographic group-diabetes or age group-diabetes relationships can be further investigated within each state* (American Diabetes Association, March 22, 2018) *to identify concentrations of diabetes warranting direction of resources in natural disasters.*

- Burrows, et al (2014; 2017) report that Puerto Rico had 6,091 ESRD patients over 18 in 2010, with 1,462 starting treatment.

- Bonilla-Felix and Suarez-Rivera (2018, Figure 1) provides a map of the 52 hemodialysis (HD) units on the island, which are used for ESRD patients, with 48 of them able to continue working immediately after Hurricane Maria, including the only pediatric dialysis unit on PR. But, all had to use generators and water tanks.

- Nationally, deaths from, in order: heart disease, chronic low respiratory, cerebrovascular, Alzheimer's, diabetes and influenza/pneumonia diseases are among those most likely found among those >=65 (DHHS/CDC, 2017); *therefore, the conditions in the aftermath of disasters like Hurricane Maria likely endangered an already vulnerable population.*

- Records from Puerto Rico's government show that some of the leading categories of causes of death in September (2017) were, in order: diabetes, Alzheimer's/Parkinson's, emphysema/other breathing disorders, sepsis and pneumonia. Cruz-Cano and Mead (2019) list the number of excess deaths by top five diseases for September and October as (a) heart disease, (b) other, (c) diabetes, (d) Alzheimer's and (e) septicemia, with a total of 1,205 deaths *– 86.1% of all deaths were >=60.* Robles, et al. (Dec 9 2017) note that "the highest surge was in deaths from sepsis — a complication of severe infection — which jumped 50 percent over last year. That change is notable and could be explained by delayed medical treatment or poor conditions in homes and hospitals."

- FEMA coordinated with other federal agencies (e.g., Army Corps of Engineers, Department of Energy), private sector, to move generators, water pumps, water treatment units and other equipment to have electrical power restoration (DHS/FEMA, 2018; Wolf & Curren, December, 14, 2017). FEMA provided generators to 30 critical medical facilities: 14 hospitals and 16 diagnostic treatment centers. *But, FEMA could not decide which lower level medical facilities would receive generators. FEMA gave the Puerto Rico agency for public water and wastewater system a number of these generators. Distribution rules in other states may need to be worked out ahead of time.*

- One of the lessons emerging from the 2017 hurricane season is that generators typically are built to run for a week or two, not long-term, and they require regular maintenance (Wolf & Curren, December 14, 2017). Private physicians' offices, too, need to talk with their building owners about whether the building has a generator maintained regularly and of suitable size to allow the offices to remain open in long-term power outages. This infrastructure challenge needs to be addressed in other states.

- DHHS (December 20, 2017) lists DHHS involvement, (e.g., deployed 3,037 personnel and assisted 31,011 patients) and allocation of resources "to assist local hospitals, dialysis facilities, clinics, and medical supply manufacturers in obtaining the resources needed to continue or restore operations" (Wolf & Curren, December, 14, 2017). *At issue, is whether there could have been a larger, more comprehensive positive impact within a shorter time frame with better preparation (DHHS, January, 2012), coordination through greater investment in resources (DHHS, January, 2012; DHS/FEMA, July 12, 2018) and better apriori use of available public health information (Czarnolewski, 2019).*

- Hurricane Maria significantly damaged key transportation, communication and electricity infrastructure, which exacerbated search, rescue and administration of extensive aid needed to deal with challenging health conditions (Bonilla-Felix & Suarez-Rivera, 2018; DHS/FEMA, July 12, 2018; Michaud & Kates, 2017). Such conditions require an integrated delivery of care with larger investment in resources than currently employed (DHS/FEMA, July 12, 2018; Robles, July 12, 2018). Such an investment increases the likelihood to successfully handle such a large scale disaster within a shorter time-frame where there was such massive destruction, as with Hurricane Maria.

- Data bases with information on hemodialysis units can be obtained for those who have access to the website operated by the University of Michigan Kidney Epidemiology and Cost Center that is produced under contract with the Centers of Medicare and Medicaid. (https://www.dialysisdata.org) Questions may be submitted to [redacted]. However, as previously noted, Bonilla-Felix and Suarez-Rivera (2018, Figure 1) provides a map of the 52 hemodialysis (HD) units on the island, thus showing that critical location information may be obtained without access to the dialysis data base.

- Czarnolewski (2019) was consistent with other calls (U.S. Department of Health and Human Services (DHHS), January, 2012; U.S. Department of Homeland Security. Federal Emergency Management Agency, July 12, 2018); Wolf & Curren, December 14, 2017) for *apriori* preparation for natural disasters predicted to strike or have already started to strike. Czarnolewski (2019) documented that readily available public information (e.g., Government reports, peer-reviewed journals, media, etc.) are available for *apriori* use for natural disasters. *Therefore, when an all-encompassing disaster, such as Hurricane Maria, and other hurricanes, floods, fires, earthquakes, etc. appear likely to strike, public health information likely is available to help guide and amass appropriate interventions, such as medical, psychological, social service and nutritional interventions*.

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7. In which agencies, programs, regions, or communities *are there unmet needs, broken processes, or problems related to participation and accountability* that could be remedied through stronger collaborations and transparency around equitable data?

The Biden Administration is clearly committed to diversity, equity, and inclusivity, which are values that the Rhode Island Department of Labor and Training shares and strives to uphold across the programs we administer. However, there are areas related to federal data collection, specifically within U.S. Department of Labor (USDOL) programs, where improvements could be made to better reflect this commitment. The Rhode Island Department of Labor and Training has identified two major problem areas with regard to non-inclusive language in demographic data collection, specifically in terms of mismatch in data fields and values between federal requirements and demographic realities of race/ethnicity and sex/gender identity, detailed below.

Federal guidelines for demographic data collection have been static for decades even while social norms and our understanding of demographic realities and inclusive language have changed dramatically. Instead of being able to incorporate more inclusive language for demographic questions, state and local entities must adhere to strict federal reporting requirements, often at the expense of the public we are trying to serve. One major consequence of these mismatches are high rates of non-responsive/unknown data around demographics and thus a lack of transparency and accuracy around equitable data. As a result, it is difficult to gain a complete, accurate understanding of the communities we serve – and difficult to identify potentially underserved communities.

1) Race and Ethnicity

Federal programs such as the Workforce Innovation and Opportunity Act (WIOA) and Unemployment Insurance (UI) require race and ethnicity data to be reported (and therefore collected) separately, with a field for Hispanic ethnicity in addition to a field about race. This separation does not align with how many people of Hispanic origin self-identify, and therefore data collected results in many “unknown” or null responses where participants do not know how or do not wish to respond. The US Census Bureau identified and researched this issue in 2015 and determined that the optimal question format for race and ethnicity data is a combined question with detailed checkbox options, including a separate MENA (Middle Eastern and North African) option. **We recommend that all Federal data requirements on race and ethnicity adjust immediately to a singular field with detailed options as outlined on pp. 88-89 of the US Census Bureau Report noted above, and allowance for multiple values.**

In addition, we would like to flag that UI REPORT HANDBOOK NO.401 implies that UI staff can enter data about race and ethnicity of a claimant on their behalf: “…if the claimant does not self-code *or is not seen*, this information will have to be recorded as INA [is not available] in the appropriate category” (Section IV-1-154; emphasis ours). We strongly recommend removing this guidance as it is inappropriate; race and ethnicity data should always be self-identified and reported, and not assumed.

2) Sex and Gender

Federal programs such as the Workforce Innovation and Opportunity Act (WIOA) and Unemployment Insurance (UI) require data on sex to be reported in one field and under two binary options: male and female. This does not align with the reality of how many people identify; in some cases, biological sex may be different from their gender identity. Across the country, many states have taken steps to offer more inclusive options on official documentation and government forms. For instance, Rhode Island, along with nearly half of all states, now offer a non-binary/gender-neutral option ("X") for drivers' licenses. At the federal level, earlier this year the Biden Administration announced measures aimed at LGBTQ+ inclusivity across several federal agencies, including adding a gender-neutral option on passports and EEOC complaint forms. **We recommend that USDOL data guidelines employ more inclusive language for questions around sex and gender, including at the minimum a third option for non-binary individuals.** We also recommend that USDOL considers research from the Department of Health and Human Services as well as forthcoming U.S. Census Bureau research in order to implement best practices on how to ask questions about gender identity and ideal response options.

In addition, we would like to flag that UI REPORT HANDBOOK NO.401 instructs UI staff to enter data about sex of a claimant on their behalf if needed: "Sex can usually be determined by observation or by name if this is not self-coded by the claimant" (Section IV-1-154). We strongly recommend removing this guidance as it is inappropriate; data on sex and gender should always be self-identified and reported, and not assumed.

Thank you for your consideration of our feedback. We are committed to making our programs more accessible and inclusive to all and look forward to positive changes that will allow our data collection to help us better fulfill this mission. Please do not hesitate to contact us if you wish to discuss further.

Contact
Pauline Abetti
Office of Community Engagement
Rhode Island Department of Labor and Training
[redacted]

The problem with many data collection efforts by the government is the amount of data collected, with much of it being highly confidential. I am particularly familiar with the HMIS data collection that HUD requires and this is so detailed on every family member that we steer clear of such programs.   If the government would limit the data collection it would be easier to participate.

I write many grant applications and would love to find a portal to gather data in support of such requests. A data portal with a user friendly series of links to gather data from the Census bureau with tips on collecting data on poverty rates by race and ethnicity for various geographies, tips on collecting language data, and other tips would be helpful. Links to data from the Social security administration with tips on running reports and similar links and tips to other federal agencies would be helpful   This central data site might have links to research on job readiness, re-entry programs, housing for populations at risk of homelessness, models for serving populations with disabilities, and similar issues.

I personally would like to see a data central website focused on reducing poverty and homelessness as its focus. This might include housing programs, job training, re-entry, food security, and advocacy programs. It might have sub-population data for Veterans, domestic violence victims, elderly, disabled, and persons with mental impairments or substance abuse disorders.

Gail Tilkin Walsh
Director of Program Development
pronouns she/her/hers
[redacted]

Please note that the comment button did not work on the RFI for Equitable Data Engagement and Accountability, so I am sending this email instead.

My primary request for data to be disaggregable by race at the Small Business Administration is grounded in my experience with the datasets created out of the PPP loan program during the previous administration. While the variable existed in the dataset, banks were under no obligation to complete that part of the file and therefore there is far too much missing data on that variable in many state files. So although the data is technically disaggregable by race, the missing data makes doing so completely useless. Looking at datasets reported by non-federal sources but maintained by federal agencies is the broader category at stake.

Thus I am requesting an administrative rule that mandates collection entities (e.g. banks for the SBA, local law enforcement agencies at Justice, etc.) involved in these more recent processes of data collection be required to submit information about race/ethnicity.

Thank you,
Dr. Ange-Marie Hancock

Sent from my iPad

1. Local communities compare their YRBS data to state and national findings and the State compares it's data to national data. I would like to see larger samples in order to look at data by race and ethnicity and specific tribes.

2. It is helpful to have the ability to look at YRBS trends over time, and it would be wonderful to be able to segment the data further, for example, by race and ethnicity by state controlling for other variables.

3. See #2. It would be helpful to oversample Native Americans to enable states to look at measures overtime, especially for substance misuse and protective factors. Historically oppressed and underserved, it is always important to share findings in concert with input from Tribes and Tribal organizations.

4. Scholarships and fellowships, including cost of living stipends, for all levels of post-high school education support individuals entering the data field. A simplified grant application process for community-based participatory and rigorous research would encourage research insitutions to set up Centers to: 1) conduct research in collaboration with different levels of government; and 2) train students and community members on collaborative research.

5. A yearly reporting requirement could be considered. Universities or research centers who receive this specialized funding could be expected to do "user-friendly" online presentations and encourage dialogue with the general public, para-proffessionals, education and human service providers. These could be followed by free webinars on developing analytical and evaluation skills.

6. Data visualizations, with clear explanations, can be enlightening. Taking this one step further, artists who present concepts visually could portray effective means of addressing the health disparities presented. Simplified grant applications with 3-4 month response times would enable states and local governments to collaborate with researchers to plan, implement, and evaluate policies and programs.

7. There are unmet needs for urban Native Americans, who have limited IHS services and substance misuse prevention programming. It can be a challenge to engender trust, but trust can be build through skillfully guided collaborative processes, reliability, and transparency. Because collaborations are built over time, funding recommended in #6 should span at least 5-7 years, and be followed by additional means to make successes sustainable over time. Career ladders for those involved helps to ensure continuity over time.
In regards to accountability, it is important to regularly report to communities the progress and results of data collection.

Best of luck in this essential effort.

Hello. I would love to see public access demographic data on Section 8 Housing Choice Voucher (non-MTW) success rates, revocation numbers, rent reasonableness rates, time to lease numbers, extension requests granted, and neighborhood economic indicators where leases are made.

Thanks.

Hello. My name is Sharon Lurye and I am a data journalist for the Education Reporting Network of the Associated Press. I'm writing in response to the RFI on equitable data.

The mission of the Education Reporting Network is to help inform the public about how our nation's public schools were impacted by and how they are recovering from the COVID-19 pandemic. Throughout the course of our work, we make frequent use of federal data, particularly from the U.S. Department of Education's Office of Civil Rights, the National Center for Education Statistics, and the Census, in order to learn more about students, teachers and schools.

There are two data equity issues I'd like to highlight in particular: teacher shortages and tracking the spending of COVID relief funds.

Teacher Shortages:

There has been extensive discussion in the media about the issue of teacher shortages, with many claiming that teachers are quitting "in droves" and that there is a "classroom crisis" or "mass exodus" of teachers.

Unfortunately, the lack of federal data on this issue makes it extremely difficult to see whether there truly is a crisis, and if so, what kind of policy solutions can be used to address it.

The Bureau of Labor Statistics has data on employment in public schools, but it does not distinguish between different job titles -- teachers, bus drivers and cafeteria workers are all lumped in together. The Census has some more granular data on employment that is broken down by job title, but this data is generally published years after the fact. The Department of Education teacher shortage areas going back to 1990 on tsa.ed.gov, but the site provides no indication whatsoever of how the word "shortage" is defined by each state, so there is no way to compare states or to understand the magnitude of the issue.

None of these data sources allow policymakers, journalists or researchers to compare vacancy data by a common definition across states. This makes it impossible to know the extent of the issue of teacher shortages or where the problem is worst. Secretary of Education Miguel Cardona has promised to address the issue of teacher shortages, but how can know which regions of the country are most in need of support without adequate data? As one researcher recently told me, "If we don't know how many vacant positions there are, it's really hard to think of solutions that could be used for this issue."

Two recent working papers illustrate the dire need for more data on this issue: "Is there a national teacher shortage? A systematic examination of reports of teacher shortages in the United States" (>https://edworkingpapers.com/sites/default/files/ai22-631.pdf<) and "What happened to the K-12 education labor market during COVID? The acute need for better data systems" (>https://www.edworkingpapers.com/sites/default/files/ai22-544_0.pdf<). The former paper found that 13 states – including hugely populous states like New York, Ohio and California -- had no teacher vacancy data available whatsoever.

States are already required to report areas of teacher shortages to the federal government. I would propose that the Department of Education should update its Teacher Shortage Areas website so it include information on the extent and magnitude of shortages according to a common definition, instead of simply stating whether or not a shortage exists. This would allow policymakers, journalists and researchers to pinpoint which states are struggling most with teacher shortages, which subjects face the highest need for more teachers, and how vacancies change over time. It would be even better if the data also included racial demographic information on teachers in each state, so that policymakers could also track efforts to diversify the teacher workforce.

Federal COVID relief funds

The U.S. Department of Education has a transparency portal, found at https://covid-relief-data.ed.gov, which tracks how states are spending $263 in emergency relief funds intended to support educational institutions. When states report data on spending to the federal government, it is displayed on the website within two weeks, which is excellent. Unfortunately, the website only includes data on how much money was granted to each state and district and how much has already been spent. It does not detail HOW that money has been spent. Those details, so far, are only available for the 2019-20 school year.

COVID vastly exacerbated already longstanding inequities in the educational system, as the nation's most vulnerable students also saw the largest drops in academic achievement. The purpose of the emergency relief funds was to remedy those inequities. But how can we track whether equity gaps are closing and hold schools accountable, if we have no idea how the money is actually being spent until years after the fact? I strongly urge the federal government to prioritize more rapid publication of spending data so that we can see how much is being spent on different categories such as academics, mental health and activities for underserved students. The government should prioritize making spending plans available in a common format across states.

Thanks very much for taking the time to read my views. I hope this leads to more equitable and transparent sharing of data in the future.

Sincerely,

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AP

Sharon Lurye
Data Reporter, Education Reporting Network
The Associated Press
[redacted]

Good morning,

I was delighted to see the call for ideas for advancing equity with community data partnerships, and am writing to **request that these efforts include addressing data quality and availability for stillbirths**, or pregnancy losses that occur anytime from 20 weeks' of pregnancy onward.

By way of introduction, I am an Assistant Professor of Epidemiology at Emory's Rollins School of Public Health, with expertise on stillbirth in the United States (see also, here).

Stillbirths are far more common in the US than many people believe – nearly 22,000 families lose babies to stillbirth each year in the United States, which is about 1 in every 175 pregnancies that make it to 20 weeks' gestation. These losses are absolutely devastating, and are felt no differently than the deaths of babies who were born alive. There is a dangerous misconception that stillbirths are inevitable; rather, at least 25% of US stillbirths are preventable, and if we matched the rates of the best performing high-income countries, we could prevent up to 75% of stillbirths. Our performance on the world stage is dismal: from 2005-2015, the United States ranked 183rd out of 195 countries in reducing stillbirth rates, with a mere 0.45% decrease during this 10-year period.

On the topic of health equity – **stillbirths are far from equitably distributed**. Stillbirth rates among American Indian or Alaska Native and Black individuals are more than twice that of their White counterparts. Stillbirths are more likely to occur among younger and older pregnant people, and there is substantial variation by state.

Major impediments to addressing the stillbirth crisis in the United States are concerns related to data quality and availability. Just as all births are required to be registered, so are stillbirths (although stillbirth definitions do vary by state). These vital statistics data are publicly available through CDC Wonder and National Vital Statics Reports. While annual birth data are prioritized for timely release, the same is not true for stillbirth (also called fetal death) data. As an example, provisional 2020 birth data were available in May 2021, and the final 2020 birth report was released on February 7, 2022. Provisional 2020 stillbirth data were never released, and the final 2020 stillbirth report was only just published on August 4, 2022 – a full 15 months after the initial release of the 2020 birth data. **In order for these data to inform public health decision making to advance equity, stillbirth data must be released in a timely fashion**. This is particularly problematic in light of the COVID-19 pandemic, because it is only just now that we are able to begin to understand the impact that the pandemic has had on stillbirth rates nationwide. Given that COVID-19 increases the risk of stillbirth, this extreme lag in data availability may contribute to unnecessary increases in the stillbirth rate if potential areas for prevention are missed.

Even if stillbirth data were to be made available in a timely manner, **there remain concerns about data completeness and accuracy**. Efforts to improve reporting of birth data have not spilled over to improve stillbirth reporting. Assistance is needed at the state and local level to explain the importance of high quality stillbirth data and improve the data collection process.

An item which requires special attention is collection of information about the birthing parent's race and ethnicity. Given known racial and ethnic disparities, it is imperative to have access to accurate race and ethnicity data to track trends by these groups over time. Due to small numbers, race information is not available in CDC Wonder for 14 states. While these data may be available internally, transparency is needed to assure that these trends are being monitored and addressed.

Although this is a large task, it is a worthy cause. In fact, legislation to begin to address the stillbirth crisis has recently passed the US House of Representatives with overwhelming bipartisan support in suspension, and has been introduced in the US Senate. Among other things, The SHINE for Autumn Act of 2022 would appropriate funds to begin to address concerns related to stillbirth data quality. Coupled with this initiative to advance equity with community data partnerships, we have an opportunity to turn the tide on stillbirth in the United States.

Thank you for your consideration of this important issue. If you have questions, please do not hesitate to reach out. I would be thrilled to assist with any efforts to work with local, state, and federal agencies to address the challenges we face in stillbirth reporting nationwide.

Best wishes,
Lauren

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Lauren Christiansen-Lindquist, PhD, MPH | *she/her/hers*

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Director of Graduate Studies, MPH & MSPH Programs

Department of Epidemiology | Rollins School of Public Health | Emory University

[redacted]

[redacted]

[redacted]

Nationwide Car Crash Database

I wish I could get car crash data from USDOT broken down by race / ethnicity / age / gender / disability status and location / cause / injury / death / vehicle types so I can work with cities and bolster community support to improve infrastructure and design to make our right of way safer and more equitable for our most vulnerable groups.

Cities collect this data to some degree now, and many cities roll this up to states. You can see KY State Police's online database here which is actually very good (except some geocoding issues) and pulls in data from all cities and counties.

>http://crashinformationky.org/AdvancedSearch<

Some fields available here:

Air Bag Code
Air bag Switch Code
Between Street Roadway #1
Between Street Roadway #2
Between Streets Indicator
Street Number
Bus Use
Cargo Body Type
Carrier Type
Collision Day of Week
Collision Last Modified Date
Collision Time
Commercial Unit Indicator
Commercial Veh Collision Ind
County Code
Crash Avoidance Code
Dir Analysis Code
Driver Age At Incident
Driver CDL Indicator
Driver County Resident Indicator
Driver Gender
Driver Identified Code
Driver License State
Ejection From Vehicle Code
Ejection Path Code
Enforcement Issue Indicator
Fire Indicator
First Aid At Scene Indicator
Event Coll With First
Event Coll With Second
Event Coll With Third
Event Coll With Fourth
Function Class Code

GPS Latitude Decimal
GPS Longitude Decimal
GVWR Code
GVWR Number
Haz Mat Class
Hazardous Cargo Code
Hazardous Cargo Indicator
Hazardous Spill Indicator
Hit And Run Indicator
Incident Type
In City Limits
Individual Injury Severity
Individuals Age At Collision
Injured Removed By
Intersection Indicator
Intersection Roadway
Investigation Complete
Officer Beat/Post
KARS City Code
KSP Post Area
Land Use Code
Large Truck/Bus
Light Conditions
Location First Event Code
Make
Model
Manner of Collision Code
Median Crossover
Milepoint
Milepoint Derived
Most Harmful Event Code
Motor Carrier Name
Motor Units Involved
NCIC Veh Type Code
One Way Indicator
Overturned Indicator
Parking Lot Indicator
Pedestrian Factors
Person Type Code
Photos Taken
Placard Present Indicator
Pos. In Vehicle Code
Pre Collision Action
Property Damage Indicator
Property Damage Type Code
Rdwy RSE Unique
Ramp From Rdwy ID
Ramp Indicator

Ramp To Rdwy ID
Restraint Use Code
Rdwy Character Code
Rdwy Condition Code
Rdwy Direction
Rdwy ID
Rdwy Name
Rdwy Number
Rdwy Sfx
Rdwy Surface Code
Rdwy Type Code
School Bus Related Code
Secondary Collision
Speed Limit
Submission Type
Suspected Of Drinking
Test Offered
Test Refused
Tested For
Total Lanes
CollisionUnit Towed
Traffic Controls
Number of Trailers
Trapped Code
Cargo/Commodity Type
US DOT Number Curr
US DOT Number Rpt
CollisionUnit Under/Override
Unit Number
Unit Type Code
Vehicle Config
Vehicle Factors
Vehicle Insured
Vehicle Type
Violation Code
Violation Type
Weather Code

Much like UCR crime codes and mandatory rollup to the federal level for crime, I'd like to see the same thing for transportation incidents nationwide and downloadable in a machine readable format.

Thanks,

Michael Schnuerle
Director of Open Source Operations
[redacted]. [redacted]

Thank you for the opportunity to comment on this matter. I will keep my comment short and to the point. In two key areas of research (redistricting/Voting Rights Act and school segregation) it is essential to be able to understand the interactions among race, ethnicity, and age for small geographies. At present we can get Race by Age and Race by Hispanic/Not Hispanic, but we cannot see Hispanic/Not Hispanic by Race by Age. The result is that it is difficult to work with Hispanic voting-age population and even harder to estimate the allocation of school age Hispanic children to line up with other Federal data sources such as the National Center for Education Statistics' Common Core of Data.

The basis for this problem is the fundamentally flawed strategy of treating Hispanic as an ethnicity so that it creates a weird binary category on top of the other racial categories. All of these categories are socially constructed, and to separate Hispanic out as distinct from Black or Asian is simply flawed. The ideal path forward would be to include Hispanic as an additional 'race' category (and probably add North African, Middle Eastern, and Southeast Asian as well) and drop the whole ethnicity thing entirely. Failing that, the Hispanic by Race by Age table needs to be made available for small geographies.

Thank you for the opportunity to comment,
Chris Fowler

--
Christopher S. Fowler
Associate Professor of Geography and Demography
Penn State University

Thank you for the opportunity to comment.

The OMB in 2016 made recommendations on formally adding Middle Eastern/North African to the race/ethnicity federally recognized categories. However, those recommendations never made it to implementation. I am writing to urge this administration to revisit those recommendations and formally implement this recommendation. Without a dedicated category, ME/NA individuals are classified as White at all levels of government and therefore a data-invisible population. As a result, arrest data, school data, foster care data, etc. not only does it not reflect disparities ME/NA individuals face, but also artificially deflates disparities between White and BIPOC populations.

This was an issue I personally faced as a child of the 80's, and now as a parent of a K-12 students, I am witnessing the same with them.

Thank you for considering my comments.

Sana Fadel
Newton, MA

I write to respond to question 4 What policies, resources, programs, training, or other tools can facilitate increased data sharing between different levels of government (Tribal, territorial, local, State, or Federal) around equitable data?

I want to encourage policymakers to talk more about the multidimensional nature of data and the import of data sharing. By promoting greater understanding of how data can help Americans collaborate to solve complex problems, we can build greater support for data sharing.

Policymakers in the US talk about data as if it is solely a commercial asset but rarely discuss the public good nature of data. Policymakers should do more to talk about the multidimensional nature of data and how sharing is a strategy to solve complex problems.

As example, before the US entered WWII, President Roosevelt used the analogy of a neighbor's house on fire and noted that Americans would lend them a garden house.

"Suppose my neighbor's home catches fire, and Ihave a length of garden hose four or five hundred feet away. If he can take my garden hose and connect it up with his hydrant, I may help him to put out his fire."

Climate change (and the resulting fires) are different and Americans need to share not garden hoses but data. While researchers talk about data, the general public is not involved in this discussion and may not understand the importance of openness for gaining new insights and testing for replicability. I don't think we can build trust in AI and other data driven technologies if citizens don't understand the importance of data and how it is governed.

--

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To see many of my publications go to**:http://goo.gl/j9bdKY**

4. Access to data from pre-disaster conditions to understand housing and the interconnectedness and dependencies of social networks in vulnerable communities. Training on how to understand connectedness to place and connecting social indicators to community resilience.

5. Programs of using past or pre-disaster data to understand the vulnerabilities, especially on small scales such as blocks. Expansion of Census data to block-level would provide the ability to model these differences on a small scale within local governments and small communities.

6. Smaller resolution on Census and post-disaster data. Having training on how to access surveys and how to understand from where these data are coming.

7. Local disaster management agencies and within research partnerships with them.

WELCOMING AMERICA

NSTC Subcommittee on Equitable Data
Office of Science and Technology Policy
Eisenhower Executive Office Building
[redacted] Washington, DC 20504

Re: Comment in Response to the RFI from The White House Office of Science and Technology Policy (OSTP), on behalf of the Subcommittee on Equitable Data of the National Science and Technology Council.

To whom it may concern:

Welcoming America issues the Comment in Response to the request for information issued by The White House Office of Science and Technology Policy (OSTP), on behalf of the Subcommittee on Equitable Data of the National Science and Technology Council on how Federal agencies can better support collaboration with other levels of government, civil society, and the research community around the production and use of equitable data.

Welcoming America is a nonprofit that supports communities in building a welcoming society where every person, including immigrants, can fully contribute to and shape our shared prosperity. Our network encompasses more than 300 local government and nonprofit members in 47 states, working through public-private partnerships to advance inclusion and equity for people with migrant backgrounds. We commend the agency for seeking stakeholder input and seeking to build longer-term partnerships with states and localities and know that our membership of government Offices of Racial Equity and New Americans, and community-based coalitions, welcome the opportunity to engage over the long term, as we have with numerous federal agencies on issues of access, opportunity and equity among underserved communities.

The Equitable Data Working Group emphasized the need for the Federal government to use equitable data to (1) encourage diverse collaborations across levels of government, civil society, and the research community and (2) be accountable to the American public and Welcoming America strongly agrees with these assertions. Our members and local city and county jurisdictions often need data that supports commitment to policies and programs of inclusion and would be better able to trust federal data if they knew more equitable practices were in place. They would also be able to better advocate for specific groups of underserved and under-represented populations if data could be and was on a regular basis aggregated in ways that supported targeted programs.

Welcoming America is not a think tank but works directly with communities, therefore we would like to address the following questions referenced in the RFI.

What resources, programs, training, or other tools *can facilitate increased data sharing between different levels of government (Tribal, territorial, local, State, or Federal) related to equitable data*?

We strongly believe that activating the Task Force on New Americans which was laid out via the Executive Order on Legal Immigration to help “ensure that our laws and policies encourage full participation by immigrants, including refugees” is one way to facilitate data sharing. Critical data on the needs and assets of our immigrant communities is siloed in specific agencies and that failure to share that data stifles creative and innovative approaches to programming, as well as access to critical services like language and workforce development. We also believe an active and robust Task Force on New Americans is an essential component of the administration’s broader goals of advancing racial equity and reducing undue burdens for Americans to access critical government services.

Within the jurisdiction of the agency, we urge a specific focus on underserved populations reflected among immigrant communities where data may be difficult to identify because of fears related to status or the challenges of disaggregating data to discern between native-born and immigrant Black populations, for example.

Trusted intermediaries like Welcoming America can serve as a resource to the agency in identifying such opportunities and gaps.

What resources, programs, training, or tools *can increase opportunities for community-based organizations to use equitable data to hold the government accountable to the American public*?

Welcoming America serves as a link to numerous community-based organizations and would welcome the opportunity to support capacity building and linkages. Many community-based organizations are unaware of existing resources or the appropriate channels to utilize data for accountability, and this is particularly the case among organizations representing and serving immigrant populations.

Communities that support immigrant civic leadership through programs like “natural helpers” are perfectly poised to act as the link between governmental agencies and community partners. These programs are also very well positioned to be engaged stakeholders and support the kinds of accountability that will make data more useful and accessible to communities.

Thank you for your consideration,

Welcoming America

Increasing Data Equity Through Accessibility

Position statement, submitted to OSTP, October 2022

Signatories: Frank Elavsky, Carnegie Mellon University; Jennifer Mankoff, Co-Director Center for Research and Education on Accessible Technology and Experiences, University of Washington; Arvind Satyanarayan, MIT Visualization Group.

Overview: This response considers data equity specifically for people with disabilities[1]. The RFI asks "how Federal agencies can better support collaboration with other levels of government, civil society, and the research community around the production and use of equitable data." We argue that one critically underserved community in the context of data equity is people with disabilities. Today's tools make it extremely difficult for disabled people to (1) interact with data and data visualizations and (2) take jobs that involve working with and visualizing data. Yet access to such data is increasingly critical, and integral, to engaging with government and civil society. We must change the standards and expectations around data practices to include disabled people, and support the research necessary to achieve those goals.

We define *disability* here in terms of the discriminatory and often systemic problems with available infrastructure's ability to meet the needs of all people [UN 2017, Oliver, 2013]. We define *accessibility* as the creation of resources that can be accessed by anyone, regardless of their disability, with standard accessibility tools. We define *resources* as any data related analysis, production, and visualization platforms, as well as any data visualizations.

Data equity can level the playing field for people with disabilities both in opening new employment opportunities and through access to information, while data inequity may amplify disability by disenfranchising people with disabilities. Further, as Whittaker and colleagues (2019) state, "...discrimination against people of color, women, and other historically marginalized groups has often been justified by representing these groups as disabled…. Thus disability is entwined with, and serves to justify, practices of marginalization." (p. 11). Below we address three of the questions in the RFI that are most pertinent to the needs of disabled people: Questions 4, 5 and 6.

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[1] We use the terms "people with disabilities" and "disabled people" and variations of them interchangeably in this document to reflect the varied choices that disabled people and theorists themselves choose.

4. What resources, programs, training, or other tools can expand opportunities for historically underrepresented scholars and research institutions to access and use equitable data across levels of government? 5. What resources, programs, training, or tools can increase opportunities for community-based organizations to use equitable data to hold government accountable to the American public?

We combine two questions into one here because we believe that the same underlying barriers impact access for scholars, research institutions, and community groups. We are focused specifically on scholars, research institutions, and community-based organizations that are underrepresented due to disability. We note that disability is not exclusive and can include anyone and at any phase of life. Thus, in addition to being a need in its own right, if we do not address disability access, we are further marginalizing underrepresented scholars and excluding research institutions and community-based organizations that serve any underrepresented population, due to the fact that their constituents will surely include people who are disabled *and* have other marginalized identities.

Our primary goal in answering this question is to highlight the opportunity to expand upon the government's use of accessible tools to produce accessible visualizations. While the government maintains a website containing accessibility information, which mentions data visualization,[2] there is an opportunity to expand this information and ensure that government workers are trained to make use of best practices[3] and the best tools[4] available when producing data visualizations. For example, while the United States Web Design System (USWDS) provides some guidance on data visualization, it is not sufficient for passing Section 508 or addressing the more complex access barriers involved in data visualization. Chartability, as an example, is an attempt to consolidate web standards, research, and practitioner knowledge towards a set of accessibility guidelines specific to the practice of visualizing and representing data and data interfaces (Elavsky, 2022).

Further, these standards must become integral to how the government produces data, across all areas of government. From the CDC to the Census Bureau, critical data that is highly important to all historically underrepresented peoples and should be available to underrepresented scholars and research institutions to access and use, must be accessible to fully include everyone.

6. What resources, programs, training, or tools can make equitable data more accessible and useable for members of the public?

In responding to this question, we will focus on two domains. First, as the question asks, we address *what can be done to make equitable data available to members of the public* with disabilities. However we note that Just having access to data is not enough, or just, when

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[2] https://designsystem.digital.gov/components/data-visualizations/

[3] https://chartability.fizz.studio/

[4] https://github.com/dataviza11y/resources

power, understanding and action are in the hands of government agents, computer scientists, business people and the many other stakeholders implementing data systems who do not themselves have disabilities. As Bennett and Keyes (2020) argue, we must look beyond fairness, which can only "reproduce the discrimination it seeks to remedy," to disability justice, a term used by activist scholars steeped in the Black Lives Matter movement (Wong, 2020). This means the government should also be able to equitably employ people with disabilities in jobs that produce equitable data. As such, the second half of our response to this question addresses *who can create equitable data resources.* Finally, we discuss the critical nature of *forward looking research investments* in advancing our ability to address both of these issues.

1. Improving the prevalence of accessible data for members of the public

We must expand the roles, education, laws, and processes around accessible data for current builders, makers, and practitioners. This is *the greatest area of impact for improving the accessibility of equitable data for members of the public.*

Processes: "Nothing about us without us" is a basic tenet of the disability rights movement (Charlton, 1998), and this applies in every domain. Thus, people with disabilities must be consulted when authoring policies that involve data, access, and equitable technology. Calls for information, involvement, and action should explicitly invite and encourage participation of those most affected.

Roles: Federal effort should be devoted to incentivizing affirmative action towards hiring and including people with disabilities in the US data workforce. This is critical to ensuring that data access is driven by and for people with disabilities, and guided by a deep understanding of how to meet the needs of this population. They must be a voice in the room when making decisions about data access.

Education: In some sense, we are all knowledge workers in today's world. Whether we are trying to understand election-related polling data or make informed decisions about COVID safety, we are interacting with data, often from a very young age. Thus, federal effort should be devoted to including technical accessibility topics and equitable data topics in K-12 curriculums. Similarly, higher education institutions, particularly those receiving government funding, should be expected to include accessibility topics in relevant curricula. Throughout the educational system, we should be training members of the public to have the skills to make use of accessible visualizations, and the skills and knowledge to produce them.

Laws: Given the critical nature of data for everything from making personal safety decisions to civic engagement, data access should be viewed as a human right. Thus, Section 508 (US DOJ, 1998) should be expanded from its current focus on federal contexts to enshrine access to information as an essential human right that applies to all domains where data and information are provided to the public and consumers.

Tools: The best visualizations we produce are often only as good as the tools we produce them with. We must find ways to lower barriers to producing accessible and equitable data. The tools that industry and local and state governments use are largely inadequate for producing robust, accessible data experiences. Our tools need to be improved. The USWDS's Data Visualization work should be expanded to include components that can be leveraged and not just guidelines. We note that a basic tenet of accessibility is that the *same resources* available to the general public should be accessible to people with disabilities -- it is not enough to simply place a data set on the web in an accessible tabular form, for example, and call that "equivalent" or "done". Time has shown that these parallel efforts frequently fall out of date, and rarely have the same features and capabilities of their original sources.

2. Including people with disabilities in the production of accessible data

Improving access to tools and improving the outcomes of our tools is one of the lowest-hanging areas of impact for addressing the scale of accessibility barriers in data

Access to the means of production: Currently, the production of accessible data visualizations is not readily available to the general public. This means that members of the public may sometimes request accessible visualizations (as when a blind student is provided with tactile graphics) or may sometimes encounter them (should a news report or government website follow best practices for accessible visualization production) but rarely have the means to create their own visualizations. An exception to this is the New York Public Libraries' Dimension Lab, which provides access to accessible materials for the general public to make sense of data. Federal programs should be developed to ensure that such programs are widely available in public spaces across the nation.

Improving tool accessibility: On a related note, many data visualization platforms assume that people with disabilities (particularly people who are blind or low vision) will never themselves engage in the production of data visualizations. However, it is not only possible for people with disabilities to produce visualizations, it is productive and important due to the nature of visualization as a tool that itself serves other goals and learning (Potluri et al., 2022). As with any other technology, data visualization production tools should be expected, themselves, to adhere to best practices for accessibility.

3. Investing in an accessible, equitable data future

Anticipating future goals and challenges is an area sorely under-addressed in accessibility policy and strategy but will be vital to the success of equitable data in the future. Most efforts for accessibility are largely devoted to auditing and remediating based on minimum standards and guidelines, which consumes time, resources, and energy that should also be considered for longer-term goals.

Research investment: Funding must be provided for forward-thinking research that investigates structural and strategic limitations to equitable data access. More research is needed to investigate the ways that various cultural and socio-economic factors intersect with disability and access to technology; and to ensure that as data visualizations expand to include dashboards and other complex communication tools, our understanding of how to improve their accessibility and the tools to support that advance alongside. Further research is also needed to improve the accessibility of tools that are used to produce data visualizations.

Community/local investment: Funding must also be provided for community action and programs already in place, such as in schools, libraries, schools for the blind, in addition to programs that can be replicated from one context to another.

Sharing: In addition, the guidelines, tools, and findings between federal and non-federal efforts must be shared. Significant re-work takes place as initiatives are organized at the local level, such as the work from the City of San Francisco's efforts towards accessible public data services for COVID-19, when other localities embark on similar projects. This work could be systematically shared or organized at the federal level to improve how other cities, states, localities, or communities do this work as well as foster future collaborations.

About the signatories

Frank Elavsky
Currently a PhD student at Carnegie Mellon University, researcher at Apple, and an invited expert and contributor to the Accessible Rich Internet Applications (ARIA) working group (a global accessibility guidelines working group, part of the W3C). Former lead engineer for Visa's accessible, open-source design system chart component library, Visa Chart Components and creator of Chartability, a set of guidelines, examples, and heuristics for evaluating the accessibility of data visualizations.

Jennifer Mankoff
Prof. Mankoff is co-director of the Center for Research and Education on Accessible Technology and Experiences. She is the Richard E. Ladner Professor in the Paul G. Allen School of Computer Science & Engineering at the University of Washington. Her research is focused on accessibility through giving people the voice, tools and agency to advocate for themselves. She strives to bring both structural and personal perspectives to her work. She identifies as a person with a disability and her recent work has focused on accessible data access, including access to streaming data, data visualization dashboards, and new and more affordable means for the production of accessible tactile graphics. Her previous faculty positions include UC Berkeley's EECS department and Carnegie Mellon's HCI Institute. Jennifer is a CHI Academy member and has been recognized with an Alfred P. Sloan Fellowship, IBM Faculty Fellowship and SIGCHI Social Impact Award.

Arvind Satyanarayan
Prof. Satyanarayan is an Associate Professor of Computer Science in the Electrical Engineering and Computer Science (EECS) department at MIT, and a member of the MIT Computer Science and Artificial Intelligence Lab (MIT CSAIL). He leads the MIT Visualization Group, which uses data visualization as a petri dish to study intelligence augmentation (IA), or how computation can help amplify our cognition and creativity while respecting our agency. His group's recent work has focused on making data visualizations accessible to people with

disabilities through screen reader technologies and natural language descriptions. Arvind’s work has been recognized with an NSF CAREER award, a National Academy of Science Kavli Fellowship, an IEEE VGTC Significant New Researcher Award, and a Google Research Scholar Award. Visualization toolkits he has developed with collaborators are widely used in industry (including at Apple, Google, and Microsoft), on Wikipedia, and in the Jupyter data science community.

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Justice for
Migrant Women

October 3, 2022

Submitted via [redacted]

NSTC Subcommittee on Equitable Data
Office of Science and Technology Policy
Eisenhower Executive Office Building
[redacted] Washington, DC 20504

Comments in response to Request for Information: Equitable Data Engagement and Accountability

Dear Ms. Ross:

Justice for Migrant Women protects and advances migrant women's rights through education, public awareness and advocacy. We aim to ensure that all migrant women are guaranteed human and civil rights, including the freedom of mobility, the ability to live and work with dignity, and the right to be free of threats of violence against them and their families, whether they are migrating across borders, around regions or within states. We work closely alongside rural women, immigrant women, and women who work in low paid sectors.

The intersecting identities make these women among the most vulnerable and least visible people in the United States. This has also resulted in their exclusion from some of the most basic legal protections. Our work in the community allows us to hear directly from migrant women about their challenges and concerns. Their powerful stories and firsthand accounts demonstrate the need for policy change. Existing data does not often reflect their reality, despite the fact that we should be accountable to them as we all benefit from their labor in myriad ways. It is worth noting that minimal data is available regarding global migration, particularly as it pertains to economic migrants. Even less data is available related to the experiences of women who identify as economic migrants. Many of these community members are of different racial and ethnic identities. Finally, the data does not often capture or distinguish the differing experiences of people who migrate for work, but are not immigrants.

This body of work– understanding who is moving for economic security and health and safety reasons, with a particular focus on women of color– has a significant impact on better understanding the needs of the entire U.S. population that it is accountable to, including migrant women workers. Limited resources and antiquated data collection methods contribute to the invisibility of an already vulnerable population.

For these reasons, Justice for Migrant Women welcomes efforts by the U.S. Office of Science and Technology Policy to advance racial justice and equity through equitable data engagement and accountability. We applaud your acknowledgement that a significant factor to achieve equitable data collection requires disaggregating data by demographic information, geographic information or other variables. To this end, we thank you for the opportunity to provide comments. Justice for Migrant Women offers perspective on the following questions to which you requested input:

> **Question 5:** What resources, programs, training, or tools can increase opportunities for community-based organizations to use equitable data to hold government accountable to the American public?
>
> **Question 7**: In which agencies, programs, regions, or communities are there unmet needs, broken processes, or problems related to participation and accountability that could be remedied through stronger collaborations and transparency around equitable data?

Justice for Migrant Women will address these questions in two of our main areas of focus: economic justice and health and safety.

ECONOMIC JUSTICE

Migrant workers, including farmworkers, perform labor that is vital to the fabric of our society, yet they face greater economic instability due to low pay, poor working conditions, and job insecurity.

National Agricultural Worker Survey: Improve Data Sharing on Women

Justice for Migrant Women works closely with the farmworker community and in particular women who migrate for agricultural work. The National Agricultural Workers Survey (NAWS) is conducted periodically (most recently in 2015-16) to collect demographic, employment, and health data in face-to-face interviews with farmworkers. The survey yields valuable information that informs policymaking. However, the survey report does not include disaggregated gender-specific data on wages and other measures. When the data is disaggregated we see that there is a stark experience between men and women's experiences. For example, in Southern Poverty Law Center's report, Injustice on Our Plates, they requested disaggregated data from the Department of Labor on wages for men and women. They found that [t]he average personal income of female crop workers is $11,250, compared to $16,250 for male crop workers."[1] These shortcomings deprive policymakers and advocates of the data they need to better address the needs of women working in agriculture. The Biden Administration should ensure that public release of NAWS results disaggregate data by gender, especially wage and income data.

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[1] (2010). *Injustice on our Plates*. Southern Poverty Law Center. https://www.splcenter.org/20101107/injustice-our-plates#exploitation

While the data that exists for farmworkers is deficient, it is even more dismal for migrant women working in other fields. Migrant women are working across industries as domestic workers, gig workers, disaster clean up and in other jobs where little to no data exists, specifically disaggregated data to distinguish the experience of women workers.

Pay Data Collection

As a leader in advocating for policies that will close the gender wage gap, Justice for Migrant Women emphasizes the importance of requiring employers to collect and report compensation data by race, ethnicity, gender, and part-time status to the EEOC and OFCCP. The EEO-1 form should provide options when sharing one's gender identity that are more inclusive than the binary male or female option. This is a critical tool that will help identify and address pay discrimination.

This year, for the first time, due to the leadership of Justice for Migrant Women and the National Asian Pacific American Women's Forum, the gender wage gap calculated by race includes part time and full-time workers. Previous data calculations that represented only full-time, year round workers excluded migrant and seasonal workers and in total left out 33 million women workers. Partnerships with community based organizations are critical to ensure that 1) communicating how and why the wage gap is calculated is uniform across government and 2) further gaps in data calculation are addressed, such as the inability to understand the wage gap for Afrolatinas or independent contractors.

While the new data calculation provides additional insight, it still fails to tell the whole story. We do not fully understand the experience of trans women, non-binary people and all immigrant women. Given that the wage gap is largest for women of color, immediate and decisive action to combat compensation discrimination and pay inequity is not only a matter of economic security, but also gender and racial equity. Measures must be taken to expand the community members whose data has not been collected and whose circumstances remain unknown or underinvestigated.

HEALTH AND SAFETY

We are addressing some of the most fundamental needs and rights that migrant communities are too often denied, including protection from gender-based violence and mental health care.

Anti-Sexual Violence

Sexual violence remains a taboo issue, and as a result, it is often difficult for survivors to seek help. This is a barrier to collecting data for all victims and survivors, which prevents us from being able to understand the scope and scale of the problem, not to mention the specific needs of survivors. Sexual harassment is a form of sexual violence. Sexual harassment is a legal term of art that was defined by employment law and the U,S. Equal Employment Opportunity Commission to define unwanted sexual attention against an employee. Like other forms of sexual violence, sexual harassment remains under reported.

It is critical that the EEOC continue with its data collection methods. In addition to requiring employers to comply with mandated data collection requirements, the federal government must also create a process by which this data is separated by industry, race, and gender to have a better understanding of whether there are higher rates of sexual harassment in certain industries, whether people of certain backgrounds are experiencing it at higher rates and to determine whether targeted education, outreach or other services need to be provided to particular demographics.

Mental Health and the Workplace

In response to listening to the community following the outset of the pandemic, Justice for Migrant Women piloted a program called Healing Voices which provided direct mental health support to farmworkers. The goal was to both provide a direct service and to pilot a program which would hopefully expand to support the provision of mental health services to migrant workers across sectors. As we continue this work, it has become evident that mental health and the workplace is a priority for leaders from the local level to the international level. The U.S. Conference of Mayors recently launched a task force on mental health in the workplace, which was closely followed by a policy brief from the World Health Organization and the International Labour Organization calling for global action to address mental health at work. We know that in order for migrant women to be reflected in solutions regarding mental health and the workplace, processes for collecting this data must be prioritized. Justice for Migrant Women is in the process of conducting a survey in partnership with organizations who serve migrant women across demographic groups and geographic regions within the United States to gain a better understanding of how the unique circumstances facing migrant women impact their emotional health and wellbeing, particularly as it relates to the workplace. Being able to replicate this on scale with support from partnerships and the federal government would be instrumental as policies are further developed regarding workplace protections that include mental health.

Conclusion

Through Justice for Migrant Women's own experiences in data collection with the community, we know the value of partnership with community based organizations and the importance of having the resources to collect data in person and in accessible languages, which includes not only translation, but also framing in a way that is sensitive to cultural context. When exploring challenges such as mental health and sexual violence in communities where those issues have been stigmatized, the way that data is both collected and messaged upon release is important to ensuring data does not cause undue harm. As the OSTP seeks to address systemic inequity, it is important that migrant women—who play a vital role in America's communities—are not left behind. If you have any questions, please feel free to contact Catherine Hinshaw, Policy Manager at [redacted]

Sincerely,

[redacted]

Mónica Ramírez
Founder & President, Justice for Migrant Women

To whom it may concern, please excuse the delay in our submission and hope this information will be helpful to your work in Advancing Equity with Community Data Partnerships. We welcome the opportunity to discuss this further.

What We Learned From Evaluating Drinking Water Funding & Why It's Currently Too Hard to Effectively Track

EPIC and the Environmental Defense Fund, in partnership with the Massive Data Institute at Georgetown University, are monitoring allocations for lead service line replacement through Drinking Water State Revolving Funds (DWSRFs) in light of a new influx of investment through the Infrastructure Investment and Jobs Act (IIJA) of 2021, to determine how states intend to prioritize the use of their allocations and which communities are on states' Priority Project Lists to receive these funds (and which are not).

Ethan Rosenbaum at Massive Data Institute details barriers to access data below and how this can best be improved to more easily track where the Drinking Water State Revolving Funds are distributed for lead service line replacement.

—

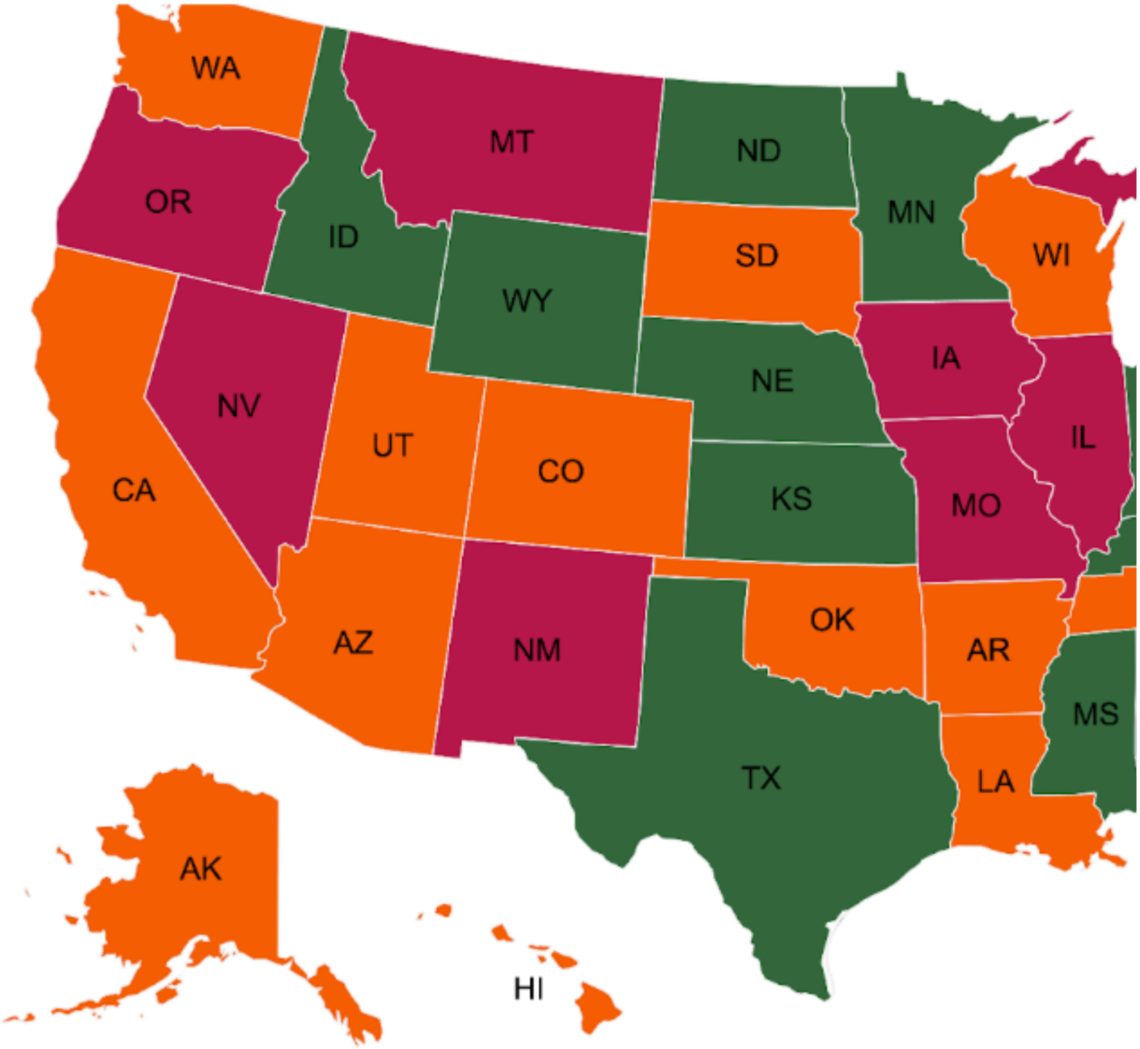
America is set to invest over $50 billion in water infrastructure funding over the next five years through the *Infrastructure Investment and Jobs Act (IIJA)*, including $15 billion for replacing lead service lines. The US EPA's DWSRF represent the primary mechanism through which the funds will be disbursed. EPIC and our partners set out to understand how well states are set up to prioritize and track which communities are utilizing these funds to quickly and equitably replace lead pipes. We found that we will not be able to effectively evaluate Justice40 and lead pipe replacement goals without far better digital infrastructure, data, and utilization of that data in prioritizing investments.

Let me explain.

The EPA allocates drinking water infrastructure funding to each state through Drinking Water State Revolving Funds (DWSRFs), and each state assigns funds to drinking water projects according to their Intended Use Plans (IUPs), or how they are planning to use their allocated funds for that year. Project Priority Lists (PPLs), or the projects that are priority to be funded each year, are added to the IUPs as an appendix. Analyzing these PPLs is crucial to identify where funds are going and who is set to receive them. As a Data Scholar at Georgetown University's Massive Data Institute, I evaluated robustness and standardization of information from PPLs across the states, and reviewed how many projects were earmarked for lead pipe replacement between 2020 and 2021, which is prior to the funding available from IIJA.

This blog will dive into the technical challenges I encountered with respect to how this data is captured, shared, and made easily accessible to evaluate. (Stay tuned for further updates on our project to track funding for lead service line replacement through SRFs in the coming months!)

What did I learn?



Quality of PPLs per state for machine-readability and robustness of data related to lead pipe replacements. To see the full categorization per state, see our spreadsheet here.

Unfortunately, some states will directly scan in their PPL tables, and this carbon copy-style paper reporting that meets yesterday's transparency standards misses many opportunities to more easily evaluate and track where money is being spent today. Almost every state publishes PPLs as PDFs on websites that are difficult to navigate and in a format that is not usable by most data analysis tools - even for researchers that specialize in evaluating this type of data. So, we wanted to dive in and understand how to make this information more accessible to increase our understanding of who is actually benefiting from investments in water infrastructure. Following this analysis, here are some lessons learned to improve data accessibility and tracking of water infrastructure spending for the entire PPL:

1. States currently publish all Project Priority Lists as PDFs - sharing them as data tables in CSV or XLSX files would make it easier for data to be analyzed and collated into a central national repository for easier access and evaluation.
2. There is currently no standardized baseline set of variable names that are consistent across all state PPLs. Forums like the Environmental Council of the States (ECOS), USEPA, and ASDWA could all be good outlets for setting such standards, and then states could easily add additional variables as helpful to their respective programs.
3. For lead pipe replacement and other investments, utilities should flag related projects in the project descriptions, or in a separate column of the PPL. (Note: We saw a few states starting to create separate tables for lead in FY2023, and I'd encourage others to do the same!)

Let's dive into the details.

For this analysis, we collated 50 states' PPLs and evaluated all the columns and robustness of data across the varying PPLs. From there, we established a baseline set of variables that were comparable across all states to analyze funding specific to lead pipe replacement. Because of extreme variability across states, we established three tiers of state data quality that could be used for the analysis based on:

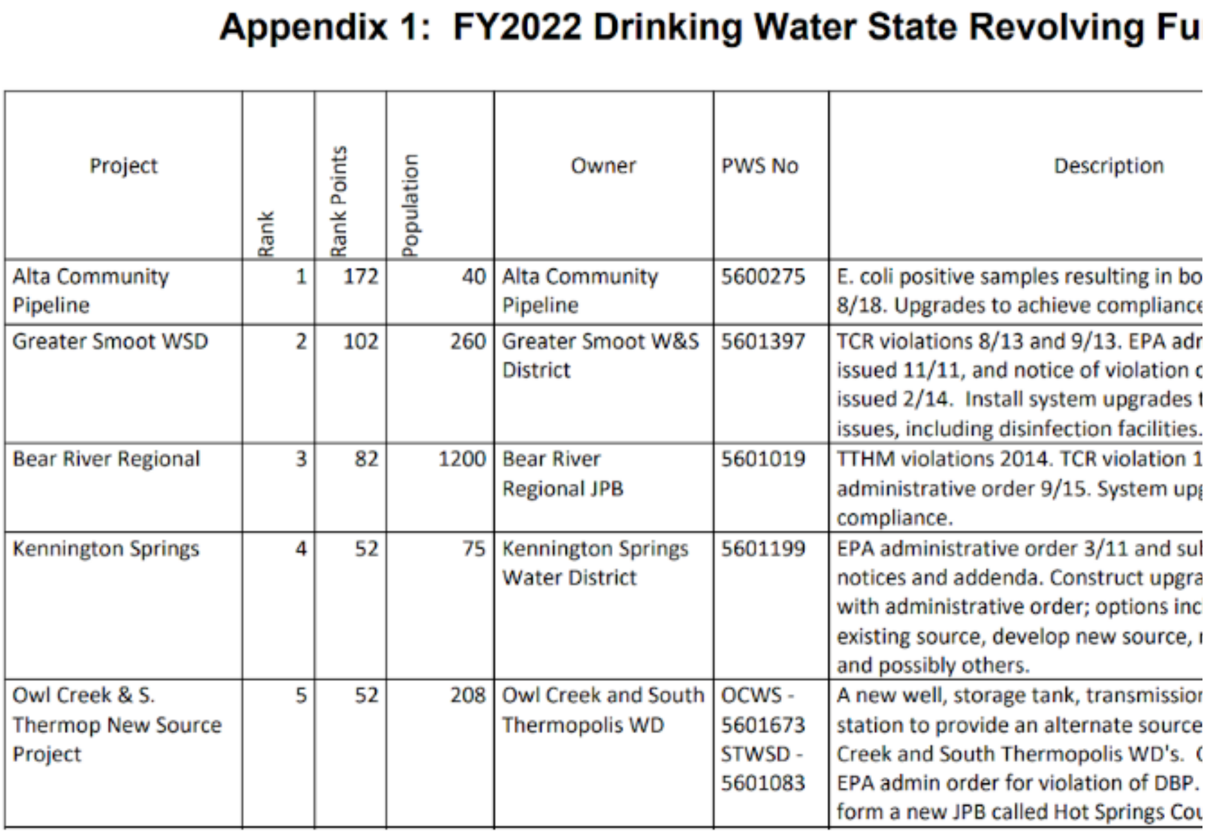
- **Overall quality of the data:** How many fields were included within the PPL? How many of the fields were completed? (e.g. Were there unique identifiers for each water system?)

- **Ease of evaluating the information**: Was the information provided as a table within the PDF? Was the PDF machine readable?
- **Robustness of the data**: Did the PPL provide additional data that is useful? How much detail was provided about proposed projects? (e.g. median household income, disadvantaged status, “green” projects, did the project descriptions mention lead, etc.)

From this preparatory work, we realized that with the current state of the data, we were not able to evaluate funding specific to lead pipe replacement across all 50 states. This further illuminated the importance of data standardization and sharing information in an easily machine readable format.

The state of the states.

There are some states that have high quality data and provide a wide array of indicators and metrics about the projects and communities they serve - we call these Tier 1. They further include a unique identifier for the water system (PWSIDs), thoroughly detailed descriptions about how the funding will be used, and many contain specific information about lead funding projects. This includes the following 17 states: Alabama, Connecticut, Florida, Idaho, Indiana, Kansas, Kentucky, Minnesota, Mississippi, Nebraska, New York, North Dakota, Rhode Island, South Carolina, Texas, Virginia, and Wyoming.



Appendix 1: FY2022 Drinking Water State Revolving Fu

Project	Rank	Rank Points	Population	Owner	PWS No	Description
Alta Community Pipeline	1	172	40	Alta Community Pipeline	5600275	E. coli positive samples resulting in bo 8/18. Upgrades to achieve complianc
Greater Smoot WSD	2	102	260	Greater Smoot W&S District	5601397	TCR violations 8/13 and 9/13. EPA adr issued 11/11, and notice of violation c issued 2/14. Install system upgrades t issues, including disinfection facilities.
Bear River Regional	3	82	1200	Bear River Regional JPB	5601019	TTHM violations 2014. TCR violation 1 administrative order 9/15. System upg compliance.
Kennington Springs	4	52	75	Kennington Springs Water District	5601199	EPA administrative order 3/11 and sul notices and addenda. Construct upgra with administrative order; options inc existing source, develop new source, r and possibly others.
Owl Creek & S. Thermop New Source Project	5	52	208	Owl Creek and South Thermopolis WD	OCWS - 5601673 STWSD - 5601083	A new well, storage tank, transmissior station to provide an alternate source Creek and South Thermopolis WD's. (EPA admin order for violation of DBP. form a new JPB called Hot Springs Cou

Example: *Wyoming Project Priority List (PPL) for FY2022*

Secondly, there are several states that are Tier 2, meaning they include much less detailed descriptions and fewer indicators or metrics, though they do provide the data in a more easily accessible format for analysis. These include the following 19 states: Alaska, Arizona, Arkansas, California, Colorado, Delaware, Hawaii, Louisiana, Massachusetts, New Hampshire, Ohio, Oklahoma, Pennsylvania, Puerto Rico, South Dakota, Tennessee, Utah, Washington, and Wisconsin.

Lastly, the remaining states post their information in formats that are very difficult to parse, and most fail to provide any descriptions and/or PWSIDs - these are Tier 3 states. These include the following 15 states: Georgia, Illinois, Iowa, Maine, Maryland, Michigan, Missouri, Montana, Nevada, New Jersey, New Mexico, North Carolina, Oregon, Vermont, and West Virginia.

The Importance of Publishing CSVs

Although premium software like Adobe Acrobat can automate the task of extracting information from a PDF reasonably well, it can be prohibitively expensive for many who want to examine this issue. At MDI, we developed a script using Python that downloads PPLs from state government websites and converts them into CSV files. While useful for this first analysis, this workaround would require modification each year as states will likely alter their publishing format. It is also a barrier to entry for most who do not have coding experience in Python. Some states fail to even publish the information in a table which makes it extremely difficult to parse the information for cross-comparison with other states (see Pennsylvania's 2021 Project Priority List as an example).

The script had to be extensively altered to draw the information and convert it into a usable format. Further, if Pennsylvania alters this format at all in future years, the script will have to be carefully modified. If all states instead were to publish the CSV or Excel form of their PPLs, the information would be much more accessible and usable by anyone wishing to examine where SRFs are allocated in a given state.

The Importance of Standardizing Variables

Another obstacle in evaluating this data is the inconsistent naming of variables by different states. My approach to this issue was to synthesize each state's PPL into one unified spreadsheet using a script in R. To do so, we had to evaluate all state columns and then choose standardized variables based on those with different names, but the same meaning - for example, "PWS_ID" and "PWSID." We further had to manually rename certain columns that had identical names but different meanings - for example, "Name" could signify water district names in some states and project names in others. Because of the significant variety in variable names from state to state, our code for this work will require extensive changes if a state alters their variable list, and once again, it is only of use to those familiar with R.

It would be far more accessible for policymakers, researchers, community advocates, and others if the EPA required each state to use the same nomenclature for variables, even if some states use variables that others do not. Even setting a standard spelling for universal categories like “Project Name” and “Funds Requested” would make the data significantly easier for users to evaluate. Some suggested terms are listed below:

- PWSID: Public water system identification number
- Water System: The name of the water system that the project will serve
- Project Name: The title of the project to which the funds are being directed
- Project Description: Details that elaborate on the Project Name
- Funding Amount: The total number of dollars (in 1 dollar units) given to the project by the state
- Population Served: The number of people affected by the project
- Project Priority Points: The number of points awarded to the project based on whatever a given state’s metrics are

There are other terms that would be useful to standardize and unanimously include across states, such as disadvantaged status, principal forgiveness, and household income. Including such variables would increase transparency about the communities to which funding is directed and enable easier tracking of Justice40 and lead pipe replacement goals.

You can read more on our blog here.

Warmly,
Jessie Mahr

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Jessie @ LinkedIn
pronouns: she/her/hers
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SEARAC

October 3, 2022
Denice Ross
U.S. Chief Data Scientist
White House Office of Science and Technology Policy

Re: Regarding Equitable Data Engagement and Accountability
Docket ID: 2022-19007

Dear Ms. Ross:

Thank you for the opportunity to provide comments on the Office of Science and Technology Policy's (OSTP) Request for Information (ROI). The Southeast Asia Resource Action Center (SEARAC), the Hmong Cultural Center of Butte County (HCCBC), and Coalition for Asian American Families and Children (CACF) submits this comment in response to questions 1, 2, 3, 5, and 7 of the ROI. These responses also reflect community-based organizations and partners. Our comments will focus on Asian American, Native Hawaiian, and Pacific Islanders (AANHPI) and how data collection and use impacts this unique population.

SEARAC is a national civil rights organization that empowers Cambodian, Laotian, and Vietnamese American communities to create a socially just and equitable society. As representatives of the largest refugee community ever resettled in the United States, SEARAC works to ensure that Southeast Asian refugees and their descents have equitable access to health and mental health care. Specifically, SEARAC aims to increase culturally and linguistically competent care and eliminate barriers to care for our the most vulnerable members of our communities, including children, elderly, female identifying, and LGBTQ+ individuals, that allows them to heal from the trauma they carry in their escape from war, political persecution, and genocide.

SEARAC supports expanded demographic data collection and reporting as part of federal and state policy. Federal and state agencies can do more to collect and publicly report specific ethnic data for a range of programs and services (i.e. education performance and attainment data). While the Office of Budget Management's Statistical Policy Directive No. 15 allows federal agencies to collect demographic data beyond the five major racial/ ethnic categories[1], few agencies are actively expanding racial data collection beyond the minimum requirements, outdated and insufficient as they are to address inequities across and within these categories.

Southeast Asians in historical context

For SEARAC, Southeast Asian American (SEAA) is a political identity that comes from the shared experiences of people who came to this country as refugees from the U.S. occupation of Cambodia, Laos, and Vietnam. SEAAs now number nearly 3 million, and unlike most other Asian American immigrant communities, the vast majority of SEAAs resettled in the United States as refugees. While the initial wave of the refugees was relatively educated, had familiarity with English, and were from largely higher economic backgrounds, the vast majority of the 1.3 million SEAA refugees resettled between 1997 and 2005 lacked formal education and knew little to no English. The limited English proficiency within SEAA communities continue to persist to this day. According to U.S. Census estimates from 2011-2015, 38.3 percent of Cambodian, 36.7 percent of Hmong, 34.5 percent of Lao, and 48.6 percent of Vietnamese households that speak English less than "very well," compared to 8.6 percent of total U.S. households. These innate challenges are compounded by existing mental health trauma from the war and violence in the broader Southeast Asian region and their escape from the area, resulting in high rates of post-traumatic stress disorder among refugees.

Data disaggregation is one of the most important civil rights issues for AANHPIs today. More data is needed to better understand the unique challenges that the AANHPI communities face and provide appropriate solutions.

Question 1: The Department of Education's Asian American and Pacific Islander Data Disaggregation Initiative is an example of successful collaboration involving equitable data between the Federal government, State government, and local communities.

In 2016, the Department of Education launched the Asian American and Pacific Islander Data Disaggregation Initiative (D2) grants. The goal of the D2 grant program was to provide grants to State Education Agencies (SEAs), in partnership with Local Education Agencies (LEAs), to

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[1] American Indian, Black, White, Hispanic, Asian, Native Hawaiian and Pacific Islander

obtain and evaluate disaggregated data on English Learner (EL) AAPI subpopulations beyond the existing seven racial and ethnic categories within.

In preparation for the rollout of this grant program, local education advocates in Minnesota and Washington State worked with SEA staff to apply for the D2. Three states received grants to improve data collection practices in Minnesota, Washington, and Hawaii. The Department provided a total of $836,000 to these three states. While Minnesota, Washington, and Hawaii had already begun implementing or considering collecting disaggregated racial and ethnic data for AANHPI LEP students, the grants allowed the states to accelerate implementation. Specifically, based on our conversations with staff from staff at SEAs and local education advocates in Minnesota and Washington, local campaigns led to successfully passing data disaggregation policies in education research. Currently, these states are working on implementing their data disaggregation policies and reporting the data publicly.

Additionally, the grants provided an opportunity for SEAs and LEAs to work directly with local communities to identify the racial and ethnic data that needed to be collected and the format in which the data would be collected. The D2 grant opened a line of communication between the Federal government and local communities to gather feedback from those communities.

The D2 program is a great opportunity for the Department to continue to cultivate innovation and improvement to expand state data collection and reporting systems and should be revamped. However, while implementation of systems as complex as data improvement and management requires continuous investment, this program was never renewed nor has the Department of Education released findings from the one year grant period, as promised. Continued funding for this program would have allowed these states to follow-through with monitoring implementation, reviewed lessons learned, and created opportunities for other states, such as Rhode Island, New York, and New Jersey, to follow this lead. Regardless, the D2 grant program illustrates a successful collaboration between the Federal government, State government, and local communities.

Question 2: States cannot reshape their data collection infrastructure without Federal government support, and local communities are unable fully engage in data equity policy implementation without knowledgeable, consistent staffing in state departments overseeing data collection.

For example, data is limited for local community organizations to get involved. In Rhode Island, local community-based organizations had to step up and provide technical assistance when data disaggregation policy was passed due to a lack of guidance on how school districts could implement the policy. CBOs in the state reached out to districts and found that the state agency did not provide communications or guidance around expanded data collection and that districts didn't know how to collect expanded racial data. Our partners had to extend their capacity to help shape the questionnaires for updated data collection and assisted in outreach and communications efforts. This shows the resiliency of our SEAA community to push for data equity policy and implementation as well as the lack of preparedness by state - and federal - agencies to follow-through with fidelity after data collection policies are passed. The federal government could do more in setting examples for expanded data collection, reporting, and implementation so that the people campaigning for data equity are not also fulfilling the roles of government agencies.

Question 3: Provide training and in multiple languages on how to access public federal and state agency data.

Our communities need training on resources, programs that can be shared with community organizations, local, and state governments so that all can be at the same page for serving the community and meeting their needs. With regards to resources and training, federal and state government should provide guidance on how to access and read state and federal data (i.e., educational achievement on state and federal agency websites). Federal and state agencies should also provide this resource in several different languages, including Khmer, Hmong, Vietnamese.

Question 5: Increased, consistent funding for SEAs and LEAs to reshape their data collection systems and disaggregate data collected would allow for larger data teams within the state departments overseeing this implementation. That consistent staffing would ensure that local communities have a regular point of contact and open line of communication with these agencies. Additionally, creating opportunities, such as public portals, for the Federal government and states to share accessible, publicly available disaggregated data would allow local communities to hold the government accountable to the American public.

In Washington State, funding resources provided by SEARAC enabled the Southeast Asian American Education Coalition (SEAeD) to hire staff to lead a state campaign regarding data disaggregation. SEAeD's staff educated and organized community members about the lack of data collection and data access regarding their SEAA community. In addition to collaborating with other organizations, the effort resulted in state level advocacy efforts that made it possible for Washington State to pass state legislation to enhance data collection efforts. This would have not been possible without staff funding capacity as our communities and organizations are already stretched thin and lack such resources.

One example of the type of collaboration that is being encouraged are language learning sessions for community-based organizations on how to access and use federal data to help identify and address social and economic disparities facing their cities and towns. While groups may not have had the opportunity to comment on this FRN, we are looking to collect ideas on how these sessions could be structured to provide further feedback. SEAA community-based organizations have also asked for more resources to provide staff with equity training to the community that they serve.

For National Center of Education Statistics (NCES) data collected by the Institutes of Education Statistics (IES) at the Department of Education, it is important that for the Asian American demographic categories, specific Southeast Asian American ethnicities are included in the data. Currently, NCES collects Asian American ethnicities that disaggregate by a few country of origin, including a category for Southeast Asian countries that include Cambodian, Laos, Vietnam and Thailand in its restricted data set. Due to the unique experiences of war, trauma, and refugee migration patterns for Cambodian, Hmong, Laos, and Vietnamese people, NCES should consider separating Thailand from grouping "Southeast Asian" together. NCES can also consider separating all Southeast Asian ethnicities and improve the over-sampling of these ethnic communities to yield a high enough sample size needed to provide analysis. Further, NCES and IES should improve their collection and reporting of disaggregated racial and ethnic data such that it is publicly available data. In instances where raw data cannot be provided publicly, NCES should produce yearly reports of how Southeast Asian American populations are faring in schools, including achievement patterns and school climate responses.

Efforts must also be taken across federal education agencies to equitably collect, analyze, and report disaggregated AANHPI data by race and ethnicity, not citizenship and nationality, in order to better inform the policy.

Question 7: There is a need for increased allocation of resources, increased access to educational data, and increased spotlighting of Asian American, Native Hawaiian and Pacific Islanders in schools. Our communities' stories deserve to be visible in the data and our call for data equity deserves policies that hold teeth and are followed-through.

Federal: At the federal level, AANHPI communities have asked for disaggregated Asian data for several decades, yet the federal government has stalled on developing a plan to implement data equity. In education, the AANHPI community is still awaiting feedback from the Department of Education on several data equity-related projects. The AANHPI community is eagerly waiting on the Department's report from the D2 data disaggregation grant program that was supposed to come out fall 2021 and have requested on numerous occasions that the Department provide more information on when we can expect this report.

California: At the state level, agencies like the California Department of Public Health are accountable to laws that mandate the collection and reporting of disaggregated health indicators for wider AANHPI communities, yet the lack of standardization in requirements and processes across public health stakeholders (i.e. from providers, labs, and hospitals to local public health departments) create barriers to meaningful data. For example, CDPH are unable to collect uniform public health data due to different local electronic health records/systems (which may be through private or public entities), and local health departments are unable to collect uniform public health data as providers and laboratories are not required to gather and report information in standardized ways. There are significant inconsistencies in the level of data reported and collected at all levels, especially at root levels of service providers and local counties.

Thank you for your consideration of the issues and recommendations we have brought forth. For more information or questions, please contact Natalie Truong, [redacted] and Kham Moua, [redacted]

Sincerely,

Quyen Dinh, Southeast Asia Action Resource Center
Seng S. Yang, Hmong Cultural Center of Butte County
Lloyd Feng, Coalition for Asian American Children and Families

October 4, 2022

NSTC Subcommittee on Equitable Data
Office of Science and Technology Policy
[redacted] Building

RE: Equitable Data Engagement and Accountability Request for Information

Thank you for the opportunity to submit comments regarding equitable data. These reflections and suggestions emanate from the Reimagining Federal Rural Policy initiative at the Brookings Center for Sustainable Development, which provides analysis and recommendations to improve the effectiveness, coherence, and relevance of U.S. federal rural policy to expand equitable rural prosperity. We strongly support the effort to use equitable data to assess and measure federal programs, allowing them to improve efficacy in providing much-needed investment in underserved rural and Native communities.

Equitable data is critical to enable rural prosperity. Several considerations might facilitate and improve the ability of the federal government to collaborate with other levels of government and local organization in ways that improve equity for rural areas:

I. Using metrics that differentiate outcomes below the county level provides a better basis for engaging local places on equity data

Many publicly available economic indicators produced by the Census Bureau, the Bureau of Labor Statistics, the Bureau of Economic Analysis, and other federal agencies use the county as their unit of anlaysis. However, aggregate county-level measures can mask significant and important variation in economic and social well-being among the communities within their boundaries. The challenges and realities of small, highly vulnerable communities may be misstated or misunderstood because larger, more prosperous communities in the same county boost the overall county's metrics. This is an especially important consideration for rural counties.

There are measurement classifications within the federal landscape that demonstrate the value in measuring community-level outcomes below the county level. For example, in addition to categorizing counties according to their level of economic distress, the Appalachian Regional Commission (ARC) also identifies "isolated areas of distress," which are distressed census tracts located within non-distressed counties. This additional classification provides an added dimension that better reflects the diversity of economic and social well-being present in the communities within a single county. Similarly, the CDC's Social Vulnerability Index applies its measurement at the census tract level.

Engaging federal statistical agencies to develop new data tools at more granular levels of geography would provide a better basis for data collaborations at the local level and promote greater geographic equity.

II. Employing nuanced measurement schemes facilitates a better understanding of equity

Classifying communities along a continuum of well-being, rather than creating binary thresholds, better reflects the realities of communities and can draw a stronger picture of inequities and limits of capacity. This additionally provides improved transparency and accountability for programs, making it easier for other levels of government to be a partner in providing quantitative and qualitative data to flesh out the full picture. For example, the CDC's Social Vulnerability Index places communities at a point along a scale that seeks to capture the complexity of a community's relative status.

Using clear cutoffs or multiple measurement criteria can also help draw a better picture of community inequities. For example, the Delta Regional Authority and the Economic Development Administration each use the same two economic criteria to determine "distress," based on unemployment rates and per capita income. However, EDA stipulates that an area must meet **one** criterion to be considered distressed, while DRA requires counties and parishes to meet **both** criteria. The difference in the resulting maps is significant. Being attentive to the nuances of different definitions, and the sensitivity of different indicators, will provide the federal government with a deeper understanding of the well-being of different communities and offer a basis for community engagement and qualitative assessments that give further meaning to the quantitative pictures.

III. Increase transparency and federal investment in data

Community members know too little about the level of investment being made by the federal government in their community, and both local leaders and federal officials know too little about what interventions work and the level of impact that is achieved from these investments. The federal government must be more intentional about investing in rigorous, third-party outcome data, especially as those outcomes relate to different racial and demographic groups, from resources that they make available to communities.

In the past we have recommended a mandate to set aside and spend 5 percent of program funding to collect and analyze data, inform evaluation design and objectives, and transparently evaluate success. Measurable goals and performance metrics should be developed in collaboration with the intended local beneficiaries, incorporating relative benchmarks and ratios that are meaningful and appropriate. Local rural communities will likely want evaluations to prioritize learning and assessments of well-being, for example, rather than per capita output.

Dedicated funding for rigorous analysis in planning and design, and a significant expansion of program evaluation, is badly needed to provide practitioners and policymakers with the data and information to determine what works, what needs adjustment, and how to ensure our public investments maximize the positive impact on people's lives. Increased transparency about successes and failures is also vital to improve the effectiveness of those investments. Providing the funding, and developing an evaluation policy that prioritizes the voice of local leaders and community members in designing the metrics to be used, will enable trust-building and can help facilitate collaboration on equity data.

Local levels of government and local community organizations are in need of investment to build their ability to collect and report data, qualitative and quantitative. Small rural and economically distressed areas have limited capacity to perform these actions without technical assistance. The federal government is well-situated to play an effective role in capacity strengthening by dedicating investment for this data and supporting intermediaries with local, cultural, and historical context and knowledge that employ models such as "see one, do one, teach one" or training the trainer.

Easily accessible data on the financial flows from the federal government to rural areas, especially data that differentiates and disaggregates among demographics, geography, and local economies is lacking. Assessment of the effectiveness and proportionality of the federal assistance accessed by rural areas is complicated by challenges in following where the funding actually flows at basic levels of disaggregation.

A commitment to transparently providing information on how funding is flowing to local levels will lower a significant barrier for community members to understand what is meant to be happening in their communities and provide feedback on its impact.

Many thanks for your partnership in helping maximize federal impact in rural places that need investment most. Thank you.

Sincerely,

Tony Pipa
Senior Fellow, Center for Sustainable Development
[redacted]ion

Justice for
Migrant Women

October 3, 2022

Submitted via [redacted]

NSTC Subcommittee on Equitable Data
Office of Science and Technology Policy
Eisenhower Executive Office Building
[redacted] Washington, DC 20504

Comments in response to Request for Information: Equitable Data Engagement and Accountability

Dear Ms. Ross:

Justice for Migrant Women protects and advances migrant women's rights through education, public awareness and advocacy. We aim to ensure that all migrant women are guaranteed human and civil rights, including the freedom of mobility, the ability to live and work with dignity, and the right to be free of threats of violence against them and their families, whether they are migrating across borders, around regions or within states. We work closely alongside rural women, immigrant women, and women who work in low paid sectors.

The intersecting identities make these women among the most vulnerable and least visible people in the United States. This has also resulted in their exclusion from some of the most basic legal protections. Our work in the community allows us to hear directly from migrant women about their challenges and concerns. Their powerful stories and firsthand accounts demonstrate the need for policy change. Existing data does not often reflect their reality, despite the fact that we should be accountable to them as we all benefit from their labor in myriad ways. It is worth noting that minimal data is available regarding global migration, particularly as it pertains to economic migrants. Even less data is available related to the experiences of women who identify as economic migrants. Many of these community members are of different racial and ethnic identities. Finally, the data does not often capture or distinguish the differing experiences of people who migrate for work, but are not immigrants.

This body of work– understanding who is moving for economic security and health and safety reasons, with a particular focus on women of color– has a significant impact on better understanding the needs of the entire U.S. population that it is accountable to, including migrant women workers. Limited resources and antiquated data collection methods contribute to the invisibility of an already vulnerable population.

For these reasons, Justice for Migrant Women welcomes efforts by the U.S. Office of Science and Technology Policy to advance racial justice and equity through equitable data engagement and accountability. We applaud your acknowledgement that a significant factor to achieve equitable data collection requires disaggregating data by demographic information, geographic information or other variables. To this end, we thank you for the opportunity to provide comments. Justice for Migrant Women offers perspective on the following questions to which you requested input:

> **Question 5:** What resources, programs, training, or tools can increase opportunities for community-based organizations to use equitable data to hold government accountable to the American public?
>
> **Question 7**: In which agencies, programs, regions, or communities are there unmet needs, broken processes, or problems related to participation and accountability that could be remedied through stronger collaborations and transparency around equitable data?

Justice for Migrant Women will address these questions in two of our main areas of focus: economic justice and health and safety.

ECONOMIC JUSTICE

Migrant workers, including farmworkers, perform labor that is vital to the fabric of our society, yet they face greater economic instability due to low pay, poor working conditions, and job insecurity.

National Agricultural Worker Survey: Improve Data Sharing on Women

Justice for Migrant Women works closely with the farmworker community and in particular women who migrate for agricultural work. The National Agricultural Workers Survey (NAWS) is conducted periodically (most recently in 2015-16) to collect demographic, employment, and health data in face-to-face interviews with farmworkers. The survey yields valuable information that informs policymaking. However, the survey report does not include disaggregated gender-specific data on wages and other measures. When the data is disaggregated we see that there is a stark experience between men and women's experiences. For example, in Southern Poverty Law Center's report, Injustice on Our Plates, they requested disaggregated data from the Department of Labor on wages for men and women. They found that [t]he average personal income of female crop workers is $11,250, compared to $16,250 for male crop workers."[1] These shortcomings deprive policymakers and advocates of the data they need to better address the needs of women working in agriculture. The Biden Administration should ensure that public release of NAWS results disaggregate data by gender, especially wage and income data.

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[1] (2010). *Injustice on our Plates*. Southern Poverty Law Center. https://www.splcenter.org/20101107/injustice-our-plates#exploitation

While the data that exists for farmworkers is deficient, it is even more dismal for migrant women working in other fields. Migrant women are working across industries as domestic workers, gig workers, disaster clean up and in other jobs where little to no data exists, specifically disaggregated data to distinguish the experience of women workers.

Pay Data Collection

As a leader in advocating for policies that will close the gender wage gap, Justice for Migrant Women emphasizes the importance of requiring employers to collect and report compensation data by race, ethnicity, gender, and part-time status to the EEOC and OFCCP. The EEO-1 form should provide options when sharing one's gender identity that are more inclusive than the binary male or female option. This is a critical tool that will help identify and address pay discrimination.

This year, for the first time, due to the leadership of Justice for Migrant Women and the National Asian Pacific American Women's Forum, the gender wage gap calculated by race includes part time and full-time workers. Previous data calculations that represented only full-time, year round workers excluded migrant and seasonal workers and in total left out 33 million women workers. Partnerships with community based organizations are critical to ensure that 1) communicating how and why the wage gap is calculated is uniform across government and 2) further gaps in data calculation are addressed, such as the inability to understand the wage gap for Afrolatinas or independent contractors.

While the new data calculation provides additional insight, it still fails to tell the whole story. We do not fully understand the experience of trans women, non-binary people and all immigrant women. Given that the wage gap is largest for women of color, immediate and decisive action to combat compensation discrimination and pay inequity is not only a matter of economic security, but also gender and racial equity. Measures must be taken to expand the community members whose data has not been collected and whose circumstances remain unknown or underinvestigated.

HEALTH AND SAFETY

We are addressing some of the most fundamental needs and rights that migrant communities are too often denied, including protection from gender-based violence and mental health care.

Anti-Sexual Violence

Sexual violence remains a taboo issue, and as a result, it is often difficult for survivors to seek help. This is a barrier to collecting data for all victims and survivors, which prevents us from being able to understand the scope and scale of the problem, not to mention the specific needs of survivors. Sexual harassment is a form of sexual violence. Sexual harassment is a legal term of art that was defined by employment law and the U,S. Equal Employment Opportunity Commission to define unwanted sexual attention against an employee. Like other forms of sexual violence, sexual harassment remains under reported.

It is critical that the EEOC continue with its data collection methods. In addition to requiring employers to comply with mandated data collection requirements, the federal government must also create a process by which this data is separated by industry, race, and gender to have a better understanding of whether there are higher rates of sexual harassment in certain industries, whether people of certain backgrounds are experiencing it at higher rates and to determine whether targeted education, outreach or other services need to be provided to particular demographics.

Mental Health and the Workplace

In response to listening to the community following the outset of the pandemic, Justice for Migrant Women piloted a program called Healing Voices which provided direct mental health support to farmworkers. The goal was to both provide a direct service and to pilot a program which would hopefully expand to support the provision of mental health services to migrant workers across sectors. As we continue this work, it has become evident that mental health and the workplace is a priority for leaders from the local level to the international level. The U.S. Conference of Mayors recently launched a task force on mental health in the workplace, which was closely followed by a policy brief from the World Health Organization and the International Labour Organization calling for global action to address mental health at work. We know that in order for migrant women to be reflected in solutions regarding mental health and the workplace, processes for collecting this data must be prioritized. Justice for Migrant Women is in the process of conducting a survey in partnership with organizations who serve migrant women across demographic groups and geographic regions within the United States to gain a better understanding of how the unique circumstances facing migrant women impact their emotional health and wellbeing, particularly as it relates to the workplace. Being able to replicate this on scale with support from partnerships and the federal government would be instrumental as policies are further developed regarding workplace protections that include mental health.

Conclusion

Through Justice for Migrant Women's own experiences in data collection with the community, we know the value of partnership with community based organizations and the importance of having the resources to collect data in person and in accessible languages, which includes not only translation, but also framing in a way that is sensitive to cultural context. When exploring challenges such as mental health and sexual violence in communities where those issues have been stigmatized, the way that data is both collected and messaged upon release is important to ensuring data does not cause undue harm. As the OSTP seeks to address systemic inequity, it is important that migrant women—who play a vital role in America's communities—are not left behind. If you have any questions, please feel free to contact Catherine Hinshaw, Policy Manager at [redacted]

Sincerely,

[redacted]

Mónica Ramírez
Founder & President, Justice for Migrant Women

Office of Science and Technology Policy and Office of Information and Regulatory Affairs
The White House
[redacted]
Washington, DC 20500

Submitted via email to: [redacted]

October 6, 2022

RE: Public Request for Information; Advancing Equity with Community Data Partnerships: We Need to Hear From You

Justice in Aging appreciates the opportunity to comment on the above referenced public request for information.

Justice in Aging is an advocacy organization with the mission of improving the lives of low-income older adults nationwide. We use the power of the law to fight senior poverty by securing access to affordable health care, economic security, and the courts for older adults with limited resources—particularly populations that have been marginalized and excluded from justice, such as older adults of color, older adults with disabilities, LGBTQ older adults, and older adults with limited English proficiency. We have decades of experience with programs and services established by federal agencies, including the Centers for Medicare & Medicaid Services, Social Security Administration, and the Administration for Community Living.

We also have experience with state and local agencies and programs that impact the lives of older adults. Justice in Aging administers the National Center on Law and Elder Rights (NCLER) on through our contract with the Administration for Community Living. Through NCLER, we connect with front-line advocates at legal and aging services throughout the country who work directly with older adults to access State and local programs.

Our comments focus on policies and practices that can improve equitable data sharing and collection to advance equity for older adults with marginalized identities.

I. What are examples of successful collaborations between the Federal government and (a) Tribal, territorial, local, and State governments or (b) local communities involving equitable data?

We offer two examples of successful collaborations to share equitable data specific to the context of services and programs for older adults.

a. *The National Adult Maltreatment Reporting System (NAMRS)*[1]

NAMRS is a data reporting system used to understand adult maltreatment in the U.S.; it is operated by the Administration for Community Living (ACL) and the data is collected and submitted by adult

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[1] Administration for Community Living, National Adult Maltreatment Reporting System, https://namrs.acl.gov/ (last visited Sept. 29, 2022).

protective services (APS) programs in every state, the District of Columbia, and the territories.[2] While APS programs operate within the same statutory framework of services, there is great variation across programs in the populations they serve and their policies and practices. NAMRS is a comprehensive reporting system established by ACL—the federal agency that oversees APS programs—that provides insight into adult maltreatment at the client level and the supports needed to prevent it. The APS Technical Resource Center (APS TARC), also funded by ACL, provides training and technical assistance to states regarding NAMRS requirements.

NAMRS collects de-identified data from over one million reports of adult maltreatment annually,[3] and collects both quantitative and qualitative data on APS policies and outcomes of maltreatment investigations.[4] The collected client-level data includes data points that are directly relevant to APS's impetus, such as clients' and victims' age, disabilities, and residence. Additionally, the majority of states also report gender, race, and ethnicity data on some, but not all, APS clients and victims.[5] Less than half of state APS programs also report demographic information (age and gender) regarding the perpetrators of adult maltreatment.[6]

NAMRS data has been useful to advocates, policymakers, and service providers in understanding of the types of maltreatment experienced by different populations and identifying risk factors. It has also been useful in understanding maltreatment reports during the COVID-19 pandemic, during which social isolation and increased dependency on others for daily activities potentially increased exposure to maltreatment.[7]

b. Title III Older Americans Act State Performance Report (SPR)

The Older Americans Act (OAA) authorizes services through a national network of state agencies; local area agencies on aging; and American Indian, Alaskan Native and Native Hawaiian organizations to promote the rights of older adults. The State Performance Report (SPR) effort fulfills a requirement of the OAA, which requires "collection of statistical data regarding the programs and activities carried out with funds provided under the OAA" and reporting this data to the federal agency. Not only does SPR indicate how the national aging network and state agencies on aging use OAA funds, it now also provides information on the characteristics of the people serviced. The demographic information collected includes data points such as race, ethnicity, age, gender, and poverty status.[8]

While the new addition of demographics of OAA service recipients has not yet been reported publicly, this data will be aggregated at the state-level and de-identified where appropriate. The collection of

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[2] Adult Protective Services (APS) are federally mandated State-level programs that investigate reports of abuse, exploitation, neglect, and self-neglect relating to older adults and adults with disabilities.

[3] *Supra* note 1.

[4] Administration for Community Living & Administration on Aging, Adult Maltreatment Report 3 (2020), https://namrs.acl.gov/getattachment/Learning-Resources/Adult-Maltreatment-Reports/2020-Adult-Maltreatment-Report/2020_NAMRS_Report_ADA-Final.pdf.aspx?lang=en-US.

[5] *Id*. at 18. NAMRS also collects data relating to the practices of the investigation, such as the length of the investigation, reasons for case closure, and prior reports of maltreatment.

[6] *Id.* at 22.

[7] *Id.* at 24 (reporting that APS reports dropped in the early months of the pandemic and rose above normal levels after the initial shut-down period).

[8] Other data points include geographic distribution (i.e., rural/non-rural), household status, minority status, and number of functional limitations, and nutritional risk.

demographic data for SPR purposes will allow for a better understanding of the older adults who are impacted by OAA funded programs—which statutorily requires that some programs target services to older adults with the greatest social and economic need. For example, pro-bono legal assistance providers that represent older adults using OAA funding will report de-identified, aggregated demographic and other information related to their clients and cases which will be useful to both the federal government and the providers in identifying unmet needs in different communities.

II. What policies, resources, programs, training, or other tools can facilitate increased data sharing between different levels of government (Tribal, territorial, local, State, or Federal) around equitable data?

a. *Data Collection as Standard Practice and Improved Data Points.*

A current barrier in gaining perspective on the impact of government-funded social services programs that are administered at the state or local level is inconsistencies in reported data points. Policies that define universal data points in federally-funded programs will facilitate cross-county and cross-state comparisons and provide a better perspective on the impact of social services programs nationally. This is particularly true for programs that are federally funded, but have state-by-state variations in implementation and impact, such as Medicaid-funded home- and community-based services and OAA funded legal and aging services.

These policies should emphasize the standard collection of demographic data, including race, ethnicity, sexual orientation and gender identity, age, disability, and languages spoken. Additionally, while many state and local programs gather some demographic information, the data points can be improved. For example, most self-reported accounts of race and ethnicity do not ask about Middle Eastern and Northern African (MENA) heritage.[9] Similarly, programs vary in how they collect information on sexual orientation and gender identity (SOGI). Traditional self-reported demographics questions that only allow one to identify as female or male "do[] not necessarily capture information on transgender or gender non-conforming individuals."[10] We encourage OIRA and OSTP to connect with trusted advocates from impacted communities to develop uniform standards for the type of information that should be collected by localities and states and these specific considerations for each type of data.

States and localities would benefit from resources and guidance on collecting this data, for example: Internet-based tools; trainings on gathering, and de-aggregating and de-identifying data; and targeted assistance in engaging impacted communities and improving data collection where it has historically been lacking. Resources on how to ask about demographic information in a culturally appropriate and sensitive manner are critical (addressed further in subsection(b)). Additionally, programs at all levels of government would benefit from resources on evaluating disparities and intervention impacts on populations with intersecting marginalized identities.

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[9] The Federal government categorizes people with MENA origins as White, despite the fact that many such individuals do not self-identify as White and may experience different health and social outcomes than White populations. *See* Neda Maghbouleh et al., *Middle Eastern and North African Americans may not be perceived, nor perceive themselves, to be White* (2022), https://www.pnas.org/doi/10.1073/pnas.2117940119. While some government forms allow individuals to self-identify as "Other" on government forms and occasionally write in a response, there is no uniform policy for how these selections are reported.

[10] NATIONAL RESOURCE CENTER ON LGBT AGING, INCLUSIVE SERVICES FOR LGBT OLDER ADULTS 8 (2018), https://www.sageusa.org/wp-content/uploads/2018/05/sageusa-welcoming-agency-guide-inclusive-services-for-lgbt-older-adults.pdf.

b. *Best Practices for Data Collection.*

As uniform data reporting standards develop, so should standards of practice for data collection. Sharing one's detailed demographic information on race, ethnicity, SOGI, language, disability, and age is a sensitive matter, and many individuals may rightly feel hesitant to share this information due to perceived or lived experiences of bias and danger.[11] These hesitancies can be barriers to accurate and reliable data collection, which impacts data sharing across levels of government and limits our ability to draw relevant conclusions about the success of interventions that advance equity.

States, localities, Tribes, and territories would benefit from resources that are derived from input from impacted communities on how to collect, store, and report this information to build and maintain trust with self-identifying individuals. This includes, but is not limited to, guidance on framing culturally competent and trauma-informed questions; communicating confidentiality and privacy measures; and creating safe spaces to self-report data.[12]

c. *Tools and Resources.*

Another barrier to gaining equitable data is the administrative burden data collection places on the frontline service providers who work directly with clients from impacted communities. Because social services and government systems at the local, state, territorial, and Tribal level already gather some demographic information during intake procedures, resources to incorporate improved data points in providers' existing intake procedures—such as by facilitating case management and intake systems to collect this information—may reduce the burden of data reporting.

Another barrier in equitable data sharing is that the tools to compile and compare data between different levels of government is lacking. For example, courts in every state oversee guardianship proceedings for adults with diminished capacity, and all courts monitor issues such as the financial security and health of the adult through regular reporting requirements. However, there is no mechanism to compare the demographics and outcomes of adults under guardianship because states use different methods to record this information—ranging from Internet-based tools to paper records—and there are variances in the type of information that is collected.[13] While some federally-funded programs have national data reporting requirements and systems (including NAMRS and SPR), one ongoing challenge is that these mechanisms are not available for all social services programs.

III. What policies, resources, programs, training, or other tools can expand opportunities for historically underrepresented scholars and research institutions to access and use equitable data across levels of government?

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[11] For example, researchers have found that the way questions regarding sexual orientation are worded—"same sex attraction" versus "same-sex behaviors" and identifying as LBGTQ—impacts self-reported response rates. M.V. Lee Badget et al., *LGBTQ* Economics, 35 J. ECON. PERSPECTIVES 141, 144 (2021), https://pubs.aeaweb.org/doi/pdfplus/10.1257/jep.35.2.141.

[12] *See, e.g.*, NATIONAL RESOURCE CENTER ON LGBT AGING *supra* note 10 at 11-13 (discussing first impressions that demonstrate inclusivity); Badget, *supra* note 11 at 144 (noting differences in in-person versus computer-based data collection).

[13] While state courts are not federally funded, States can receive federal funding for guardianship-related efforts. *See, e.g.*, Administration for Community Living, Elder Justice Innovation Grants: Improving Guardianship (2022), https://acl.gov/grants/elder-justice-innovation-grants-improving-guardianship-fy2022.

a. *Publicizing Information*.

Universally, a major barrier in achieving health and social equity is lack of sufficient data around access to and outcomes of social programs for marginalized communities. Not having this information perpetuates structural disparities because government agencies and advocates are unable to accurately identify gaps in services and tailor solutions. Even when data are collected, it sometimes goes unreported or is reported in limited circumstances, such as being shared in a private meeting but not available publicly.

As data collection efforts are enhanced across federal and federally-funded programs, we encourage the agencies to report all collected data and stratify it by demographics. Additionally, intersectional data for all demographics should be reported as much as possible. While some data may be insufficiently large to include in analyses and trend reports, it should be publicized nonetheless in some format with the appropriate disclaimers.

IV. What policies, resources, programs, training, or tools can increase opportunities for community-based organizations to use equitable data to hold government accountable to the American public?

As discussed in Section IV, we encourage policies surrounding publicizing data.

a. *Engage with Impacted Communities*.

As a general policy, we encourage engaging impacted communities at the onset of data collection efforts to help identify unmet needs, inform where to find the information, and develop community-informed equitable data practices. Additionally, we encourage keeping the community engaged during and post-data collection efforts, and sharing the results with the impacted communities.

Frequently, data-related efforts are often geared to the needs of the funders, and not the impacted community. It is vital that the outcomes of surveys, trend reports, and other data collection exercises are shared with community organizations that can use the information in making decisions regarding their programs.

One example from our experience of government accountability in data collection was in the recent COVID-19 context. California, like many other states, failed to report COVID-19 vaccine demographic data intersectionally. Instead, it reported uptake by race, gender, and age, but not at the intersection of any of those demographic characteristics. Therefore, it was virtually impossible to identify more precise trends among the older adult community because as a whole, it appeared that older Californians 65+ were embracing the vaccines. However, through efforts from Justice in Aging and others on the California Community Vaccine Advisory Committee, the state finally began reporting vaccine uptake for older adults by race, which revealed vacation rates among older adults in communities of color lagged behind white older Californians.[14] This led to more specific investments and outreach strategies tailored

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[14] More about the Community Vaccine Advisory Committee can be found on the California Department of Public Health's website at: https://www.cdph.ca.gov/Programs/CID/DCDC/Pages/COVID-19/Community-Vaccine-

to older adults of color.

V. What policies, resources, programs, training, or tools can make equitable data more accessible and useable for members of the public?

As discussed in Section IV, we encourage policies surrounding publicizing data.

VI. In which agencies, programs, regions, or communities are there unmet needs broken processes, or problems around participation and accountability that could be remedied through stronger collaborations and transparency round equitable data?

a. *Unmet Needs for Older Adults of Color and Older Adults with Other Marginalized Identities.*

While age is often a reported demographic data point, data on age and other intersecting identities (e.g., age and race, age and sexual orientation and gender identity) are not frequently reported. This was exemplified in the California vaccination example discussed in IV(a). Lack of data is a barrier that stymies efforts to advance equity at the policy and legislative level as well as the program level. Policies that uplift intersectionality in data collection across all sectors are necessary to advance equity in programs serving older adults.

VII. Conclusion

Thank you again for the opportunity to comment. If any concerns arise concerning submission, please contact Sahar Takshi at [redacted]

Sincerely,

[redacted]

Denny Chan
Managing Director, Equity Advocacy

Advisory-Committee.aspx. The state's vaccine uptake data can be found on the COVID19.ca.gov webpage: https://covid19.ca.gov/vaccination-progress-data/#overview.

October 4, 2022

NSTC Subcommittee on Equitable Data
Office of Science and Technology Policy
[redacted] Building

RE: Equitable Data Engagement and Accountability Request for Information

Thank you for the opportunity to submit comments regarding equitable data. These reflections and suggestions emanate from the Reimagining Federal Rural Policy initiative at the Brookings Center for Sustainable Development, which provides analysis and recommendations to improve the effectiveness, coherence, and relevance of U.S. federal rural policy to expand equitable rural prosperity. We strongly support the effort to use equitable data to assess and measure federal programs, allowing them to improve efficacy in providing much-needed investment in underserved rural and Native communities.

Equitable data is critical to enable rural prosperity. Several considerations might facilitate and improve the ability of the federal government to collaborate with other levels of government and local organization in ways that improve equity for rural areas:

I. Using metrics that differentiate outcomes below the county level provides a better basis for engaging local places on equity data

Many publicly available economic indicators produced by the Census Bureau, the Bureau of Labor Statistics, the Bureau of Economic Analysis, and other federal agencies use the county as their unit of anlaysis. However, aggregate county-level measures can mask significant and important variation in economic and social well-being among the communities within their boundaries. The challenges and realities of small, highly vulnerable communities may be misstated or misunderstood because larger, more prosperous communities in the same county boost the overall county's metrics. This is an especially important consideration for rural counties.

There are measurement classifications within the federal landscape that demonstrate the value in measuring community-level outcomes below the county level. For example, in addition to categorizing counties according to their level of economic distress, the Appalachian Regional Commission (ARC) also identifies "isolated areas of distress," which are distressed census tracts located within non-distressed counties. This additional classification provides an added dimension that better reflects the diversity of economic and social well-being present in the communities within a single county. Similarly, the CDC's Social Vulnerability Index applies its measurement at the census tract level.

Engaging federal statistical agencies to develop new data tools at more granular levels of geography would provide a better basis for data collaborations at the local level and promote greater geographic equity.

II. Employing nuanced measurement schemes facilitates a better understanding of equity

Classifying communities along a continuum of well-being, rather than creating binary thresholds, better reflects the realities of communities and can draw a stronger picture of inequities and limits of capacity. This additionally provides improved transparency and accountability for programs, making it easier for other levels of government to be a partner in providing quantitative and qualitative data to flesh out the full picture. For example, the CDC's Social Vulnerability Index places communities at a point along a scale that seeks to capture the complexity of a community's relative status.

Using clear cutoffs or multiple measurement criteria can also help draw a better picture of community inequities. For example, the Delta Regional Authority and the Economic Development Administration each use the same two economic criteria to determine "distress," based on unemployment rates and per capita income. However, EDA stipulates that an area must meet **one** criterion to be considered distressed, while DRA requires counties and parishes to meet **both** criteria. The difference in the resulting maps is significant. Being attentive to the nuances of different definitions, and the sensitivity of different indicators, will provide the federal government with a deeper understanding of the well-being of different communities and offer a basis for community engagement and qualitative assessments that give further meaning to the quantitative pictures.

III. Increase transparency and federal investment in data

Community members know too little about the level of investment being made by the federal government in their community, and both local leaders and federal officials know too little about what interventions work and the level of impact that is achieved from these investments. The federal government must be more intentional about investing in rigorous, third-party outcome data, especially as those outcomes relate to different racial and demographic groups, from resources that they make available to communities.

In the past we have recommended a mandate to set aside and spend 5 percent of program funding to collect and analyze data, inform evaluation design and objectives, and transparently evaluate success. Measurable goals and performance metrics should be developed in collaboration with the intended local beneficiaries, incorporating relative benchmarks and ratios that are meaningful and appropriate. Local rural communities will likely want evaluations to prioritize learning and assessments of well-being, for example, rather than per capita output.

Dedicated funding for rigorous analysis in planning and design, and a significant expansion of program evaluation, is badly needed to provide practitioners and policymakers with the data and information to determine what works, what needs adjustment, and how to ensure our public investments maximize the positive impact on people's lives. Increased transparency about successes and failures is also vital to improve the effectiveness of those investments. Providing the funding, and developing an evaluation policy that prioritizes the voice of local leaders and community members in designing the metrics to be used, will enable trust-building and can help facilitate collaboration on equity data.

Local levels of government and local community organizations are in need of investment to build their ability to collect and report data, qualitative and quantitative. Small rural and economically distressed areas have limited capacity to perform these actions without technical assistance. The federal government is well-situated to play an effective role in capacity strengthening by dedicating investment for this data and supporting intermediaries with local, cultural, and historical context and knowledge that employ models such as "see one, do one, teach one" or training the trainer.

Easily accessible data on the financial flows from the federal government to rural areas, especially data that differentiates and disaggregates among demographics, geography, and local economies is lacking. Assessment of the effectiveness and proportionality of the federal assistance accessed by rural areas is complicated by challenges in following where the funding actually flows at basic levels of disaggregation.

A commitment to transparently providing information on how funding is flowing to local levels will lower a significant barrier for community members to understand what is meant to be happening in their communities and provide feedback on its impact.

Many thanks for your partnership in helping maximize federal impact in rural places that need investment most. Thank you.

Sincerely,

Tony Pipa
Senior Fellow, Center for Sustainable Development
[redacted]ion

Justice for
Migrant Women

October 3, 2022

Submitted via [redacted]

NSTC Subcommittee on Equitable Data
Office of Science and Technology Policy
Eisenhower Executive Office Building
[redacted] Washington, DC 20504

Comments in response to Request for Information: Equitable Data Engagement and Accountability

Dear Ms. Ross:

Justice for Migrant Women protects and advances migrant women's rights through education, public awareness and advocacy. We aim to ensure that all migrant women are guaranteed human and civil rights, including the freedom of mobility, the ability to live and work with dignity, and the right to be free of threats of violence against them and their families, whether they are migrating across borders, around regions or within states. We work closely alongside rural women, immigrant women, and women who work in low paid sectors.

The intersecting identities make these women among the most vulnerable and least visible people in the United States. This has also resulted in their exclusion from some of the most basic legal protections. Our work in the community allows us to hear directly from migrant women about their challenges and concerns. Their powerful stories and firsthand accounts demonstrate the need for policy change. Existing data does not often reflect their reality, despite the fact that we should be accountable to them as we all benefit from their labor in myriad ways. It is worth noting that minimal data is available regarding global migration, particularly as it pertains to economic migrants. Even less data is available related to the experiences of women who identify as economic migrants. Many of these community members are of different racial and ethnic identities. Finally, the data does not often capture or distinguish the differing experiences of people who migrate for work, but are not immigrants.

This body of work– understanding who is moving for economic security and health and safety reasons, with a particular focus on women of color– has a significant impact on better understanding the needs of the entire U.S. population that it is accountable to, including migrant women workers. Limited resources and antiquated data collection methods contribute to the invisibility of an already vulnerable population.

For these reasons, Justice for Migrant Women welcomes efforts by the U.S. Office of Science and Technology Policy to advance racial justice and equity through equitable data engagement and accountability. We applaud your acknowledgement that a significant factor to achieve equitable data collection requires disaggregating data by demographic information, geographic information or other variables. To this end, we thank you for the opportunity to provide comments. Justice for Migrant Women offers perspective on the following questions to which you requested input:

> **Question 5:** What resources, programs, training, or tools can increase opportunities for community-based organizations to use equitable data to hold government accountable to the American public?
>
> **Question 7**: In which agencies, programs, regions, or communities are there unmet needs, broken processes, or problems related to participation and accountability that could be remedied through stronger collaborations and transparency around equitable data?

Justice for Migrant Women will address these questions in two of our main areas of focus: economic justice and health and safety.

ECONOMIC JUSTICE

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Pay Data Collection

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This year, for the first time, due to the leadership of Justice for Migrant Women and the National Asian Pacific American Women's Forum, the gender wage gap calculated by race includes part time and full-time workers. Previous data calculations that represented only full-time, year round workers excluded migrant and seasonal workers and in total left out 33 million women workers. Partnerships with community based organizations are critical to ensure that 1) communicating how and why the wage gap is calculated is uniform across government and 2) further gaps in data calculation are addressed, such as the inability to understand the wage gap for Afrolatinas or independent contractors.

While the new data calculation provides additional insight, it still fails to tell the whole story. We do not fully understand the experience of trans women, non-binary people and all immigrant women. Given that the wage gap is largest for women of color, immediate and decisive action to combat compensation discrimination and pay inequity is not only a matter of economic security, but also gender and racial equity. Measures must be taken to expand the community members whose data has not been collected and whose circumstances remain unknown or underinvestigated.

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We are addressing some of the most fundamental needs and rights that migrant communities are too often denied, including protection from gender-based violence and mental health care.

Anti-Sexual Violence

Sexual violence remains a taboo issue, and as a result, it is often difficult for survivors to seek help. This is a barrier to collecting data for all victims and survivors, which prevents us from being able to understand the scope and scale of the problem, not to mention the specific needs of survivors. Sexual harassment is a form of sexual violence. Sexual harassment is a legal term of art that was defined by employment law and the U,S. Equal Employment Opportunity Commission to define unwanted sexual attention against an employee. Like other forms of sexual violence, sexual harassment remains under reported.

It is critical that the EEOC continue with its data collection methods. In addition to requiring employers to comply with mandated data collection requirements, the federal government must also create a process by which this data is separated by industry, race, and gender to have a better understanding of whether there are higher rates of sexual harassment in certain industries, whether people of certain backgrounds are experiencing it at higher rates and to determine whether targeted education, outreach or other services need to be provided to particular demographics.

Mental Health and the Workplace

In response to listening to the community following the outset of the pandemic, Justice for Migrant Women piloted a program called Healing Voices which provided direct mental health support to farmworkers. The goal was to both provide a direct service and to pilot a program which would hopefully expand to support the provision of mental health services to migrant workers across sectors. As we continue this work, it has become evident that mental health and the workplace is a priority for leaders from the local level to the international level. The U.S. Conference of Mayors recently launched a task force on mental health in the workplace, which was closely followed by a policy brief from the World Health Organization and the International Labour Organization calling for global action to address mental health at work. We know that in order for migrant women to be reflected in solutions regarding mental health and the workplace, processes for collecting this data must be prioritized. Justice for Migrant Women is in the process of conducting a survey in partnership with organizations who serve migrant women across demographic groups and geographic regions within the United States to gain a better understanding of how the unique circumstances facing migrant women impact their emotional health and wellbeing, particularly as it relates to the workplace. Being able to replicate this on scale with support from partnerships and the federal government would be instrumental as policies are further developed regarding workplace protections that include mental health.

Conclusion

Through Justice for Migrant Women's own experiences in data collection with the community, we know the value of partnership with community based organizations and the importance of having the resources to collect data in person and in accessible languages, which includes not only translation, but also framing in a way that is sensitive to cultural context. When exploring challenges such as mental health and sexual violence in communities where those issues have been stigmatized, the way that data is both collected and messaged upon release is important to ensuring data does not cause undue harm. As the OSTP seeks to address systemic inequity, it is important that migrant women—who play a vital role in America's communities—are not left behind. If you have any questions, please feel free to contact Catherine Hinshaw, Policy Manager at [redacted]

Sincerely,

Mónica Ramírez
Founder & President, Justice for Migrant Women

Hello,

Please see below suggestions on equitable data collaborations. Please let us know if any questions.
Thank you!

Data set	Description	Relevant fede
Cost burden of housing	Detailed data on cost burden of housing (e.g., percent of paycheck that goes toward rent, mortgage payments) at an MSA / zip code / city / county level	HUD; IRS
Affordable housing unit development	Affordable housing unit pipeline (e.g., units inhabitable, units permitted, units planned) at an MSA-level / city / county level	HUD
Asset ownership	Average level of asset ownership (e.g., asset-to-liabilities ratio, properties, corporate structures, trust, funds)	IRS
Wealth creation score	Wealth creation ability (e.g., understand an individual’s propensity to access credit and leverage tax policies) by age, gender, race, income, and education level	IRS; FDIC; BL
Unbanked and underbanked individuals	True share of underserved, underbanked, unbanked households / individuals by race	FDIC
Employment pipeline status	Employment pipeline (e.g., entry level, manager) by industry sector and race	BLS
Wage gap status	Median annual wage by industry sector and race, adjusted for cost of living in relevant MSA	BLS

Unemployment reasons	Unemployment reasons(e.g., amount of time spent unemployed, reason for unemployment) by race	BLS
Criminal justice demographics	Demographics across criminal justice system pipeline (e.g., arrests, bail, sentencing, recidivism)	DoJ
Use of force trends	Police use of force incidents by level (e.g., empty hand technique, non-deadly weaponry, lethal force) and reason for initial interaction (e.g., routine patrol, traffic stop)	DoJ

Ayushi Gummadi
McKinsey & Company
[redacted]
Pronouns: she/her/hers

CommunicationFIRST
Because communication is a human right.

In Response to The White House Office of Science and Technology Policy Request for Information; Advancing Equity with Community Data Partnerships (LINK)

October 12, 2022

Ms. Denice Ross, U.S. Chief Data Scientist, OSTP
Dr. Alex Hertel-Fernandez, Senior Equity Fellow, OIRA
Executive Office of the President
Washington, DC 20503

Submitted via [redacted]

RE: Request for Information; Equitable Data Engagement and Accountability, 87 Fed. Reg. 54,269 (Sept. 2, 2022), Docket No. 2022-19007

Dear Ms. Ross and Dr. Hertel-Fernandez,

CommunicationFIRST is pleased to submit these comments in response to the White House Office of Science and Technology Policy (OSTP)'s recent Request for Information (RFI) on advancing equity and support for all Americans, including underserved communities, published at 87 Fed. Reg. 54,269 (Sept. 2, 2022).

Introduction

CommunicationFIRST is the nation's only nonprofit organization focused on protecting the rights and advancing the interests of the estimated 5 million people of all ages in the United States who cannot rely on speech to be heard and understood due to disability or other condition. Launched in 2019, CommunicationFIRST is led by and for people with expressive communication disabilities. We seek to advance our mission by educating and engaging the public, advocating for policy and practice change, and working within the legal system to protect rights and advance change.

CommunicationFIRST's members include children and adults who rely on various forms of augmentative and alternative communication (AAC) to be understood and includes some of the most historically marginalized, excluded, isolated, vulnerable, and underserved people in the United States.[1]

What Augmentative and Alternative Communication (AAC) Is and Why It Matters

AAC refers to the tools, strategies, and support persons with little to no understandable oral speech must use to effectively communicate. It typically includes using one or more of the following means of expression:

- Gestures, body language, facial expressions, and eye gaze
- Writing, typing, texting, signing, pointing to letters, words, phrases, or pictures
- Electronic devices that can generate spoken and written messages
- Someone who repeats another person's unclear speech so others can understand it

AAC is used to supplement or replace a person's speech.

The need to use AAC can occur in childhood or at any other point across the lifespan.

AAC can be used all the time or some of the time based on the individual's needs.

Persons who need AAC typically have significant disabilities and extensive services and support needs beyond communication.

Some may use sign language occasionally but, as is true of spoken words, they cannot rely on it as their primary expressive means.

Research shows Black, brown, non-English-using people, and those from other marginalized communities have a greater need for AAC and face greater barriers to obtaining it as well as greater discrimination.

Regardless of when in life or the reason(s) why a person may not be able to rely on spoken words to be understood, everyone in our community routinely faces discrimination in the form of low expectations, denial of opportunity, and denial of access to reasonable services and accommodations that could reduce or eliminate communication barriers. Many often wrongly assume that people who lack understandable *speech* also are incapable of understanding and using *language*. As a direct consequence of these unwarranted assumptions and biases, the vast majority of us are never even given access to robust language-based communication tools and supports that are necessary for appropriate educational and employment opportunities—and for fundamental agency, autonomy, and bodily integrity.

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[1] In these comments, we use the terms "constituents" and "members" to refer to all people who require AAC.

Overarching Comments

CommunicationFIRST urges the Administration to begin to lay the groundwork for collecting equitable data about people with expressive communication-related disabilities – an area that is now sorely neglected.

Having the opportunity and means to express ourselves is imperative to exercising all of our constitutional, civil, and human rights.   Congress underscored the importance of access to effective communication in the Americans with Disabilities Act. *See* 42 U.S.C. § 12101(a)(5) (*"Individuals with disabilities continually encounter various forms of discrimination, including outright intentional exclusion, … communication barriers, … segregation, and relegation to lesser services, programs, activities, benefits, jobs, or other opportunities"* …) (emphasis added); *id.* § 12102(2)(A) (including "speaking" and "communicating" as "major life activities," on the same level as "breathing" and "thinking"). Yet the federal government has never systematically collected data about whether a person in this country has an expressive communication disability. This is a glaring and correctable omission in federal data collection efforts. The omission makes it difficult to identify and address policy failures and unmet needs for the estimated more than 5 million Americans with communication disabilities. Rendering all socio economic disparities harming these children, adolescents, working age persons, and older adults invisible. Out of sight and out of mind of policy makers and the public. While some data exists on people with hearing and vision disabilities, the federal government fails to systematically collect data on those with speech-related disabilities, the third main type of communication disability. In part due this, we believe those with expressive disabilities, in particular, are unjustly and disproportionately segregated, restrained, secluded, consigned to guardianships that terminate many of their civil rights, denied access to equal economic and educational opportunities, and are otherwise left behind.

We therefore urge the Administration to begin to lay the groundwork for collecting national, state, and local data on:

- **The number of people in the United States with hearing, vision, and/or speech disabilities**
- **The number and characteristics of people who, due to speech-related disabilities, require augmentative and alternative communication (AAC) to communicate effectively**

- **The number and demographic characteristics of people who do and do not have the access they need to robust AAC in order to communicate effectively**. Such data should include a breakdown of the number and characteristics of students who rely primarily on: a) their natural speech, b) symbolic AAC, c) language-based AAC, and d) a combination of multi-modal strategies

- **The administration of IQ-type assessments on students, disaggregated by race, disability type, primary language, and gender** (IQ tests often are administered in a discriminatory and non-evidence-based manner to students with communication disabilities who lack access to AAC, especially those who are not white or for whom English is not a primary language. IQ tests are also often used to segregate and deny access to AAC)

- **The number of people who become subject to guardianships or conservatorships (and thus have many of their civil rights terminated), disaggregated by race, disability type, and primary language**

Specific Comments in Response to Directed Questions

These comments respond to five of the seven question areas posed in OSTP's RFI:

1. What are examples of successful collaborations between the Federal government and (a) Tribal, territorial, local, and State governments or (b) local communities involving equitable data?
2. Among examples of existing Federal collaborations with (a) Tribal, territorial, local, and State governments or (b) local communities involving equitable data, what lessons or best practices have been learned from such collaborations?
3. What policies, resources, programs, training, or other tools can facilitate increased data sharing between different levels of government (Tribal, territorial, local, State, or Federal) around equitable data?
4. What policies, resources, programs, training, or tools can make equitable data more accessible and usable for members of the public?
5. In which agencies, programs, regions, or communities are there unmet needs, broken processes, or problems around participation and accountability that could be remedied through stronger collaborations and transparency around equitable data?

Area 1: Successful Collaborations Involving the Federal Government, State and Local Governments, and Local Communities

The federal government now collects ACS and most other survey data only on non-institutionalized persons who only also have just six types of disabilities that result in difficulty: (1) hearing, (2) vision, (3) cognitive activities, (4) mobility, (5) self-care, and (6) independent living. People with speech-related disabilities are not counted separately. Some of these persons do not fit into any of the six categories, and some fit into several of them simultaneously, leaving us effectively invisible. Large population surveys are a way to involve people within local communities, particularly when information shared from such surveys are shared in a transparent manner

Large population surveys have also gathered data on the extent to which individuals with one of these six disability types rely on certain assistive devices such as wheelchairs, canes, and hearing aids. Such data first was collected in the National Health Interview Survey (NHIS) of 1990, and showed that 13 million individuals required one or multiple assistive devices to carry out essential tasks. The 1990 NHIS also found only 38,000 individuals living in the community reported using some type of AAC and that 55 percent were aged 65 and older.[2] Despite the enormous gains that have been made in AAC and related fields over the past 30 years, this marked the first and only time a federal survey asked a question on the use of AAC specifically. In 1994-1995, the CDC together with other federal agencies, carried out a major supplement to the NHIS to generate a comprehensive profile of the characteristics of children and adults with disabilities in the country. The disability supplement reported that an estimated 7.4 million people with disabilities reported using one or more of 29 different types of assistive devices to compensate for hearing, limb loss/limb difference, mobility, or sight disabilities. It paid scant attention, however, to persons needing AAC.[3]

More to the point, no data on the status, characteristics, or needs of individuals who require AAC has been collected since then either.

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[2] LaPlante, M.P., Hendershot, G.E., & Moss, A.J. (1992), Assistive Technology Devices and Home Accessibility Features: Prevalence, Payment, Need, and. Trends. CDC National Center for Health Statistics. Advance Data from Vital and Health Statistics No. 217.

[3] CDC National Center for Health Statistics, National Health Interview Survey Supplement on Disability – Number of Persons Using Assistive Technology Devices, 1994, Table 1a; *see also* J.N. Russell et al., Trends and Differential Use of Assistive Technology Devices: United States, 1994; CDC National Center for Health Statistics (November 1997). Advance Data No. 292.

__Recommendation__: **CommunicationFIRST recommends that the Administration develop and execute a plan regularly and systematically collect demographic and characteristic data on non institutionalized and institutionalized people in the U.S. who cannot rely on spoken words to be understood. Failing to accurately track us and our needs sends the clear message that those who most struggle to have a voice in our nation do not “deserve” to be heard or even counted. Rendering us invisible.**

Area 2: Lessons and Best Practices Learned from Collaborations with Local and State Governments, and Local Communities

In 2013, researchers estimated that about 1.3 percent of the total population, or 4 million people in the United States, “cannot rely on their natural speech to meet their daily communication needs,”[4] and that “the prevalence and complexity of communication disorders increase with age.”[5] The National Academies of Science, other federal agencies, and professional associations have cited the 2013 estimate as the only, and therefore the most authoritative, one available. Other studies suggest that the numbers of children, working-age persons, and older adults with significant speech disabilities likely will continue to increase due to several factors, including:

- The changing demographic makeup of the country in terms of age, longevity, race, ethnicity, primary language, education, economic mobility, digital innovation, connectivity, and other SES factors;
- The rising incidence of autism;
- Advances in medicine resulting in improved survival coupled with lifelong disability;
- Extended lifespans of individuals with communication disability; and
- Improved AAC technology that better meets the needs of people with physical and cognitive disabilities.[6]

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[4] Beukelman, D.R. & Mirenda P. (2013). *Augmentative and alternative communication: Supporting children and adults with complex communication needs*, at 4. 4th ed. Baltimore, MD: Paul H. Brookes Publishing Co.

[5] Flaubert, J.L., Spicer, C.M., Jette, A.M., eds., *The Promise of Assistive Technology to Enhance Activity and Work Participation*. Washington (DC): National Academies Press (US); 2017, May 9. 6, *Augmentative and Alternative Communication and Voice Products and Technologies*, at: https://www.ncbi.nlm.nih.gov/books/NBK453284/ (citing Yorkston K.M., Bourgeois, M.S., Baylor, C.R.. *Communication and Aging. Physical Medicine and Rehabilitation Clinics of North America*. 2010a;21(2): 309–319, at https://www.ncbi.nlm.nih.gov/pmc/articles/PMC3074568/).

[6] Flaubert, J.L., Spicer, C.M., Jette, A.M., eds., *The Promise of Assistive Technology to Enhance Activity and Work Participation*. Washington (DC): National Academies Press (US); 2017, May 9. 6, *Augmentative and Alternative Communication and Voice Products and Technologies*, at https://www.ncbi.nlm.nih.gov/books/NBK453284/ (internal citations omitted).

The pandemic and racial disparities are threatening the health and lives of our community in an unparalleled manner. Individuals who require AAC are often needlessly illiterate, institutionalized, isolated, immunocompromised, kept incommunicado, and wrongly regarded as lacking in the capacity, need, or right to communicate and thus control our lives.[7] This discrimination is endemic in health care contexts.[8] Furthermore, due to entrenched racism and health disparities, Black Americans and other people of color are more likely to experience a stroke, ALS, Parkinson's, and other conditions that may require them to use AAC. Research also indicates that individuals who belong to racial, ethnic, and linguistic minority communities who need AAC frequently face added difficulties in obtaining it.[9]

Improving the quality and comprehensiveness of data on such individuals will not erase or salve these egregious injustices in the daily lives of such persons. But, until we as a nation conscientiously count children, working-age persons, and older adults with significant expressive disabilities, and begin to fashion and implement data and evidence-based federal policies and programs that address their needs, abilities, fears, and hopes, their lives and our democracy will an be made the worse for it. When people are not counted in a valid manner they never truly count.

For a data strategy to be effective in providing an accurate and comprehensive profile of those that either currently use or need access to an array of AAC tools

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[7] See Kleinert, J., Holman, A., McSheehan, M., Kearns, J. (2010). *The Importance of Developing Communication Competence. Synthesis Report #1.* Lexington, KY: University of Kentucky National Alternate Assessment Center. USDOE OSEP #H3244040001; NAS, *Promise of Assistive Technology*, Ch. 4; CommunicationFIRST, National Survey Reveals Students with Communication Disabilities Are Being Denied Safe Access to Education (Jan. 4, 2021); CommunicationFIRST, Are AAC Users at Greater Risk of Dying from COVID? (Updated) (Dec. 20, 2020).

[8] *Stemming the Risk of Disability Bias During the COVID-19 Pandemic - CHCS Blog*. (2021, August 7). Center for Health Care Strategies. Retrieved October 11, 2022, from https://www.chcs.org/stemming-the-risk-of-disability-bias-during-the-covid-19-pandemic/; *Significant Victory for Patients with Disabilities in Response to Joint Complaint on Hospital No-Visitor Policies*. (2020, June 9). CommunicationFIRST. Retrieved October 11, 2022, from https://communicationfirst.org/significant-victory-for-patients-with-disabilities-in-response-to-joint-communicationfirst-complaint-on-hospital-no-visitor-policies/; Stransky, M. L., & Morris, M. A. (2019, March). Adults with Communication Disabilities Face Health Care Obstacles. *The ASHA Leader*, *24*(3), 46–55. https://doi.org/10.1044/leader.ftr1.24032019.46.

[9] Ellis, C., Magwood, G., & White, B. (2017, May 23). Racial Differences in Patient-Reported Post-Stroke Disability in Older Adults. *Geriatrics*, *2*(2), 16. https://doi.org/10.3390/geriatrics2020016; Atrium Health. (2019, March 29). *African-Americans with ALS Live Longer* [Press release]. https://newsroom.wakehealth.edu/news-releases/2019/03/african-americans-with-als-live-longer;

to effectively communicate throughout their lives, these nuances need to be acknowledged and addressed to the greatest extent feasible.

<u>Recommendation</u>: In addition to the OSTP and DPC developing a plan to collect data on the millions of people who cannot rely on speech to be understood, CommunicationFIRST recommends that this effort begin with creating a uniform federal classification term like "individual with significant expressive communication disability" or "individual with significant speech-related disability." This effort should also take explicit steps to involve young people and adults who require AAC as active participants in community, national, and international service efforts in order to thwart the bias that we have little to say and far less to contribute.

Area 3: Policies, Resources, Programs, Trainings, and Other Tools That Can Facilitate Increased Data Sharing Between All Levels of Government Around Equitable Data

As we have noted, the National Academies of Sciences has previously reported that data on individuals with significant communication disabilities are limited.[10] It is impossible to design and implement effective policies and programs for any population – particularly one that is as complex as ours – without having reliable data information on their diversity, commonalities, and unmet needs. We do not know how effectively the billions in federal dollars are being spent on our constituency and neither does the federal government. It is vital that comprehensive data is collected, analyze, made public, and used to answer questions like the following:

How are the lives of children, youth, working age persons, and older adults who require AAC faring in the 21st Century American community?

How do the lives, socio economic status, and equal opportunities of such persons compare with others in the U.S.?

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[10] National Academies of Sciences, Engineering, and Medicine; Health and Medicine Division; Board on Health Care Services; Committee on the Use of Selected Assistive Products and Technologies in Eliminating or Reducing the Effects of Impairments; Flaubert, J.L., Spicer, C.M., Jette, A.M., eds. *The Promise of Assistive Technology to Enhance Activity and Work Participation.* Washington (DC): National Academies Press (US); 2017, May 9. 6, *Augmentative and Alternative Communication and Voice Products and Technologies*, at: https://www.ncbi.nlm.nih.gov/books/NBK453284/

What is the estimated number of such persons living in non-institutionalized and institutionalized settings?

What major barriers and forms of discrimination do we tend to face in life?

What major gains do data show such persons have made in recent years?

How many are afforded access to the effective AAC tools, strategies, and supports they need to effectively communicate and live life? How many lack them?

What is the estimated number and percentage of children, youth, and young adults who require AAC and have access to it, are being educated alongside their nondisabled peers, earning high school diplomas, going to college, earning degrees, and working full or part time jobs?

What is the estimated number and percentage of children, youth, and adults who require AAC and do not have access to it, have been "educated" in segregated settings, and live isolated, marginalized lives?

What is the estimated number and percentage of such persons who are registered to vote and do vote?

What is the estimated number and percentage of such adults who have legal guardians?

To what extent do factors such as race, age, age of onset/disability, primary spoken language, culture, class, living situation, and other factors influence whether someone who requires AAC is able to gain it or not?

To what extent do these same types of factors make it more or less likely for a person to have or acquire the need for AAC as a child, adolescent, working age person, or older adults?

Today, data from the American Community Survey and other federal surveys can answer or at least shed light on these or similar questions regarding children and adults with any of the six, aforementioned disabilities categories. The use of the six disability categories by the Census Bureau is flawed and fails to capture critical data on a significant percentage of people with disabilities, including a wide range of cognitive, developmental, expressive, learning, mental health, physical, receptive, and multiple disabilities.[11] It is said data collected by the Current Population Survey, the National Health Interview Survey, and the Survey on Income Program Participation help fill in such data gaps. However, this is only partially true. There is survey data on people with speech disabilities but none specificity to the segment of this population who require AAC.

Recommendation: The DPC and OSTP should work with federal agencies to issue a joint RFI on what relevant demographic data exist already at federal, state, and local levels, what is missing, and how existing data collection efforts can be modified to fill this significant data gap. Specific attention should be paid to identifying and taking steps to better understand how racial, ethnic, and linguistic characteristics make the inequities experienced by those with significant expressive communication disabilities worse.

Area 4: Policies, Resources, Programs, Trainings, and Other Tools That Can Make Equitable Data More Accessible and Usable for Members of the Public

> Members of the public, including persons with significant expressive communication disabilities, our families, and our allies must play a lead role in designing, delivering, evaluating and improving policies and practices affecting access to, the financing of, and the effective use of equitable data. These same principles and expectations must drive all federal efforts concerning equitable data. The voices and views of such persons have gone unheard and unheeded generation after generation. We can and must break this cycle by insisting that our voices matter and must be heard. Early steps in doing so could include the following actions:

Recommendation: Issue an RFI, host town hall sessions, or just listen to persons who require AAC and others with disabilities discuss their lives, what's working, what's not, their dreams and fears as well as their insights and recommendations on how the federal government and others can best enable their success. Record their experiences and include the information compiled in an openly accessible database.

Area 5: In Which Agencies, Programs, Regions, or Communities are

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[11] Altman BM, Madans J, Weeks JD. An evaluation of the American Community Survey indicators of disability. Disabil Health J. 2017 Oct;10(4):485-491.

there Unmet Needs, Broken Processes, or Problems Around Participation and Accountability that Could be Remedied Through Stronger Collaborations and Transparency Around Equitable Data?

Despite abundant evidence that they are inaccurate and inappropriate for people who cannot rely on speech to be understood and have other motor disabilities, standardized IQ-type assessments are used to segregate, isolate, and deny opportunities to not just school-age people but also many adults who require public funding to survive. The federal government's encouragement in guidance and regulations of the use of these assessments sanctions widespread prejudices and stereotypes that frequently make those that use or need AAC easy marks for bullying, abuse, assault, and lifetimes of dehumanization.

In the [Communication Equity Call to Action](https://communicationfirst.org/communication-equity-call-to-action/) that CommunicationFIRST and 47 other organizations submitted to the Administration in 2021, we specifically encouraged the Department of Education to review the extent to which IQ tests and similar cognitive assessments are inappropriately used with students with motor and speech disabilities, and to determine appropriate short- and long-term actions to prevent and reverse their use and effects.[12] Currently, intellectual disabilities (whether perceived or actual) are inappropriately and regularly used as a basis to deny students access to robust, language-based AAC.

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[12] Williams, B., & Szymanski, T. (2021, January 14). *Communication Equity Call to Action*. CommunicationFIRST. https://communicationfirst.org/communication-equity-call-to-action/.

Standard IQ tests have four fatal flaws in assessing the intelligence of people unable to rely on speech alone to communicate:

1. Every IQ test assumes the test-taker can either answer questions reliably with speech or hand movements of their hands, something that many, if not most, of these individuals are unable to do.

2. IQ tests have not been normed on people with communication, sensory, or movement differences, who require but frequently lack access to robust language based AAC.

3. IQ scores are influenced significantly by racial, disability, language, socio-economic, and cultural differences.

4. When a person cannot be understood, their responses on an IQ test are often provided by a third person "proxy" introducing further chance of bias.

Such shortcomings lead to damaging assumptions that people who score poorly on IQ tests are incapable of learning, communicating, and directing their own lives.

There is also a large body of research on the biased, discriminatory impacts that standardized IQ assessments have—independent of disability status—on Black, indigenous, people of color, linguistic, and other minority individuals and communities.[13] Special attention should be paid to whether these assessments are used to disproportionately marginalize racial, ethnic, and linguistic minority populations of people with significant expressive communication disabilities. Black Americans and other people of color are more likely to experience stroke, ALS, Parkinson's, and other conditions that may require them to use AAC. Research also indicates that individuals who belong to racial, ethnic, and linguistic minority communities who need AAC frequently face added difficulties in obtaining it.[14] We must not allow such injustices to linger.

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[13] National Center for Learning Disabilities. (2020). *Significant Disproportionality in Special Education: Current Trends and Actions for Impact*. https://www.ncld.org/wp-content/uploads/2020/10/2020-NCLD-Disproportionality_Trends-and-Actions-for-Impact_FINAL-1.pdf; Gravois, T. A., & Rosenfield, S. A. (2006, January). Impact of Instructional Consultation Teams on the Disproportionate Referral and Placement of Minority Students in Special Education. *Remedial and Special Education*, *27*(1), 42–52. https://doi.org/10.1177/07419325060270010501.

[14] Ellis, C., Magwood, G., & White, B. (2017b, May 23). Racial Differences in Patient-Reported Post-Stroke Disability in Older Adults. *Geriatrics*, *2*(2), 16. https://doi.org/10.3390/geriatrics2020016; Atrium Health. (2019, March 29). *African-Americans with ALS Live Longer* [Press release]. https://newsroom.wakehealth.edu/news-releases/2019/03/african-americans-with-als-live-longer;

<u>Recommendation:</u> The Administration should stop encouraging the further marginalization of our community that occurs when the government endorses or requires us to be branded with low IQ scores from [biased assessment tools](#) before we can gain access to services and supports.[15] Specific, early steps that OSTP and the DPC can take to address the inequities caused by the inappropriate use of IQ assessments include working with the Department of Education to assure the following data is collected and use to assure students who require AAC receive an equally effective and inclusive education:

- **The total number and characteristics of students who, due to speech-related disabilities, require augmentative and alternative communication (AAC) to communicate effectively**

- **The number and demographic characteristics of students who do and do not have the access they need to robust AAC in to communicate effectively and learn**, with a breakdown of the number and characteristics of students who rely primarily on: a) their natural speech, b) symbolic AAC, c) language-based AAC, and d) a combination of multi-modal strategies

- **The number of IQ-type assessments conducted on these students** (IQ tests often are administered in a discriminatory and non-evidence-based manner to students with communication disabilities who lack access to AAC, especially those who are not white or for whom English is not a primary language, and used to segregate and deny access to AAC)

- **The distribution of IQ scores assigned to students who require AAC as a result of the assessments.** While no specific data is available, there are indications that students with little to no understandable speech are disproportionately “”assessed” to have intellectual disabilities . this can result in them to being denied robust language based AAC, an an appropriate education, and multiple forms of ife-long discrimination. Data is needed to determine whether this occurs, the reasons it does, and strategies for preventing and remedying it.

All data collected should be able to be disaggregated by race, disability type, age, educational level, educational setting, assigned IQ classifications, primary language, gender, gender identity, and other relevant factors.

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[15] CommunicationFIRST. (2019, August 14). *Comments Submitted to the American Psychiatric Association [Comment on “The Proposed Revision to the DSM-5 Definition of ‘Intellectual Disability’”].* https://drive.google.com/file/d/1fglzfdTegS_18ty2XZjvf2mWfPxPxVuw/view?usp=sharing.

* * *

It is said that individuals and communities are most at risk of experiencing overwhelming bias, discrimination, and oppression when they, others, and government regard them as lacking a voice, a positive identity, and the human agency to improve their lives. This must not continue to be the fate of millions who require AAC. Civic engagement of all forms is a powerful antidote for thwarting these forces and to enhance individuals' hearts and minds, their health, self efficacy, and sense of belonging.[16] The steps outlined here are vital for beginning this process.

Thank you once again for the opportunity to provide information on this important topic. Please contac [redacted] or clarification or additional information.

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[16] ODPHP. (n.d.). *Healthy People 2030: Building a healthier future for all*. U.S. Department of Health & Human Services. https://health.gov/healthypeople.

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[redacted]
Washington, DC 20500

Submitted via email to: [redacted]

October 6, 2022

RE: Public Request for Information; Advancing Equity with Community Data Partnerships: We Need to Hear From You

Justice in Aging appreciates the opportunity to comment on the above referenced public request for information.

Justice in Aging is an advocacy organization with the mission of improving the lives of low-income older adults nationwide. We use the power of the law to fight senior poverty by securing access to affordable health care, economic security, and the courts for older adults with limited resources—particularly populations that have been marginalized and excluded from justice, such as older adults of color, older adults with disabilities, LGBTQ older adults, and older adults with limited English proficiency. We have decades of experience with programs and services established by federal agencies, including the Centers for Medicare & Medicaid Services, Social Security Administration, and the Administration for Community Living.

We also have experience with state and local agencies and programs that impact the lives of older adults. Justice in Aging administers the National Center on Law and Elder Rights (NCLER) on through our contract with the Administration for Community Living. Through NCLER, we connect with front-line advocates at legal and aging services throughout the country who work directly with older adults to access State and local programs.

Our comments focus on policies and practices that can improve equitable data sharing and collection to advance equity for older adults with marginalized identities.

I. What are examples of successful collaborations between the Federal government and (a) Tribal, territorial, local, and State governments or (b) local communities involving equitable data?

We offer two examples of successful collaborations to share equitable data specific to the context of services and programs for older adults.

a. *The National Adult Maltreatment Reporting System (NAMRS)*[1]

NAMRS is a data reporting system used to understand adult maltreatment in the U.S.; it is operated by the Administration for Community Living (ACL) and the data is collected and submitted by adult

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[1] Administration for Community Living, National Adult Maltreatment Reporting System, https://namrs.acl.gov/ (last visited Sept. 29, 2022).

protective services (APS) programs in every state, the District of Columbia, and the territories.[2] While APS programs operate within the same statutory framework of services, there is great variation across programs in the populations they serve and their policies and practices. NAMRS is a comprehensive reporting system established by ACL—the federal agency that oversees APS programs—that provides insight into adult maltreatment at the client level and the supports needed to prevent it. The APS Technical Resource Center (APS TARC), also funded by ACL, provides training and technical assistance to states regarding NAMRS requirements.

NAMRS collects de-identified data from over one million reports of adult maltreatment annually,[3] and collects both quantitative and qualitative data on APS policies and outcomes of maltreatment investigations.[4] The collected client-level data includes data points that are directly relevant to APS's impetus, such as clients' and victims' age, disabilities, and residence. Additionally, the majority of states also report gender, race, and ethnicity data on some, but not all, APS clients and victims.[5] Less than half of state APS programs also report demographic information (age and gender) regarding the perpetrators of adult maltreatment.[6]

NAMRS data has been useful to advocates, policymakers, and service providers in understanding of the types of maltreatment experienced by different populations and identifying risk factors. It has also been useful in understanding maltreatment reports during the COVID-19 pandemic, during which social isolation and increased dependency on others for daily activities potentially increased exposure to maltreatment.[7]

b. Title III Older Americans Act State Performance Report (SPR)

The Older Americans Act (OAA) authorizes services through a national network of state agencies; local area agencies on aging; and American Indian, Alaskan Native and Native Hawaiian organizations to promote the rights of older adults. The State Performance Report (SPR) effort fulfills a requirement of the OAA, which requires "collection of statistical data regarding the programs and activities carried out with funds provided under the OAA" and reporting this data to the federal agency. Not only does SPR indicate how the national aging network and state agencies on aging use OAA funds, it now also provides information on the characteristics of the people serviced. The demographic information collected includes data points such as race, ethnicity, age, gender, and poverty status.[8]

While the new addition of demographics of OAA service recipients has not yet been reported publicly, this data will be aggregated at the state-level and de-identified where appropriate. The collection of

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[2] Adult Protective Services (APS) are federally mandated State-level programs that investigate reports of abuse, exploitation, neglect, and self-neglect relating to older adults and adults with disabilities.

[3] *Supra* note 1.

[4] Administration for Community Living & Administration on Aging, Adult Maltreatment Report 3 (2020), https://namrs.acl.gov/getattachment/Learning-Resources/Adult-Maltreatment-Reports/2020-Adult-Maltreatment-Report/2020_NAMRS_Report_ADA-Final.pdf.aspx?lang=en-US.

[5] *Id*. at 18. NAMRS also collects data relating to the practices of the investigation, such as the length of the investigation, reasons for case closure, and prior reports of maltreatment.

[6] *Id.* at 22.

[7] *Id.* at 24 (reporting that APS reports dropped in the early months of the pandemic and rose above normal levels after the initial shut-down period).

[8] Other data points include geographic distribution (i.e., rural/non-rural), household status, minority status, and number of functional limitations, and nutritional risk.

demographic data for SPR purposes will allow for a better understanding of the older adults who are impacted by OAA funded programs—which statutorily requires that some programs target services to older adults with the greatest social and economic need. For example, pro-bono legal assistance providers that represent older adults using OAA funding will report de-identified, aggregated demographic and other information related to their clients and cases which will be useful to both the federal government and the providers in identifying unmet needs in different communities.

II. What policies, resources, programs, training, or other tools can facilitate increased data sharing between different levels of government (Tribal, territorial, local, State, or Federal) around equitable data?

a. *Data Collection as Standard Practice and Improved Data Points.*

A current barrier in gaining perspective on the impact of government-funded social services programs that are administered at the state or local level is inconsistencies in reported data points. Policies that define universal data points in federally-funded programs will facilitate cross-county and cross-state comparisons and provide a better perspective on the impact of social services programs nationally. This is particularly true for programs that are federally funded, but have state-by-state variations in implementation and impact, such as Medicaid-funded home- and community-based services and OAA funded legal and aging services.

These policies should emphasize the standard collection of demographic data, including race, ethnicity, sexual orientation and gender identity, age, disability, and languages spoken. Additionally, while many state and local programs gather some demographic information, the data points can be improved. For example, most self-reported accounts of race and ethnicity do not ask about Middle Eastern and Northern African (MENA) heritage.[9] Similarly, programs vary in how they collect information on sexual orientation and gender identity (SOGI). Traditional self-reported demographics questions that only allow one to identify as female or male "do[] not necessarily capture information on transgender or gender non-conforming individuals."[10] We encourage OIRA and OSTP to connect with trusted advocates from impacted communities to develop uniform standards for the type of information that should be collected by localities and states and these specific considerations for each type of data.

States and localities would benefit from resources and guidance on collecting this data, for example: Internet-based tools; trainings on gathering, and de-aggregating and de-identifying data; and targeted assistance in engaging impacted communities and improving data collection where it has historically been lacking. Resources on how to ask about demographic information in a culturally appropriate and sensitive manner are critical (addressed further in subsection(b)). Additionally, programs at all levels of government would benefit from resources on evaluating disparaties and intervention impacts on populations with intersecting marginalized identities.

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[9] The Federal government categorizes people with MENA origins as White, despite the fact that many such individuals do not self-identify as White and may experience different health and social outcomes than White populations. *See* Neda Maghbouleh et al., *Middle Eastern and North African Americans may not be perceived, nor perceive themselves, to be White* (2022), https://www.pnas.org/doi/10.1073/pnas.2117940119. While some government forms allow individuals to self-identify as "Other" on government forms and occasionally write in a response, there is no uniform policy for how these selections are reported.

[10] NATIONAL RESOURCE CENTER ON LGBT AGING, INCLUSIVE SERVICES FOR LGBT OLDER ADULTS 8 (2018), https://www.sageusa.org/wp-content/uploads/2018/05/sageusa-welcoming-agency-guide-inclusive-services-for-lgbt-older-adults.pdf.

b. *Best Practices for Data Collection.*

As uniform data reporting standards develop, so should standards of practice for data collection. Sharing one's detailed demographic information on race, ethnicity, SOGI, language, disability, and age is a sensitive matter, and many individuals may rightly feel hesitant to share this information due to perceived or lived experiences of bias and danger.[11] These hesitancies can be barriers to accurate and reliable data collection, which impacts data sharing across levels of government and limits our ability to draw relevant conclusions about the success of interventions that advance equity.

States, localities, Tribes, and territories would benefit from resources that are derived from input from impacted communities on how to collect, store, and report this information to build and maintain trust with self-identifying individuals. This includes, but is not limited to, guidance on framing culturally competent and trauma-informed questions; communicating confidentiality and privacy measures; and creating safe spaces to self-report data.[12]

c. *Tools and Resources.*

Another barrier to gaining equitable data is the administrative burden data collection places on the frontline service providers who work directly with clients from impacted communities. Because social services and government systems at the local, state, territorial, and Tribal level already gather some demographic information during intake procedures, resources to incorporate improved data points in providers' existing intake procedures—such as by facilitating case management and intake systems to collect this information—may reduce the burden of data reporting.

Another barrier in equitable data sharing is that the tools to compile and compare data between different levels of government is lacking. For example, courts in every state oversee guardianship proceedings for adults with diminished capacity, and all courts monitor issues such as the financial security and health of the adult through regular reporting requirements. However, there is no mechanism to compare the demographics and outcomes of adults under guardianship because states use different methods to record this information—ranging from Internet-based tools to paper records—and there are variances in the type of information that is collected.[13] While some federally-funded programs have national data reporting requirements and systems (including NAMRS and SPR), one ongoing challenge is that these mechanisms are not available for all social services programs.

III. What policies, resources, programs, training, or other tools can expand opportunities for historically underrepresented scholars and research institutions to access and use equitable data across levels of government?

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[11] For example, researchers have found that the way questions regarding sexual orientation are worded—"same sex attraction" versus "same-sex behaviors" and identifying as LBGTQ—impacts self-reported response rates. M.V. Lee Badget et al., *LGBTQ* Economics, 35 J. ECON. PERSPECTIVES 141, 144 (2021), https://pubs.aeaweb.org/doi/pdfplus/10.1257/jep.35.2.141.

[12] *See, e.g.*, NATIONAL RESOURCE CENTER ON LGBT AGING *supra* note 10 at 11-13 (discussing first impressions that demonstrate inclusivity); Badget, *supra* note 11 at 144 (noting differences in in-person versus computer-based data collection).

[13] While state courts are not federally funded, States can receive federal funding for guardianship-related efforts. *See, e.g.*, Administration for Community Living, Elder Justice Innovation Grants: Improving Guardianship (2022), https://acl.gov/grants/elder-justice-innovation-grants-improving-guardianship-fy2022.

a. *Publicizing Information*.

Universally, a major barrier in achieving health and social equity is lack of sufficient data around access to and outcomes of social programs for marginalized communities. Not having this information perpetuates structural disparities because government agencies and advocates are unable to accurately identify gaps in services and tailor solutions. Even when data are collected, it sometimes goes unreported or is reported in limited circumstances, such as being shared in a private meeting but not available publicly.

As data collection efforts are enhanced across federal and federally-funded programs, we encourage the agencies to report all collected data and stratify it by demographics. Additionally, intersectional data for all demographics should be reported as much as possible. While some data may be insufficiently large to include in analyses and trend reports, it should be publicized nonetheless in some format with the appropriate disclaimers.

IV. What policies, resources, programs, training, or tools can increase opportunities for community-based organizations to use equitable data to hold government accountable to the American public?

As discussed in Section IV, we encourage policies surrounding publicizing data.

a. *Engage with Impacted Communities*.

As a general policy, we encourage engaging impacted communities at the onset of data collection efforts to help identify unmet needs, inform where to find the information, and develop community-informed equitable data practices. Additionally, we encourage keeping the community engaged during and post-data collection efforts, and sharing the results with the impacted communities.

Frequently, data-related efforts are often geared to the needs of the funders, and not the impacted community. It is vital that the outcomes of surveys, trend reports, and other data collection exercises are shared with community organizations that can use the information in making decisions regarding their programs.

One example from our experience of government accountability in data collection was in the recent COVID-19 context. California, like many other states, failed to report COVID-19 vaccine demographic data intersectionally. Instead, it reported uptake by race, gender, and age, but not at the intersection of any of those demographic characteristics. Therefore, it was virtually impossible to identify more precise trends among the older adult community because as a whole, it appeared that older Californians 65+ were embracing the vaccines. However, through efforts from Justice in Aging and others on the California Community Vaccine Advisory Committee, the state finally began reporting vaccine uptake for older adults by race, which revealed vacation rates among older adults in communities of color lagged behind white older Californians.[14] This led to more specific investments and outreach strategies tailored

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[14] More about the Community Vaccine Advisory Committee can be found on the California Department of Public Health's website at: https://www.cdph.ca.gov/Programs/CID/DCDC/Pages/COVID-19/Community-Vaccine-

to older adults of color.

V. What policies, resources, programs, training, or tools can make equitable data more accessible and useable for members of the public?

As discussed in Section IV, we encourage policies surrounding publicizing data.

VI. In which agencies, programs, regions, or communities are there unmet needs broken processes, or problems around participation and accountability that could be remedied through stronger collaborations and transparency round equitable data?

a. *Unmet Needs for Older Adults of Color and Older Adults with Other Marginalized Identities.*

While age is often a reported demographic data point, data on age and other intersecting identities (e.g., age and race, age and sexual orientation and gender identity) are not frequently reported. This was exemplified in the California vaccination example discussed in IV(a). Lack of data is a barrier that stymies efforts to advance equity at the policy and legislative level as well as the program level. Policies that uplift intersectionality in data collection across all sectors are necessary to advance equity in programs serving older adults.

VII. Conclusion

Thank you again for the opportunity to comment. If any concerns arise concerning submission, please contact Sahar Takshi at [redacted]

Sincerely,

[redacted]

Denny Chan
Managing Director, Equity Advocacy

Advisory-Committee.aspx. The state's vaccine uptake data can be found on the COVID19.ca.gov webpage: https://covid19.ca.gov/vaccination-progress-data/#overview.

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October 3, 2022

Advancing Equity with Community Data Partnerships: Request for Information

The following inputs represent the informal views of several experts at the Partnership for Public Service, to include the Research, Evaluation, and Modernizing Government team.

[redacted] contact Sarah Philbrick, Research Manager,

3. **What policies, resources, programs, training, or other tools can facilitate increased data sharing between different levels of government (Tribal, territorial, local, State, or Federal) around equitable data?**

The Partnership for Public Service released an issue brief in October 2021 focusing on lessons learned from managing public health data infrastructure used to facilitate responses to the COVID-19 pandemic. In this issue brief, we offer a range of policies, resources, and other tools that can increase data sharing between different levels of government in an equitable manner. The following is a list of recommendations we found from our research that can be applied to equitable data writ large.

Policies

Invest in data infrastructure maturity and funding at all levels of government. Historically, federal government funding for data collection mechanisms to specific problems, resulting in fragmented, siloed systems and processes. The federal government, leveraging help from Congress, should invest in comprehensive, core data infrastructure capabilities in federal, state and local systems.

Standardize data & reporting processes. In critical policy and programmatic areas federal government should provide standardized data definitions and reporting guidance, particularly for demographic data that are replicable and usable by all levels of government. Such definitions—as well as reporting processes--can be generated by multi-stakeholder processes to ensure community buy-in. To the degree possible in relevant policy and programmatic areas, the federal government could enforce these definitions and processes as condition for relevant funding or partnership.

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Resources & Training

Invest in accessible and agile training opportunities supporting data acumen, data stewardship, and knowledge mobilization. To create and support an equitable data infrastructure and collect equitable data, the nation needs trained professionals who can respond to emergent needs over time, at all levels of government and within community partners. The required skill sets are not exclusively academically trained data scientists, but rather professionals who understand the technology infrastructure, standards, distribution networks, utilization, and protection of data—and the appropriate means to use it. The federal government should work with academic partners to develop a wide-range of training, credentialing, and interdisciplinary frameworks, and encourage the use of these resources provide upskilling to local, state, and federal workforces. Programs should include understanding of agile technologies, project management, knowledge mobilization, and adaptability—all core components of the future of data management.

Programs

Partner with well-established existing bridge organizations. Many non-profits and industry or professional associations already try to improve data equity within the United States and understand the needs of their stakeholders. Partnering with these organizations can help promote data equity solutions and build trust with local and state governments. Examples in the public health data space include the Council of State and Territorial Epidemiologists, the Association of State and Territorial Health Offices and more.

Tools

Invest in agile and cloud systems that allow for adapting and scaling data infrastructure quickly. Agile systems, wherein practitioners can add and take away software features to respond to changing data, are crucial for data practitioners to respond to emergent needs. This can allow policy makers and data practitioners to better collect equitable data, the data needed for equity might change over time. Cloud systems can scale up storage techniques when needed during times of increased data production, like national emergencies, pandemics, or even increased use of government services, allowing for agencies to collect the amount of data they need at the right time.

Create comprehensive data use agreements. To create equitable data systems, it is often important to link together data storages that are currently disparate. Data use and data transfer agreements are critical when working with protected personal information. It can be helpful if these data exchange agreements are comprehensive rather than needed a variety of different agreements for different types of data. While the federal Chief Data Officer Council has done extensive and valuable work in creating resources supporting data use agreements, more investment is needed in support and approval processes – particularly among the legal community—to enable such agreements for specific ends.

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5. What policies, resources, programs, training, or tools can increase opportunities for community-based organizations to use equitable data to hold government accountable to the American public?

The Partnership for Public Service encourages the Office of Management and Budget to ensure federal workforce, performance, and other relevant government data is, when published, made available in accessible formats for analysis and reporting (e.g., using APIs for all public performance or workforce data sets).

In addition to the work referenced above, the Partnership for Public Service is working on an issue brief, to be published in October 2022, focusing on agencies who have used data and evidence to implement President's Management Agenda goals in talent, customer experience, and government business operations In this issue brief, we offera range of policies, resources, and other tools that can increase data accessibility for federal partners, members of the public and community-based organizations. The following is a list of recommendations we found from our research that can be applied to equitable data writ large.

Policies

Transparency: There is more to data transparency than simply publishing data. In order for data to be useful to stakeholders, it must be easy to find, easy to use and include information about limitations and sources. All published data should be published in machine readable formats and include metadata about its sources and variables.

Collection: Data collection, especially customer experience data collection, is cyclical. By collecting detailed demographic information on customers, agencies can use data to provide relevant services. An agency can then collect user data on the service experience and continue improving iteratively. Data collection should be part of all program administration.

Resources and training

Creating a Culture of Data: Creating an evidence-based culture facilitates data-driven decision making across every level of an agency. Agencies should invest in data trainings for employees at every level of an organization so even when employees do not engage in data analysis, they understand how data is collected and used to make decisions.

[redacted]

America FORWARD

October 27, 2022

Mr. Scott Gibbons
Chief Data Officer
Office of the Assistant Secretary for Policy
U.S. Department of Labor
[redacted]
Washington, DC 20210

Dear Mr. Gibbons:

On behalf of our respective organizations, we are writing in response to the Department of Labor's "Request for information on design and implementation features for open data services provided by the Department of Labor" (Docket No. DOL-2021-0005). Thank you for the opportunity to provide input on these important issues. Our comments relate to the following categories in the Department's RFI: #1 Data content and format; #2 Data documentation; #3 Data formats specific to certain analysis patterns; #4 Data quality issues; #5 Challenges with data comparability; and #10 Specific data sets and methodologies.

We write to recommend that the Department prioritize the creation of a national employment metrics system for workforce development programs that leverages national labor market outcomes information to substantially improve the transparency, availability, and quality of provider participation and outcomes data and support innovation across the workforce system. While our comment focuses on data for Eligible Training Programs (ETPs) under the Workforce Innovation and Opportunity Act (WIOA), we believe this prospective new system could also incorporate providers across the array of federal workforce funding streams, such as SNAP Employment and Training (E&T).

Today, it is far too difficult for stakeholders across the workforce system to access even basic information about federally funded training programs and participants' outcomes, including long-term labor market outcomes. This persistent challenge has frustrated informed decision-making by workers, providers, career navigators, and policymakers at every level of government and makes it more difficult to help participants achieve sustained economic mobility. It is very difficult, for example, to assess the degree to which programs may or may not advance equity goals without information on participants' demographics.

In addition, the current reporting system places substantial burden on stakeholders across the system, particularly providers, while providing little support for continuous improvement and innovation. Providers that report into the current system, for the most part, are not able to leverage the outcomes data ultimately produced for continuous improvement beyond the limited public data available. A more streamlined system that leverages federal labor market outcomes data would substantially improve quality while reducing burden.

Moreover, the current system does not provide sufficient opportunity to highlight the potential contributions of effective providers that could advance economic mobility. Innovative providers who seek to know and publicly release their outcomes data but do not already receive WIOA funds in a given state are unable to participate in the existing performance infrastructure and make their case for funding moving forward.

We call on the Department to build on the foundation it has already established, as well as an array of excellent state-led efforts. The current federal resource, TrainingProviderResults.gov, offers a starting point, but issues with missing data, data quality, and inaccessibility of data make it far less useful than it could be. At the state level, we believe providing national infrastructure can enable far more states to publish locally-relevant scorecards. The Department can help jurisdictions access national labor market outcomes data and provide a common technical framework that enables states to focus on developing locally-relevant tools, as opposed to reinventing the wheel in each jurisdiction.

I. Issues with the Present System

First, we discuss issues with the present system that have substantially limited its utility: missing data, data quality, inaccessibility of data, and infrastructure barriers.

A. Missing Data

TrainingProviderResults.gov is missing or has suppressed costs and outcomes data on a tremendous number of programs, as any user will quickly find. For example, an applicant starting their search from the Department of Labor headquarters' zip code of 22201 will find that only six of the first 30 programs reported alphabetically have any outcomes data available – and only two of those six programs report on employment and earnings outcomes as opposed to simply completion rates. Across the nearly 75,000 programs with data reported on TrainingProviderResults.gov, only 18 percent have any data available on median earnings two quarters after participants' exit. And while about 96 percent of programs have data available on participants' out-of-pocket tuition cost, only 5 percent of programs have any published data on average individual training account expenditures.

In a 2022 paper, Diego Briones and Sarah Turner of the University of Virginia analyzed TrainingProviderResults.gov data from Washington and Texas—two states with better-than-average reporting—and found that "[t]he proportion of missing data on outcomes across states is striking."[1] In Washington, for instance, 38 percent of ETPs had no completion rate data and 48 percent had no 2nd quarter median earnings data available. Data on programs not delivered by institutions eligible under Title IV of the Higher Education Act are particularly limited: In Washington, 76 percent of non-Title IV programs had no completion data available, compared with 25 percent of Title IV programs. It is simply not possible for any user—a prospective training participant, navigator, or policy analyst—to use the system and compare programs in a reasonable manner.

Although it appears that both small program sizes and limited years of data have contributed to this problem, Briones and Turner comment that "[t]he data, unfortunately, do not allow us to distinguish how these factors contribute to the missing data problem." While we recognize that states only began reporting this data for program year 2018, by September 2022, TrainingProviderResults.gov has still not uploaded data for program year 2021, nearly a year after states reported that data by October 2021.[2]

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[1] Briones and Turner (2022), "Performance Measures and Postsecondary Investments for Adult Students," in *Student Outcomes and Earnings in Higher Education Policy* at p. 57-92, American Enterprise Institute, https://www.aei.org/wp-content/uploads/2022/01/Student-Outcomes-and-Earnings-in-Higher-Education-Policy.pdf.

[2] According to a timeline outlined in the Department's Training and Employment Notice 8-21, https://www.dol.gov/sites/dolgov/files/ETA/advisories/TEN/2021/TEN_08-21.pdf.

Regarding data suppression, it is not clear exactly which rules ETA has applied and how they may have suppressed outcomes for small programs.[3] As we discuss below, recent research offers guidance on ways to roll up data across program years that could substantially improve transparency on program outcomes.

B. Data Quality

In addition, there are issues with the quality of the underlying outcomes data available. We appreciate the Department's continual efforts to strengthen validation of the data and to encourage participants to engage in data matching using administrative data, including efforts across states, and call on the Department to build on this progress moving forward.[4]

First, there is an ongoing issue with employment rate data quality. Briones and Turner's report notes that these data may not be trustworthy, "resulting in part from limited data and misalignment in the points of observation."[5] As Briones and Turner show, TrainingProviderResults.gov shows duplicate observations of training providers and it is difficult to understand which observation matches to which cohort; they also point out that the Department is aware of these issues. As the Department responded in a 2020 information collection regarding WIOA reporting through the Participant Individual Record Layout (PIRL), "Under the current collection, the denominators of the performance indicator cohorts do not align to the numerator cohorts, nor are they aligned to the WIOA reports submitted as a part of the PIRL reports submitted. This is not only out of alignment, but can result in scenarios where states report accurate counts that cannot be converted into accurate rates over 100%, which is not helpful to consumers."[6]

Second, it is not clear to TrainingProviderResults.gov users which median earnings data is reported. The data documentation appears to only include median earnings for *all* students, as opposed to WIOA participants alone, whereas other outcomes measured are reported both for all students and for WIOA participants alone where available. As the site describes in a footnote to program outcome pages, "While states generally have reported the 'all students' data they were able to collect, for some programs of study the "all students" data may be limited to only the WIOA students who received training through the program." It is not immediately clear why the site does not also report median

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[3] TrainingProviderResults.gov states only that the Employment and Training Administration (ETA) "applies suppression rules to the data before publishing." https://www.trainingproviderresults.gov/#!/about Our understanding is that the Department has access to the original, unsuppressed data as reported by states, per the Department's Training and Employment Guidance Letter No. 03-18, and as such can make its own suppression determinations: "All data, regardless of the ultimate application of suppression standards for the protection of PII, still must be reported to DOL to comply with the statute. States may provide additional information that they determine to be useful." https://www.dol.gov/sites/dolgov/files/ETA/advisories/TEGL/2018/TEGL_3-18.pdf.

[4] E.g., the 2016 joint guidance on data matching of performance data and recommending that states calculate wage and employment outcomes by matching data. See Training and Employment Guidance Letter No. 7-16, https://www.dol.gov/sites/dolgov/files/ETA/advisories/TEGL/2016/TEGL_7-16.pdf; and Training and Employment Guidance Letter No. 3-18 attachment 2. https://www.dol.gov/sites/dolgov/files/ETA/advisories/TEGL/2018/TEGL_3-18_Attachment_2_acc.pdf.

[5] See Briones and Turner at page 66.

[6] Departments of Labor and Education (2020), "Information Collection Request: Workforce Innovation and Opportunity Act (WIOA) Common Performance Reporting Summary of 60-Day Federal Register Notice (FRN) Comments and Responses," https://www.dol.gov/sites/dolgov/files/ETA/Performance/pdfs/Comments%20and%20Responses_Joint%20ICR.pdf

earnings specific to only WIOA participants, as that data is already collected in standard ETP program reporting.[7]

By comparison, a growing body of research in the higher education context demonstrates that earnings data from state-level data alone, as opposed to national-level estimates, may underestimate program outcomes. For instance, as a 2017 Department-funded study found, states' systems may provide a substantially different picture of outcomes than national data in regions where labor markets stretch across states–such as in New Jersey, which borders the New York and Philadelphia labor markets.[8] A 2020 analysis by the Urban Institute found that earnings estimates from in-state wage data tend to be lower than national estimates, particularly for colleges close to metro areas in a different state.[9] A 2019 analysis by the Census Bureau suggests that in-state estimates of colleges' earnings outcomes may be lower than national estimates (e.g., from the Longitudinal Employer-Household Dynamics program) because students who move out of state might be more likely to earn more than those who do not move.[10]

Third, the data on costs seems potentially suspect based on our review. For example, TrainingProviderResults.gov reports that a handful of programs reportedly receive nearly $100,000 per WIOA participant from individual training accounts—far more than we would expect any local board to expend. These outliers suggest additional data cleaning and review is necessary to catch potential reporting and calculation errors.

C. Inaccessibility of Data

Critically, the data available at TrainingProviderResults.gov has significant gaps that hamstring its usefulness for any audience, whether jobseekers or policymakers. Major issues include:

- The site only reports median earnings in the second quarter after participants exited the program, not even including the subsequent fourth quarter data the Department already collects through the ETA-9171 form—much less longer-term earnings data that could provide a better sense of long-run impacts. [11]
- There is no data regarding participants' demographics, in sharp contrast to the College Scorecard. However, the Department already collects this data through the ETA-9171 form (e.g., ages of participants, race/ethnicity). This data is essential to understand programs' impact. The U.S. House of Representatives Appropriation Committee's Fiscal Year 2023 report, for example,

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[7] See data element number 141 of the TrainingProviderResults.gov data dictionary, https://www.dol.gov/sites/dolgov/files/ETA/Performance/pdfs/ETA_9171_12.4.17.pdf.

[8] Davis et al. (2017), *Comparing State and National Approaches to Education and Training Program Scorecards*, IMPAQ International, prepared for the U.S. Department of Labor, https://www.dol.gov/sites/dolgov/files/OASP/evaluation/pdf/Comparing-State-and-National-Approaches-to-Education-and-Training-Program-Scorecards-Final-Report.pdf.

[9] Blagg and Washington (2020), *Which Dollars Get Measured? Assessing Earnings Metrics Using Data from Connecticut*, Urban Institute, https://www.urban.org/sites/default/files/publication/101637/which_dollars_get_measured_0_4.pdf.

[10] Foote et al. (2021), "Post-Secondary Employment Outcomes Technical Documentation," U.S. Census Bureau, https://lehd.ces.census.gov/doc/PSEOTechnicalDocumentation.pdf.

[11] Department of Labor, "ETA-9171: Data Element Definitions/Instructions," https://www.dol.gov/sites/dolgov/files/ETA/Performance/pdfs/ETA_9171%20PY%202022%20(Accessible)%20.pdf

noted that few federal or federally funded workforce training programs track outcomes by race and recommended “careful evaluation of disaggregated racial data.”[12]

- It is also difficult for users to have a sense of programs’ relative impacts and costs. The site does not report participants’ earnings before entering the program, limiting stakeholders’ ability to understand the true impact of a program (even recognizing the potential that some providers may cream participants). The College Scorecard, for instance, provides data comparing institutions to national midpoints for similar institutions; TrainingProviderResults.gov only provides comparisons to all programs nationwide. Moreover, TrainingProviderResults.gov’s interface buries cost data under an “Additional Data” option.
- The website provides only limited context specific to local labor markets. It is not possible for a jobseeker to understand, for instance, which professions are in short supply within their own labor market.

At the state level, several states have implemented useful tools to help jobseekers and navigators consider and compare outcomes from various workforce programs.[13] For instance:

- Washington Career Bridge provides users with data on the industry of employment for programs’ graduates, as well as statewide earnings and employment trends for jobs related to programs of that type.[14]
- Minnesota’s Career and Education Explorer tool offers jobseekers extensive data regarding demand for occupations, wages, daily work activities, required certifications, and the local cost of living specific to their region, as well as a direct link to job postings.[15] The tool also enables jobseekers to quickly find a list of relevant programs in their local area, including whether the program is WIOA-certified.
- New Jersey Training Opportunities portal provides particularly extensive performance data on workforce programs, including displaying earnings and employment data for participants up to two years post-exit, as well as in-depth costs data.[16] The site highlights programs that are in in-demand occupations as identified by the state’s Labor Demands Occupations List as those “that are expected to have a greater need for workers than there are qualified people to fill those jobs.” In addition, the site provides an array of data to help participants take advantage of programs, including bus and train routes, on-site childcare availability, and languages spoken by staff, as well as flagging programs that are particularly in-demand.

However, the quality and usefulness of these state-level resources varies dramatically.[17] For some states, it is difficult to even find the states’ Eligible Training Provider List, let alone a useful comparative

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[12] See page 22 of Report of the Committee on Appropriations (2022), *Departments of Labor, Health, and Human Services, and Education, and Related Agencies Appropriations Bill, 2023*, U.S. House of Representatives, https://www.congress.gov/117/crpt/hrpt403/CRPT-117hrpt403.pdf.

[13] See Vilsack and LaPrad (2022), *Data for an Inclusive Economic Recovery*, National Skills Coalition, https://nationalskillscoalition.org/wp-content/uploads/2022/05/FINAL-for-Web-Data-for-an-Inclusive-Economic-Recovery.pdf.

[14] https://www.careerbridge.wa.gov/

[15] https://apps.deed.state.mn.us/lmi/cpt/home

[16] https://njtrainingsystems.dol.state.nj.us/Search/SearchByOccupation.aspx

[17] While now out of date, for context a 2014 Department-funded report found that at that time, only five states had consumer report card systems available. Davis et al (2014), *Using Workforce Data Quality Initiative Databases to Develop and Improve Consumer Report Card Systems*, IMAP International, prepared for U.S. Department of Labor, https://www.dol.gov/sites/dolgov/files/OASP/legacy/files/IMPAQ_Scorecards_Report_2014-06-02.pdf.

resource. Given widespread challenges with technical capacity in state workforce agencies, as we discuss below, we believe that the unnecessary burden states face in linking and preparing data is a major reason there are not more high-quality resources available.

D. Infrastructure Barriers

While state-level workforce longitudinal administrative databases are essential, ultimately we believe that national linkages are also critical to adequately assessing and reporting on workforce development programs' participation, costs, and outcomes. This challenge has had serious consequences for innovation and effective use of workforce dollars–for instance, many of the providers with the strongest evidence of positive impacts on economic mobility have built their evidence base at significant cost and under substantial burden almost entirely outside of the WIOA system. In addition to the data quality issues we discuss above, a number of infrastructure considerations necessitate national linkages:

- While federal resources enable data sharing between states—for instance, the State Wage Interchange System (SWIS)—in practice it can be challenging to use those systems for anything beyond basic reporting. A 2019 report from the National Skills Coalition's Workforce Data Quality Campaign notes, "It's more difficult for states to use SWIS to conduct research and evaluation than it is to use the system for reporting. In order to use wage data for research and evaluation, each state from whom data is requested must consent to share it." Moreover, this data is generally difficult for other stakeholders such as providers to analyze granularly.[18]
- Outside of SWIS, state data sharing is dependent on direct agreements, posing substantial challenges for capacity. Today, only about 1 in 5 states have workforce data sharing agreements with other states for research purposes, according to a 2021 report from the National Association of State Workforce Agencies.[19] The survey also found that more than a third of states reported their staff research and data capacity as inadequate.
- As a 2020 Department-funded review of WIOA performance accountability standards found, "Title I respondents from two-thirds of states said that providers either could not or would not provide them with the required performance data—or the data needed to pull performance data—for multiple reasons," particularly with regard to non-Title I participants.[20] The Department must take action to address this issue, including making the process easier to navigate. As this 2020 report also notes, providing easier accessibility to data matching could be a strong solution: "Nine states persuaded providers of the value and feasibility of collecting participant Social Security numbers (SSNs) and matched those numbers with wage data to calculate performance results. Four states and 10 local areas worked closely with providers to assist them with filing applications and submitting performance results. And, four states coordinated with state and national higher education agencies to obtain performance data."
- The current system makes it incredibly difficult for workforce development providers that do not receive WIOA funding to assess and report on their outcomes, even when they seek to do

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[18] Leventoff (2019), "State Wage Interchange System: Better data for stronger workforce programs," National Skills Coalition, https://nationalskillscoalition.org/wp-content/uploads/2020/12/NSC-SWIS-Booklet-MR-1.pdf.

[19] Chocolaad et al. (2021), *Evidence-Building Capacity in State Workforce Agencies: A COVID-19 Pulse Survey*, National Association of State Workforce Agencies, https://www.naswa.org/system/files/2021-03/evidencebuildingcapacityinstateworkforceagencies-acovid-19survey.pdf.

[20] Mack and Dunham (2020), *Performance Accountability, Eligible Training Providers, Labor Market Information, and Evaluation Requirements Under WIOA*, Mathematica Policy Research, prepared for U.S. Department of Labor, https://mathematica.org/publications/performance-accountability-eligible-training-providers-labor-market-information-and-evaluation.

> so, stifling innovation and making it difficult for effective organizations to demonstrate their value. Many of these organizations have found it difficult to work with states, which are already overburdened with regard to WIOA reporting requirements. One America Forward Coalition member, for example, has explored paying credit reporting agencies to assess outcomes for their participants.

We recognize that WIOA bans the development of a "national database of personally identifiable information on individuals receiving services under title I or under the amendments made by title IV."[21] However, we believe that providing access to national data linkages would not run afoul of this ban—as the College Scorecard had accomplished in the Higher Education Act Title IV context despite a similar ban.

II. Recommendation: Create National Employment Metrics System

We appreciate the Department's recent efforts to address this challenge, including the ongoing pilots in Indiana and Virginia. Moving forward, we urge the Department to move ahead with planning for a new system leveraging linked federal administrative labor outcomes data on participants' earnings and employment through a partnership with other federal agencies. Potential partners include the Internal Revenue Service (IRS), with regard to longer-term annual earnings and employment data; the Department of Health and Human Services Administration on Children and Families, with regard to quarterly earnings data in the National Directory of New Hires; and the Census Bureau, which holds quarterly earnings reported by state unemployment insurance systems and annual income data from the IRS.

We recommend that the Department take lessons from the College Scorecard, while recognizing the necessity of tailoring resources to local contexts and needs in partnership with states, localities, tribal governments, and other key stakeholders. We think it makes sense for the Department to publish these data, building on the existing investments in TrainingProviderResults.gov, while tailoring the system's output to support states, tribes, and local jurisdictions and their partners in leveraging these data for locally-relevant systems.

As a first step, we suggest that the Department partner with a handful of states and workforce development providers to pilot this model, leveraging linked federal administrative data on participants' earnings and employment through a potential partnership with other federal agencies. We also urge the Department to continue its efforts to engage the field regarding the system's design, both in terms of its ultimate utility and technical aspects, and to proactively seek participation among the innovative providers that the current WIOA system does not sufficiently support.

As the Department develops this system, we also strongly recommend it identify and leverage funding sources to support its internal capacity, as well as that of partners such as pilot States and providers. In addition to leveraging internal sources of funding, we suggest that the Department prioritize funding for related efforts in forthcoming grant cycles for the Workforce Data Quality Initiative grants.

Once complete, we propose that design elements of this new national metrics system should include the following elements:

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[21] See Workforce Innovation and Opportunity Act Sec. 501(b).

Security and privacy. Security and privacy should be the starting point for any new data linkage system. We propose that the Department leverage the most up-to-date, secure privacy-protecting technologies to perform data linkages:

- *Secure linkages leveraging cutting-edge privacy-protecting technologies.* States and/or participating organizations would send participant data (primarily Social Security Numbers) to one or more federal agencies that hold income and earnings data in a secure manner, prospectively in partnership with a qualified data intermediary. These federal agencies and/or intermediaries could merge participant data with income and earnings data and report out aggregate employment statistics (e.g., average earnings of a participant cohort one year after program completion). Federal agencies that fund the grants would not need to touch the data that would be merged.
- *Qualified data intermediaries.* One or more nonprofit data intermediaries that meet federal privacy and security standards could prospectively facilitate the linkage between participating organizations and federal agencies. These intermediaries would: (1) set up standardized data-sharing agreements for use by federal agencies that hold employment data on individuals (i.e., Treasury, ACF, Census) and grantees or providers that hold participant data; (2) format participant data to be merged with federal tax and earnings data; and (3) send the formatted data to data-holding federal agencies to create aggregated outcome statistics. States would not necessarily need to provide participant data if providers are able to submit these data directly to the intermediary.

Expanded data availability. As we detail above, it is essential that this system dramatically expand the availability of data so jobseekers, navigators, government agencies, policymakers, and other stakeholders across the system have information they need to make good decisions:

- *Strengthen data reporting.* The proportion of programs with no earnings or employment data available renders TrainingProviderResults.gov largely unusable for jobseekers looking to identify programs likely to lead to sustainable careers. It seems unlikely that the incredible number of programs with no published data in many key fields, such as costs and earnings, is solely due to suppressed cells because of small n-sizes. The Department must act to ensure all ETPs are in fact reporting as required under WIOA, including for outcomes on all participants.
- *Reduce number of programs with suppressed data.* We also strongly recommend that the Department reconsider its suppression rules in light of new techniques to report on programs with relatively low n-sizes. While the Department's guidance has discussed principles around suppression, we are not aware of particular methodology that is public and believe implementation varies across states. The State of Wisconsin, for instance, reports outcomes for programs with n-sizes above 7.[22] Last year, the Urban Institute published an authoritative report laying out several solutions to n-size challenges in the context of Higher Education Act programs.[23] These recommendations include pooling multiple cohorts' data and rolling up small programs delivered by providers into a higher Classification of Instructional Programs (CIP) level. Given the efforts the Department has undertaken to align WIOA program reporting in

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[22] Wisconsin Department of Workforce Development (2020), "Wisconsin's ETP Reporting and Publishing Procedure," https://dwd.wisconsin.gov/wioa/policy/07/07.7.2.htm.

[23] Blagg et al. (2021), *The Feasibility of Program-Level Accountability in Higher Education: Guidance for Policymakers*, Urban Institute, https://www.urban.org/sites/default/files/publication/103634/the-feasibility-of-program-level-accountability-in-higher-education.pdf.

partnership with the Department of Education, these recommendations are equally applicable in the WIOA context. Similarly, the National Center on Education Statistics has published extensive guidance on setting n-sizes in the context of K-12 accountability reporting.[24]

- *Report on participant demographics.* This new system must report on the demographics of programs' participants to enable the most basic analysis of whether and how WIOA programs are serving participants equitably. The College Scorecard, for example, provides data on participants' race and ethnicity; socioeconomic status as measured by Pell grant receipt; and enrollment status. As we note above, the Department already requires ETPs to report on demographic data such as age, race/ethnicity, and barriers to employment (e.g., low-income status, homeless individuals or runaway youth). It is essential to report this demographic data to assess programs' outcomes in the context of their populations served–potentially, if necessary, rolled up across multiple program cohorts– and to do so in alignment with common WIOA definitions, such as the definition for "individuals with barriers to employment." If that reported data is not trustworthy, the Department must act to ensure its quality.
- *Expanded reporting on labor market outcomes.* As a starting point, the Department should publish the fourth-quarter earnings data that ETPs are already required to report—only second-quarter earnings data is available today. Moreover, the Department should take advantage of federal data linkages to expand the scope of reporting beyond a single year—at least three years post-exit—to offer a better assessment of whether ETPs are helping their participants achieve economic mobility. New Jersey's scorecard, for example, already provides earnings and employment data for participants up to two years post-exit. DOL should also consider providing information about participants' incomes *before* entering the program to provide a better estimate of programs' impact, which national labor market outcomes data could help provide.
- *Support program integration*. We also strongly recommend that the Department build in ways to support integration of WIOA with other federal workforce funding streams and benefits programs, such as Reemployment Services and Eligibility Assessment (RESEA) services, Supplemental Nutrition and Assistance Program (SNAP), housing benefits, and Temporary Assistance for Needy Families (TANF). This data would be instrumental to facilitate case management and provide a broader understanding of the participants programs serve. Currently, the lack of integrated data systems is a major barrier to delivering effective services, blending funding streams, and supporting continuous improvement.[25]
- *Enable participation from interested non-WIOA workforce development providers.* In many jurisdictions, the process to become an ETP is overly cumbersome and lacks sufficient consideration of programs' current outcomes before adding them to the list—it is too difficult to distinguish low-performers from innovative, highly-effective programs. The Department should enable workforce development programs not currently participating in WIOA to participate in reporting, in order to assess their program outcomes through this new system and demonstrate their value. A number of America Forward Coalition members have actively sought to assess their labor market outcomes despite considerable effort and expense required – a sharp contradiction from the many ETPs that appear to have submitted data that is incomplete.

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[24] Seastrom (2017), *Best Practices for Determining Subgroup Size in Accountability Systems While Protecting Personally Identifiable Student Information*, Institute of Education Sciences, https://nces.ed.gov/pubs2017/2017147.pdf.

[25] See Dunham et al. (2020), *Change and Continuity in the Adult and Dislocated Worker Programs under WIOA*, Mathematica Policy Research, https://www.dol.gov/sites/dolgov/files/OASP/evaluation/pdf/ETA_WIOAStudy_AdultDW.pdf.

Improve usability for key stakeholders. The new system should include components that provide substantial value for all participants in the system:

- *Local labor market information*. The Department should provide resources to help states, tribes, and local boards tailor data resources to local needs by providing relevant labor market information (LMI). This effort can build on the example of models like Washington State's ETP tool and Kentucky's interactive dashboard for local workforce areas,[26] leveraging the Department's extensive LMI resources.
- *Support for continuous improvement.* In addition to helping participants and navigators assess programs, the Department should provide complementary technical assistance to help board and workforce providers make effective use of these new data resources through ongoing continuous improvement activities, building on its existing TA resources. We need to ensure that this system supports not only accountability and transparency, but also active improvement.
- *Pilot value-added measures.* Moving forward, the Department should also pilot value-added measures that consider not just participants' outcomes but their growth as a result of participating in their program, helping to counteract incentives for providers to "cream" participants. In the higher education context, emerging research shows that value-added calculations are essential to avoid conflating provider quality and participant characteristic – given the barriers many WIOA participants face, this approach is even more important in the workforce context.[27]
- *Research access.* Finally, the Department should provide for a process to enable researchers to access the system in a secure, privacy-protected manner. Despite the Department's considerable investments in research on WIOA, the literature is shockingly thin on questions around quality, value, and equity in the system. Emerging technologies, such as those developed by the Coleridge Initiative, are now available to provide for research access while minimizing potential privacy and security risks.

We appreciate the opportunity to respond to this RFI and would welcome a meeting to discuss our recommendations further. We look forward to continuing to support the Department's critical work in this area.

Sincerely,

America Forward
Colorado Equitable Economic Mobility Initiative (CEEMI)
Data Quality Campaign
[redacted]
Per Scholas
Project QUEST
REDF (Roberts Enterprise Development Fund)
Results for America
Social Finance
Third Sector Capital Partners
Year Up Inc.

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[26] Kentucky Workforce Dashboard, https://kystats.ky.gov/latest/KWD.

[27] See Blom et al. (2020), *Comparing Colleges' Graduation Rates*, Urban Institute, https://www.urban.org/research/publication/comparing-colleges-graduation-rates.

Relationships First and Always: A Guide to Collaborations with Indigenous Communities

An EDI Community Paper to the 2020 Planetary Science and Astrobiology Decadal Survey 2023—2032

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This paper is submitted as part of a collaborative effort organized by the Equity, Diversity, and Inclusion Working Group (EDIWG), a cross Assessment Group (AG) committee.

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Abstract: Relationship building between Indigenous communities and scientists must be the foundation of all collaborations. Agencies should fund initiatives in relationship building and create an Office of Tribal relations as a supporting framework (§ 4). Guidelines for relationship building are provided (§ 5).

1. Introduction

Here in the US, we are in the midst of a great national reckoning. We have an extraordinary opportunity to acknowledge our roles in structural racism, reexamine biases, and engage in co-creating initiatives that honor the lives and livelihoods of Black, Indigenous, and People of Color. Every aspect of our lives remains deeply rooted in colonialism, which by definition marginalizes and eliminates Indigeneity. By applying a lens of racial justice and the sharp focus of history, we can examine how Western/Eurocentric cultures have interacted with Indigenous communities and, looking forward, imagine how they can coexist and thrive.

This document outlines recommendations for working with Indigenous communities under the knowledge that **relationship building with the communities is first and foremost the foundation upon which all collaborations should be centered**. This includes defining a series of wise practices for collaborating with Indigenous communities, in planetary science/astrobiology and across all fields of Science, Technology, Engineering, and Math (STEM). These wise practices apply whether the outputs are educational programs, research collaborations, or other endeavors. The onus is on the Western scientific community, through a foundation of relationship and trust, to understand that Indigenous and Western knowledge systems can reflect, resonate with, and reinforce one another, and can affirm and build upon each other when treated as equally valid, valuable, and vital.

2. Background/Findings

2.1 Historical Context and Current Approaches. The history of interaction between Western and Indigenous cultures is an ongoing narrative of colonialism, genocide, land theft, broken treaties, assimilation, erasure, extraction, and appropriation. The US is home to 574 federally-recognized, culturally-unique Indian Nations (NCAI, 2020), yet mainstream American consciousness homogenizes the individual nature of Indigenous communities. Settler-colonialism established practices of extraction and appropriation of Indigenous lands, cultures, and knowledges. Within research contexts, Indigenous peoples were objectified for purposes of study. These legacies remain and continue to inform research practices that are disrespectful, uneven, and inequitable.

For science and education, this narrative is defined by Western cultural hegemony and cognitive imperialism in which Western pedagogies and values dominate and those of Indigenous knowledges are marginalized. These approaches have resulted in lasting impacts on who is recognized as legitimate, identified as expert, and allowed to participate in the scientific enterprise broadly, and have defined the experience of many BIPOC scholars (Blanchard, 2020).

In educational programs, Indigenous youth often receive STEM instruction from non-Native educators in one of two ways: without a cultural component (“STEM-only”) or with one that is presented secondarily (“STEM-first”). These scenarios reemphasize the imbalanced power dynamic of Western dominance. The absence of proper education on Indigenous histories and cultures has led to several states mandating the inclusion of Indigenous content within school curriculum. Scenarios wherein non-Native educators attempt to convey Indigenous content in the absence of Indigenous voice or participation have increased. Much of the time, these efforts at best misrepresent and at worst tokenize and continue to minimize Indigenous culture (Williams, 2020). In most cases, Western pedagogies prevail (Cote-Meek, 2014).

The story is similar with scientific research conducted by Western scientists on the lands/waters/plants/animals/skies of Native communities. Indigenous knowledges are rarely sought and generally regarded as unscientific and therefore of little value. When Indigenous knowledges are included, such as in climate studies, the vast majority (87%) practice an extractive model in which outside researchers use Indigenous knowledges with minimal participation or decision-making authority from communities who hold them (David-Chavez & Gavin, 2018). Inclusion of community members in the research is typically relegated to the purveyance of services such as being a local guide or transporting gear vs. as a knowledge holder or cultural authority. Occasionally, young people may be included in the research in an internship capacity, and frequently there is an offering of a lecture about the science for the community. Data and samples are often extracted without community input, spiritual permission, or reciprocity. Data sets typically fail to include proper provenance on whose lands, waters, or skies they were collected. Publications resulting from this research rarely include acknowledgement, let alone co-authorship (Anderson & Christen, 2019). When the research is completed, there is typically no ongoing relationship or connection.

When using Indigenous words as names for celestial bodies (Tiscareno, 2020), the hubris of assumptive right of access by the Western "discoverer" to the cultural/intellectual property of the language is starkly apparent, even when the intention may be to honor the Indigenous culture from which the word is taken. In most cases, the word is simply appropriated, without asking permission from cultural leaders—the extractive "take" scenario. In some cases, permission is sought and granted—the "ask and take" scenario. This scenario, however, without the presence of relationship and trust between the scientists and the Native community, is an "ask, take, and leave" scenario. Co-discovery and co-authorship are all but unheard-of.

2.2 Indigenous Knowledge. Despite this, Indigenous communities past and present are inherently 'scientific.' Indigenous knowledges and languages hold profound understandings of the nature of the physical Universe and reflect sophisticated cosmologies. Indigenous technologies have been and continue to be made possible by a deep knowledge of what today are called physics, mathematics, and engineering.

Indigenous communities are the experts of their lands/waters/plants/animals/skies, as reflected in longitudinal (millennia), high-resolution data sets (David-Chavez & Gavin, 2018). These data sets are intersectional across many Western scientific disciplines, including astronomy, geography/geology, climate and environmental science, oceanography, ecology, biology, and agriculture, reflecting the interdisciplinary aspirations we hold for the sciences today. Indigenous methodologies for data curation and knowledge dissemination may differ from those of Western science, yet are no less accurate or valid.

3. Motivations for Relationship-Building

Structural racism is a societal problem. It has been created by those in power based on White/Eurocentric values and philosophies, and those who have benefitted most have the most responsibility to make change. The solution lies in working together and shifting the focus from benefit sharing to power sharing. Relationship and trust are outcomes of sharing power, not precursors to it.

The need for relationship and trust is reflected in Indigenous metaphysics and worldviews of the Universe as a place of interconnectedness, interdependence, and relationality (Littlebear, 2020; Deloria, 1973; Cajete, 2000). Everything flows from relationships, all are co-creators, all are responsible for one another, and reciprocity is the norm. Ideal relationships will continuously honor the sovereignty and self-determination of all Native Nations, Tribes, Bands, and communities, and celebrate each one as a unique entity. Ideal relationships embody the values of humility, gratitude, and respect at the center of Indigenous culture. **The purpose of relationship and trust is to facilitate co-creativity and service.** In this task, motivations must be clear. There is much talk about the motivation for Equality, Diversity and Inclusion (EDI) efforts being driven by the fact that diverse teams produce more innovative results. However, there are better motivations to be had:

> 'Diverse perspectives yield the best science' is a true statement, but it's one that commodifies the lived experience of marginalized people by reducing them to their contributions to productivity. It's a capitalistic framework that shirks the basic truth that cultivating a field where the norm is respecting the humanity and validity of all people is the right thing to do for no reason other than that it is right (Ivory, 2020).

No other motivations are needed. We co-create with Indigenous communities because it is the right thing to do.

4. Recommendations for Agencies and the Scientific/STEM Education Community

Our key recommendation is for agencies, scientists, and educators to engage in relationships and build trust with Indigenous communities, so that when agency funding is being considered for research collaborations and educational programs involving Indigenous communities and their lands/waters/plants/animals/skies, partnerships are at the ready and efforts can be co-creative. In the absence of relationship and trust, activities risk being *STEM-only* or *STEM-first*, failing to center community needs, places, perspectives, pedagogies, and cultures, and reinforcing damaging power dynamics.

We recommend that agency solicitations reflect this crucial component of building relationship and trust and provide funding for those activities directly. **We recommend agencies design a special two-part solicitation architecture that begins with a solicitation focused exclusively on investment in relationship-building activities**, allowing for flexibility based on the unique context of each Native Nation, Tribe, Band, or community involved and the amount of time needed (3-5 years min). The second part is a solicitation for programs and collaborations when the relationship has reached a point that parties are ready to start co-creating or co-researching. This part must be flexible, as it cannot be known at the beginning of the process exactly when the need for these funds will arise. Relationships and collaborations need the flexibility and support to progress at "the speed of trust." Agencies need to be prepared to continue investing in these collaborations for the long-term.

To mobilize individual or small teams of scientists to engage in relationship building and eventual programs and collaborations with Indigenous communities, **we recommend agencies implement a small grants program for awarded investigators**. Even ~\$10-20K could catalyze a new relationship, and/or enable scientists to participate in and add value to the activities of other teams that are more advanced in their programs and collaborations.

To ensure co-created programs and collaborations are progressing authentically and appropriately, **we recommend agencies stand up an Office of Tribal Relations**. Such an Office could manage and coordinate all the tribal-related work going on in the agency or parts thereof, helping to avoid duplication and enhance connectivity. It could administer funding to supplement ongoing activities and/or respond to emerging opportunities. Staff would be experienced and fluent in the dynamics of these relationships and the nuances of the work. The

Office could serve as the agency's single touchpoint to Indigenous communities, as current paradigms create confusion with numerous programs, offices, and personnel. It can serve the agency by ensuring their policies and practices are consistent with Indigenous communities' needs, thoughts, and desires on research and education. Most importantly, the Office's main goal would be to provide care, guidance, support, networking, and professional development to all, and serve to uplift and center the voices of Native employees of the agency.

As researchers, educators, and institutions become more open to developing relationships with Indigenous communities, research and training on the issues of cultural and intellectual property, Indigenous data sovereignty, and processes of knowledge management should be foundational for any program or collaboration with Indigenous communities to ensure Indigenous knowledges are not being misappropriated (Anderson & Hudson, 2020).

5. Guidelines for Building Relationships and Trust

The following steps are intended to help guide the process of relationship building for citizens of the planetary science/astrobiology community. It must be noted that each Indigenous community is a unique entity; the process for relationship building with one will not look the same with another.

5.1 Before Initiating a Relationship. Endeavor to learn as much as possible about the history and culture of the Indigenous community being approached, seeking primary sources of information and practicing healthy critique otherwise. This includes honoring Indigenous communities' knowledges about their places and the cosmos. Understanding the importance of Elders in the community is essential to understanding the community as a whole. Most importantly, self-reflect and prepare for an ongoing effort to sustain a lasting relationship; such efforts take time. If upon reflection it is found that the initiator is not prepared for the responsibility of relationship building, co-creation, and service, **we recommend suspending the initiative and returning to the idea only when such a commitment is feasible**.

5.2 Initiating a Relationship. Initial communications should not carry an "ask," such as attending an event you're hosting to give a performance, cultural activity, or blessing. Such an ask is extractive, disrespectful, and offensive if not done in the context of relationship and trust. Do not approach an Indigenous community with your research project or educational program set. Ensure your ideas percolate with those of your Indigenous partners. **Let go of your need to be the expert**. Prioritize the needs and vision being articulated by the community. Begin with an introduction, and clearly articulate a desire to truly know one another and one day co-create and serve the community. If such an invitation is received and supported, begin the process of getting to know one another. If invited, visit the community in their space, bringing your whole self to such meetings, ready to communicate with and learn from each other.

Gift-giving is an important gesture when visiting a community. If a meeting occurs at an institution instead of on Indigenous land, the host should still offer a gift and celebrate the gathering by providing food. **Listen more than you speak**. Resist any urge to control or drive the conversation. Be humble in your role as guest and learner and offer gratitude for the opportunity to receive knowledge. Finally, always follow up with notes of gratitude, recognizing that the Indigenous community is under no obligation to commit to a relationship with you.

5.3 Building Relationships. Once a relationship is started, be prepared to spend the time necessary to cultivate the relationship consistently and indefinitely. Create and hold space for the community to lead and direct. Prioritize the Indigenous community as a source of credible information. Ensure the needs of the community shape the shared vision for the collaboration. Be flexible if the needs of the community change. Trust is the key. If trust is not present or is lost, the relationship is lost. If you say you are going to do something, do it.

Share of yourself. Send notes/emails and making calls to the community to ask how people are doing. Show up to the community if there is an emergency and/or help organize a local response. If you become aware of a community-wide or public event, make sure to attend, and while doing so, be willing to engage in the community fully. Ensure the relationship with the community is not simply a scientific endeavor for your institution.

5.4 Ensuring Lasting Relationships. Together with your Native partners, it may be required to seek blessings and permission from tribal leadership (Tribal Council or other governing body) to continue the relationship. Doing so may result in Resolutions of Support, Memoranda of Understanding, and/or official commitment of resources. Follow your partners' leadership in how to move forward in this process. Ensure the community/tribe is properly represented in the grants you write together (PI, Co-PI, Co-I, etc.). Budget to compensate individuals for their expertise at the same rate as non-tribal consultants. Support tribes in enacting Indigenous Data Sovereignty, the right of Indigenous Peoples to self-determine the access, use, reuse, and attribution for their knowledges, information, and data (Snipp, 2016). Ensure relationships and contributions are properly identified in publications and reports, including co-authorship, acknowledgements, and/or using tools that clarify Indigenous interests in the research, data, and collected traditional knowledge (Anderson & Hudson, 2020).

If plans change from the institution or if there is a job change or retirement, plans need to be made in advance to ensure that relationships and collaborations continue. Include many members of your institution/scientific community in the relationship. This will safeguard the relationship that was built and maintain trust.

6. Impacts: Hallmarks of Healthy Programs and Collaborations

6.1 Privileging Indigenous Knowledges in Educational Collaborations. Bringing Indigenous culture into the classroom to improve student learning is important (Reyhner, 2015), and it matters significantly *how* it is done. In co-creating educational opportunities for Indigenous communities, interweaving cultural traditions, arts (STEM-to-STEAM), language, and community partnerships is key in order to provide authentic service (Lopez et al., 2013; Walkngstick & Bloom, 2013). Centering Indigenous language in learning environments is imperative for Indigenous students' sense of identity and academic success (Reyhner, 2017).

Reframing STEM education for Indigenous youth from a conversation about their achievement and survival in a Western world to one about the vitality of community and sustainability requires that we actively reconfigure what counts as science learning and who is teaching it (Bang, et al., 2009). Representation and role modeling by Indigenous leaders and educators has significant effects on Native learners' sense of belonging (Covarrubias, 2015). Indigenous knowledges must be taught by Indigenous educators using Indigenous pedagogies, *before* the Western science component is offered. In this way, Indigenous science is the lens through which corresponding Western STEM concepts are shared and viewed. Indigenous learners then become grounded in Indigenous science and in the understanding that their culture, and they as part of that culture, are inherently scientific. They understand that learning Western science can flow naturally for them and that they, too, may want to pursue becoming an Indigenous scientist. This has lasting implications for the diversity of the STEM workforce, and more importantly, for Indigenous youth and communities towards healthy social, cultural, and economic lifeways.

Numerous examples demonstrate how this balance may be achieved, including but not limited to: The Loololma Model (Gilbert, 2011); The *ašiihkiwi neehi kiišikwi myaamionki* curriculum (McCoy et al., 2011); NASA and the Navajo Nation (Bartels, 2019; Indian Country Today, 2016; Barney-Nez et al., 2016); Haida Geoscience Curriculum (Smythe, 2019); Native Skywatchers (Lee, 2020); Arctic and Earth SIGNs (Sparrow, 2020); Sharing the Skies (Maryboy & Begay, 2020), ‘Imaloa Astronomy Center (Kimura, 2020), and many, many more.

6.2 Research Collaborations between Western Scientists and Indigenous Communities, Lands, Waters, Plants, Animals, and Skies. David-Chavez and Gavin (2018) lay out levels of community participation in a spectrum from Contractual to Indigenous (see Figure 1), and provide guidance for responsible research practices to achieve a vision in which science is no longer complicit in continuing the legacy of colonialism. We envision a future for research collaborations wherein Western scientists do not consider a place (land, water, or sky) to become their field site or study site without first forming relationship with the Indigenous community to which the wellbeing of that place has been entrusted, without first seeking permission to be a guest in that place, without first working closely with the community to ensure the research will be co-conducted, and carried out for the health of the place and in service to the goals of the community.

Contractual	Consultative	Collaborative	Collegial	Indigenous
Community members contracted to perform tasks, researchers make all decisions	Community members asked for opinions and consulted, decisions made by researchers	Community members and researchers work together, researchers have primary authority over the process	Community members and researchers work together, community members have primary authority over the process	Process is centered in Indigenous value systems & historical context, community members have authority over the research process

Figure 1. From David-Chavez, 2018: Scale for assessing levels of Indigenous community participation based on who has authority over the research process.

Robin Wall Kimmerer offers metaphors of autonomy and co-existence between the two knowledge systems that compromises the integrity of neither. With the “Three Sisters Garden,” she describes a system of knowledge mutualism, with Indigenous knowledge as the corn, the elder knowledge, the intellectual scaffold which guides the scientific knowledge, the beans, which enrich the symbiosis (Kimmerer, 2020). The squash creates a climate for multiple species of knowledge to grow, and she adds a fourth sister–us–to tend the whole garden. In this paradigm, a research priority is identified: models of mutually beneficial relationships between land and people based on Indigenous science. Working in this way opens up pathways to reconciliation (Littlebear, 2020) and restoration.

Whether it is weaving, braiding, or integrating, when the knowledge and wisdom resident in both Indigenous and Western STEM are brought together into collaborations and programs, there are undoubtedly profound and lasting impacts. **None of this is possible without the foundation of relationship and trust.**

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Initial Pilots to Demonstrate Feasibility of a Statistical Query Service for Administrative Tax Data

August 2022

Using modern technology, privacy-protected data-linkage mechanisms modeled after The College Scorecard, and rigorous research and statistical methods, it is now possible — under current law — to measure earnings, employment, and tax outcomes by linking individual-level data held by government agencies, non-profits, and private sector organizations with federal tax data held by the Internal Revenue Service. This project will demonstrate how to set up data sharing agreements, link data using privacy-protected methods, conduct statistical analyses, and generate and disseminate aggregated privacy-protected statistics on policy-relevant outcomes.

While the United States Treasury and Internal Revenue Service possess unparalleled administrative federal income tax data, it is not possible for these institutions to set up multiple data sharing agreements and manage numerous partnerships. Given these difficulties, this project will facilitate projects by establishing data intermediary services at Georgetown University's Massive Data Institute (MDI). These data intermediary services will cover the following "end-to-end" assistance for both the US Treasury/IRS and external partners:

- Developing all necessary data sharing agreements
- Data cleaning, standardization, and preparation for secure transmission to IRS
- Merging partner data to administrative tax data within IRS computing environments
- Data analysis to identify useful, policy-relevant queries, with disclosure avoidance plan to generate public statistics on employment, earnings, and filing behavior
- Development of a private query service to produce publishable statistics from a designated set of queries to satisfy evidence building needs from IRS partners
- Training internal staff for privacy-protected data linkages and aggregated statistics, data analysis, and presentations of results
- Dissemination of process innovations across federal, state, and local government agencies and nonprofit organizations, and other public policy institutions

This project will implement multiple pilot projects that will demonstrate these data intermediary services. The pilot projects will highlight common interests in the following areas:

1. Federal Tax Administration and Safety Net Modernization
2. Federal Tax Administration and Workforce Development
3. Federal Tax Administration and K-12 School Finance Data Modernization

While these pilots and partnerships will provide academic and policy-relevant insights into interventions that impact key economic outcomes, the project's greatest potential for impact comes from its scalable process innovations for accessing federal administrative data for aggregated privacy-protected statistics on earnings, employment, and tax outcomes. In particular, the project will specifically document each step for implementation with the explicit goal being that these data sharing agreements, privacy-protection tools, and process innovations serve as templates for numerous agency staffs and future projects at a national scale.

The details of the pilot projects are as follows:

1. Federal Tax Administration and Safety Net Modernization Pilot project with the Virginia Department of Social Services

The Earned Income Tax Credit (EITC) has grown to become the largest cash-transfer, anti-poverty program in the United States. Since this program is a federal tax benefit, it is administered entirely by the United States Internal Revenue Service, and it is entirely separate from other critical safety net programs that are administered through state and local governments. This leads to critical gaps in social safety net programs that undermine their effectiveness in reducing poverty. For example, many SNAP (food stamp) recipients may not receive (EITC) benefits because they don't have access to tax filing assistance, and as a result, they may be more likely to remain dependent on SNAP assistance for longer rather than moving toward economic self-sufficiency. Data linkages could address these gaps so that social safety net programs can be modernized and reinforce one another.

To demonstrate these ideas, Professor Manoli will work with collaborators at the US Treasury/IRS and the Virginia Department of Social Services (VDSS), which administers public benefit programs including, SNAP, TANF, Medicaid, and child support. This pilot will be based on merging individual-level data from Virginia state government agencies to federal administrative tax data at the IRS. This merged data will be used to create aggregated statistics that help integrate and modernize social safety net programs:

- *What fraction of SNAP, TANF, and Medicaid recipients file tax returns and receive Earned Income Tax Credit (EITC) and Child Tax Credit (CTC) benefits?*
- *What are earnings, employment, and tax filing patterns before, during, and after receiving SNAP, TANF, and/or Medicaid benefits?*
- *What are earnings, employment, and tax filing patterns before, during, and after participation in mandatory or optional education and training programs?*
- *How much does tax outreach and tax preparation assistance from VDSS and Code for America improve tax outcomes and increase economic mobility?*

While this initial pilot is with one state government agency, the project will work to scale this pilot so that other state and local governments can participate in a "tax network." With this network, multiple state and local government agencies will be able to carry out tax outreach and understand earnings, employment and tax outcomes for their clients.

2. Federal Tax Administration and Workforce Development:
Pilot project with the Virginia Community College System, Ivy Tech Community College in Indiana, the Education Design Lab, Merit America, Per Scholas, and Year Up

Community colleges and sectoral training programs provide numerous education and training programs to students just after high school and to other adult learners and non-traditional students. However, it is difficult to understand which training providers and community college programs may serve low-income individuals and which may be effective at improving economic outcomes because there is a lack of data connecting participants with important economic outcomes.

In this pilot, Professor Manoli will work with collaborators at the US Treasury/IRS and the Virginia Community College System, Ivy Tech Community College in Indiana, the Education Design Lab, Merit America, Per Scholas, and Year Up. These education and training organizations have provided credited and non-credited courses and programs for thousands of low-income students, but they lack data on employment, earnings, and tax outcomes for participants. This pilot will merge individual-level participant data from these education organizations to federal administrative tax data. This merged data will be used to create aggregated data and answer questions that are critical for education policymakers:

- *What courses and programs serve low-income students?*
- *What courses and programs are associated with increases in employment, earnings, and tax outcomes for participants? Do any education and training courses or programs increase earnings beyond EITC eligibility thresholds?*
- *How do tuition costs, credit constraints, child care, and other potential barriers affect participation in education and training programs?*

- *What is the effect of outreach on take-up of sectoral training? What are the effects of financial stipends, child care assistance, rental assistance, or other assistance to overcome barriers on participation in sectoral training programs?*

Efforts to scale this initial pilot will be essential for ensuring that multiple training providers and community college programs around the country can understand their participants' backgrounds and outcomes and improve their education and training programs.

3. Federal Tax Administration and K-12 School Finance Data Modernization
Pilot project with the Virginia Department of Education

It is critical for education policymakers to know which schools serve low-income students since this information can play a critical role in determining school funding. Traditionally, many state and local K-12 education agencies have relied on free-and-reduced-price lunch measures to identify low-income students, but these measures were not designed to measure income and were intended for nutritional purposes. As a result, current measures of school poverty provide an incomplete understanding of poverty within and across schools. Linking data from K-12 public education systems to measure student household income and creating aggregated statistics would address these shortcomings.

To address these issues, Professor Manoli will work with collaborators at the US Treasury/IRS and Virginia Department of Education (VDOE), which administers K-12 public education systems in Virginia. This pilot will merge individual-level student data from VDOE to administrative tax data to measure family income of students' income and create aggregated statistics for each school. These aggregated statistics will answer critical questions for policymakers:

- Which schools have higher fractions of low-income students? How would the distribution of school spending change if it were based on student family income instead of free-and-reduced-price lunch measures?
- For each school, what fraction of public-school students in Virginia are claimed as dependents on filed federal income tax returns and receive EITC and CTC benefits? How do these fractions and distributions of student income vary across schools? How much income segregation is there across public schools versus neighborhood income segregation?

Professor Manoli will work to scale this pilot by partnering with other state K-12 agencies to produce similar aggregated statistics for schools across the United States. These aggregated statistics will provide transformative insights for K-12 education policymakers.

Through these three pilot projects, key questions will emerge that, we expect, remain unanswered for many other peer institutions and IRS partners. We will develop the privacy-protecting methods for a query server that adopts both input and output privacy protections to ensure that return information is protected against unauthorized access. We anticipate a secret sharing mechanism that shields the identities of the pilot cohort members from IRS view during querying, as well as application of statistical disclosure limitation methods to query results. The service would generate aggregate statistics that can be transmitted from IRS without disclosure of any federal tax information.

Building A Tax Outreach Network: Summary

Purpose and Goals:

- Coordinate with the US Treasury, the IRS, and other government agencies and organizations related to tax administration, safety net benefits, workforce development, and education
- Communicate tax information to clients, integrate tax information delivery with other social service programs to improve customer experience, tax compliance, and take-up of tax benefits
    - Work with client-facing safety net, workforce, and education programs
    - Refer eligible clients to free tax preparation resources, providing information about tax benefits and eligibility, referring clients to assistance for responding to IRS notices and audits
    - Improve tax filing, take up of Earned Income Tax Credit (EITC), Child Tax Credit (CTC), and education tax benefits
- Develop and implement efficient, scalable processes for privacy-protected data sharing
    - Send partner client-level data into the IRS/Treasury
    - Produce aggregated, privacy-protected statistics on communication strategy effectiveness
- Create evidence and develop long-term, sustainable best practices

Implementation:

- Building on current work with the Virginia Department of Social Services and the IRS
- Client-facing partners communicate tax information to clients, send client-level data to Georgetown's Massive Data Institute (MDI)
- The data intermediary (MDI) will: set up all data sharing agreements and obtain all necessary approvals, standardize data, transfer data to the IRS/Treasury, merge client-level data to administrative tax data, and create privacy-protected aggregated statistics on the effectiveness of different communication strategies
- The Georgetown-Yale project team will:
    - implement the network with collaborators at the IRS, US Treasury, other federal, state, and local government agencies and social service organizations.
    - coordinate the network so each partner only needs to have a data sharing agreement with the data intermediary (MDI)

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Building a Stronger, More User-Friendly Workforce Data System

October 2022

America Forward, members of the America Forward Coalition, and policy partners – including the Colorado Equitable Economic Mobility Initiative (CEEMI), Data Quality Campaign, Opportunity@Work, Per Scholas, Project QUEST, REDF (Roberts Enterprise Development Fund), Results for America, Social Finance, Third Sector Capital Partners, and Year Up Inc. – have called for the U.S. Department of Labor (DOL) to create a new national employment metrics system for workforce development programs. This new system should leverage national labor market outcomes information and substantially improving the transparency, availability, and quality of provider participation and outcomes data and supporting innovation across the workforce system. Our recommendation responds to DOL's request for information on open data matters released earlier in 2022.

Today, it is far too difficult for stakeholders across the workforce system to access even basic information about federally-funded training programs and participants' outcomes, including long-term labor market outcomes. This persistent challenge has frustrated informed decision-making by workers, providers, career navigators, and policymakers at every level of government, and makes it more difficult to help participants achieve sustained economic mobility. The current federal resource for eligible training providers under the Workforce Innovation and Opportunity Act (WIOA), TrainingProviderResults.gov, offers a starting point. But issues with missing data, data quality, and inaccessibility of data make this resource far less useful than it could be, including:

- *Limitations to current data.* The current system is missing or has suppressed costs and outcomes data on a tremendous number of programs, and there are potential issues with the quality of the data that is available. In addition, there are limitations to solely relying on state employment and earnings data—for instance, potentially undercounting impacts in areas where many participants work in another state.
- *Inaccessible data.* It is too difficult for participants and navigators to make sense of workforce provider data in a way that is relevant to them, with serious implications for effectiveness, equity, and innovation – such as understanding the demographics of providers' participants or programs' relative impacts and costs. In addition, the current reporting system places substantial burden on stakeholders across the system, particularly providers, while providing little support for continuous improvement and innovation. Providers that report into the current system, for the most part, are not able to leverage the resulting outcomes data for continuous improvement beyond the limited public data available.
- *Closed infrastructure for innovative providers.* The current system does not provide sufficient opportunity to highlight and expand effective strategies that could advance economic mobility and equity. Innovative providers who seek to know and publicly release their results but do not already receive WIOA funds in a given state are unable to leverage the performance infrastructure to learn their outcomes and make their case for funding moving forward.

A more streamlined, transparent, user-friendly system could substantially improve quality while reducing burden. America Forward and our partners urge DOL to build on the foundation it has already established, including recent data quality efforts and infrastructure investments, as well as several excellent state-led efforts.

Ultimately, we believe a federal-state partnership is necessary to provide the most locally-relevant solutions while harnessing national employment and outcomes data and economies of scale. At the state level, we believe providing national infrastructure can enable far more states to publish locally-relevant scorecards, such as linking program opportunities to local labor market needs. DOL can help jurisdictions access national labor market outcomes data and provide a common technical framework that frees states from reinventing the wheel in each jurisdiction. We encourage DOL to consider a range of possible data sources with federal partners, such as annual IRS employment and earnings data; quarterly data from the National Directory of New Hires; and the

Census Bureau, which holds quarterly earnings reported by state unemployment insurance systems and annual income data from IRS.

Moving forward, we suggest that DOL take lessons from the College Scorecard and engage intensively with states, localities, tribal governments, and other key stakeholders such as innovative workforce development providers. As DOL considers building this new, enhanced system, we highlight a few priorities:

- *Security and privacy.* This new system should use the most up-to-date, secure, privacy-protecting technologies, potentially including nonprofit data intermediaries to facilitate linkages.
- *Increase programs with available data.* It is crucial that this system dramatically expand the availability of data so jobseekers, navigators, government agencies, policymakers, and other stakeholders across the system have information they need to make good decisions. We recommend, for instance, that DOL consider new methodologies to reduce the number of programs with suppressed and unreported data in a privacy-protecting manner.
- *Expand available data.* This system must substantially expand the available data, including reporting on participant demographics and longer-term reporting on labor market outcomes.
- *Strengthen infrastructure for improvement.* The new system should support continuous improvement activities for providers, integration across programs, participation from interested workforce development providers who are not currently funded by WIOA, and secure research access to empower ongoing learning and development systemwide.
- *Enhance usability.* Finally, the system should support easier, improved decisionmaking by participants, navigators, and other stakeholders across the system. This should include resources to provide locally-relevant labor market information, which several states have already demonstrated.

We deeply appreciate DOL's commitment to continuing to build data resources on workforce development activities that will improve outcomes for workers, providers, and communities, as well as the Department's interest in receiving input on this issue. As organizations deeply engaged in this work, America Forward and our partners know the potential for a more streamlined, user-friendly system that will not only reduce burdens but strengthen equity, innovation, and effectiveness across the system. We look forward to working with DOL as the Department continues to strengthen its workforce data systems moving forward.

About America Forward

America Forward is the Washington, D.C.-based nonpartisan policy initiative of New Profit, a pioneering national venture philanthropy organization that invests in a portfolio of breakthrough social entrepreneurs and systems-change initiatives, catalyzes and builds their impact, and transforms how government and philanthropy pursue social change to ensure that all people can thrive.

America Forward unites social innovators with policymakers to advance a public policy agenda that strengthens equity, fosters innovation, rewards results, catalyzes cross-sector partnerships, and transforms local impact into national change. The America Forward Coalition comprises a network of over 100 social innovation organizations that champion innovative, effective, and efficient solutions to our country's most pressing social problems while working in more than 15,000 communities nationwide. Since 2007, our America Forward Coalition organizations have successfully advocated for lasting policy change in education, workforce development, and evidence-based policy; leveraged $1.7 billion for social innovation; and driven millions of federal resources toward programs that are achieving measurable results for those who need them most.

Additional Information on Tax Outreach Network

What are the benefits to state and local governments?

- Many state and local governments are interested in getting cash benefits to vulnerable populations and improving economic mobility of clients. Increasing take-up of tax benefits is a low-cost, feasible, evidence-based strategy to get significant cash benefits to low-income earners that may be the most vulnerable. These cash benefits can be a critical element of the safety net that improves economic mobility by increasing employment and reducing dependence on other social benefit programs.
- Some state and local governments have developed, are developing, or have recently expanded their EITC and CTC programs. These programs often require filing a federal tax return to get cash benefits.
- State and local government agencies need to know what outreach is effective and what outreach is not so they can implement and sustain cost-effective strategies that improve uptake and save limited administrative resources. Aggregated statistics generated by merging state and local client data with federal administrative tax data offers an unparalleled new tool to:
    - Improve targeting by knowing which geographical areas have the highest concentrations of non-filers who would be eligible for EITC and CTC.
    - Inform the design of interventions by knowing which state and locally administered health, human services, education, training and other social programs serve large numbers of non-filers who would be eligible for tax credits.
    - Measure the results of interventions on tax, employment and earnings outcomes, including their impact on racial and ethnic subpopulations.
- Begin to work with IRS and Treasury to build privacy-protecting data-linkage processes that can answer critical questions.

What are the benefits to IRS and Treasury?

- Measurable improvements in taxpayer customer experience, tax compliance, and tax administration, particularly for the Earned Income Tax Credit and Child Tax Credit;
- Leverage direct communication channels that network partner agencies and organizations have with clients:
    - Trusted messengers, communication through text, email, calls, and face-to-face meeting
    - Measure and improve equitable distribution of tax benefits using race and ethnicity data and potentially other data from network partners
    - Reduce noncompliance with clear communication of program rules, referrals to key resources
- Develop and implement privacy-protection tools and strategies
- Guidance to help states design and administer state-level EITC and CTC programs
- Learn from state and local EITC and CTC programs to improve design and administration of federal tax programs such as the Earned Income Tax Credit (EITC) and Child Tax Credit (CTC)

- Support cross-agency priorities of the Biden administration including customer experience, advancing racial equity and support for underserved communities, strengthening scientific integrity and evidence-based policymaking, and the Good Jobs Initiative.
- Build the infrastructure and processes for Treasury to collaborate with states, localities and communities to strengthen evidence-building in its non-tax programs for underserved populations, such as the State and Local Fiscal Recovery Fund, the Social Impact Partnerships to Pay for Results Act, and the Community Development Financial Institutions program.
- Minimize burden on IRS, Treasury, and other parties. By leveraging the data intermediary service provided by Georgetown's Massive Data Institute, Treasury and IRS only need to have one point of contact with the data intermediary, which will set up standardized data-sharing agreements with other parties. Treasury and IRS can still provide ideas and guidance to state and local partners as desired.

How will privacy be protected if individual-level data is exchanged between state and local agencies and IRS/Treasury to produce publicly available statistics?

- Research projects will use the same privacy-protecting methodology that IRS and the Education Department use to produce the College Scorecard, which disseminates aggregated statistics about average earnings of federal student aid beneficiaries by college and program of study. To produce the scorecard, the Education Department sends client-level data to IRS' secure data environment, which are linked with federal tax data to produce aggregated statistics. No individual-level tax information is disclosed.

- Georgetown University's Massive Data Institute, which is home to leading national privacy experts, will serve as a trusted data intermediary to develop the infrastructure for generating useful aggregated statistics while avoiding disclosure of individual data. Working with IRS, MDI will:
    - (1) develop and refine cutting-edge privacy-protecting technologies and safeguards that will be consistent with the high standards under development by national privacy experts;
    - (2) develop a single data-sharing agreement with IRS that meets IRS' and other federal privacy and security standards;
    - (3) develop standardized data-sharing agreements with other entities that will send their data to MDI to be merged;
    - (4) clean and standardize data in preparation for transfer to IRS;
    - (5) prepare statistical analyses and re-usable research designs and templates that can be populated with aggregated statistics produced by IRS;
    - (6) prepare presentations of statistical results and privacy-protecting process innovations for government agency partners.

    This approach will minimize administrative costs that the IRS would incur, relieve the IRS of having to negotiate data-sharing agreements with numerous outside entities, and create transparent standards and processes that serve as models for data-sharing across organizations and levels of government.