



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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