



July 15, 2024
Arati Prabhakar, Ph.D
White House Office of Science and Technology Policy
1650 Pennsylvania Avenue NW
Washington, DC 20502

RE: Development of the Federal Evidence Agenda on Disability Equity– Request for Information, May 30, 2024

Dear Dr. Prabhakar:

AcademyHealth is pleased to provide input to inform the development of the Federal Evidence Agenda on Disability Equity through the Disability Data Interagency Working Group (DDIWG).

As the professional home for health services and systems researchers, policy experts, and practitioners, AcademyHealth is dedicated to improving health outcomes for all, including the most vulnerable and disenfranchised populations. We are committed to a strategic plan explicitly naming diversity, equity, inclusion, and accessibility (DEIA) as core values. Our members are leaders in health equity studies, health disparities, and social determinants of health.

We are grateful that the White House Office of Science and Technology Policy (OSTP) is engaging in thoughtful stakeholder engagement in improving health equity for individuals with disabilities. For decades, disability scholars have recognized that the literature on inequality often overlooks individuals with physical disabilities, mental disabilities, substance use disorders, HIV, hepatitis, and other chronic (or potentially disabling) infectious diseases.

Describe disparities faced by individuals with disabilities that could be better understood through Federal statistics and data collection, such as disparities in health, employment, educational, and other outcomes, or in Federal program participation.

Our primary recommendation is to acknowledge the complexity and breadth of disabilities and ensure that definitions and practices are aligned. We suggest prioritizing four critical areas to bolster health data on individuals with disabilities:

- **Expand the screening of differently abled individuals:** include more expansive screening measures¹ that include mild to moderate cases² and extend outreach to underserved populations.

¹ Murray, C. J., & Lopez, A. D. (1994). Quantifying disability: data, methods, and results. *Bulletin of the World Health Organization*, 72(3), 481

² Mulcahy, A. C., Govier, D. J., Than, C. T., Chawla, N., Danan, E., Hooker, E. R., ... & Hynes, D. M. (2024). Application of a comprehensive disability measure: Disability prevalence among US veterans and non-veterans from the National Health Interview Survey Data from 2015 to 2018. *Preventive Medicine*, 108051.



- **Assess the disparities across various domains:** This includes employment, healthcare access, mental health, social health (i.e., loneliness), education, housing, transportation, community inclusion/participation, and digital and communications technology.
- **Recognize the intersectionality of these disparities:** Individuals with disabilities may experience compounded challenges due to intersecting factors such as race, ethnicity, gender, socioeconomic status, age, veteran status, and geographic location.
- **Center vulnerable populations:** Individuals with disabilities who are also experiencing other social conditions such as living in low-income neighborhoods, experiencing racism, or belonging to historically and structurally marginalized groups like those racialized as Black, Indigenous, or People of Color (BIPOC), veterans, or elderly. These groups are more likely to have a disability and have been less central in the existing literature.

Identify, in coordination with agency staff, Federal data collections where improved disability data collections may be important for advancing the Federal Government's ability to measure disparities facing individuals with disabilities; and Recommendations for collecting the best data on disabilities.

Individuals with disabilities are more likely to be low-income, and if these individuals are racialized as BIPOC or live in rural areas, they face additional barriers and challenges, including access to healthcare, education, transportation, and employment. These barriers have been identified as political and social determinants of health. Disability support programs often require individuals to have minimal or no wealth, effectively forcing them to remain in poverty or below the poverty level. This systemic requirement amplifies social and policy-driven determinants of health concerns, as it is not a random state of being but a structural condition that locks individuals into poverty to access necessary and life-saving benefits. This underscores the critical need to address these intersecting determinants to create equitable opportunities and improve health outcomes for individuals with disabilities.

Reform Existing Datasets

Conventional methods for collecting, analyzing, and disseminating data on disability have relied on cross-sectional censuses and surveys measuring prevalence over a given period. While this approach helps define the extent and demographic patterns of disabilities, it does not provide the detailed information needed for prevention, which requires understanding the underlying diseases and injuries causing disabilities. Below we have highlighted key areas of focus for reforming existing datasets.

Key Areas Currently Underrepresented in Disability Data

- **Quality of Care and Life:** It is crucial to consider the personal and qualitative aspects of disability care, including the relationships between individuals with disabilities and their caregivers. Current clinical data systems often overlook these critical quality care and life elements.
- **Civic Engagement and Social Inclusion:** Collecting data on the barriers individuals with disabilities face in civic engagement, community activities, and social inclusion initiatives. This data can highlight challenges that hinder full participation.

- **Longitudinal and Mixed-methods Studies:** Conducting longitudinal studies to track changes in disability status over time and throughout life-course transitions is crucial. Integrating data on social determinants of health with this approach can offer valuable insights into the effectiveness of interventions and policies across the lifespan.

Challenges and Innovative Approaches to Equitable Disability Data Collection

- **Challenges in Combining Data Across Datasets:** To address the difficulties in combining data across different datasets, it is essential to develop and implement standardized definitions and measures of disability across all Federal data collection efforts. This standardization will ensure data consistency, interoperability, and comparability across different agencies and studies. Interoperability goes beyond file types; it involves ensuring that data can be effectively combined and analyzed without losing critical information.
- **Inaccessibility of Health Surveys and Information:** Many health surveys and information systems are inaccessible to individuals with disabilities due to various physical and psychological reasons. A Government Accountability Office (GAO) [report](#) found that most federal websites are not [508 compliant](#), which presents a significant barrier for people with disabilities – the people with the most at stake - to accessing critical information on benefits and other government supports. Implementing universal design principles such as ADA Section 508 ensures that all people in the U.S., including people with disabilities, have equal access to digital information and communication resources from federal agencies. Efforts should also involve designing inclusive and accessible data collection instruments in multiple formats (e.g., paper, digital, large print, Braille) and ensuring that questions are clear, understandable, and multilingual. To ensure accessibility for neurodivergent individuals, agencies must consider diverse modes of learning and communication, such as moving media and still images.
- **Concerns Regarding the Use of Health-Related Quality of Life (HRQoL) Metrics:** Data collection should reflect that disability is not experienced or managed linearly and can encompass multiple complexities. Recommendations should consider the [concerns](#) within the field regarding the use of **Health-Related Quality of Life (HRQoL)** (e.g., Quality-Adjusted Life Years (QALYs), Years of Potential Life Lost (YPLL) and Patient-Reported Outcome Measures (PROMs)) which some feel devalue their own lived experiences and priorities of other people with various types of disabilities. To address this, data collection should incorporate comprehensive qualitative measures of disability, ensuring a multifaceted measurement approach that truly reflects the diverse experiences and needs of individuals with disabilities, both visible and invisible.
- **Challenges in Data Aggregation:** Current data aggregation practices obscure unique differences between groups. Even if the reason for this is ensuring privacy at the individual level and under the requirements of the Privacy Act, there is a critical need for improved mechanisms to disaggregate data by type and severity of disability, as well as intersecting factors such as race, ethnicity, gender, age, and socioeconomic status. Additionally, disaggregating data by area-level factors such as geographic region, resource deprivation, and rurality is essential, while maintaining privacy. This approach will yield a more nuanced understanding of disparities and enable the development of targeted interventions to address specific needs within diverse populations.

- **Lack of Patient Input:** Currently, patients with disabilities often have limited say in data collection processes. To address this, OSTP should support the establishment of a federal advisory committee comprising individuals with disabilities, advocacy groups, researchers, and other relevant partners to guide the design and implementation of data collection efforts. AcademyHealth is willing and able to help identify or convene such a group. Their input is crucial for ensuring that data collection methods are relevant, respectful, and effective in capturing the lived experiences of individuals with disabilities. Engage invested partners—including the disability community—meaningfully throughout the process to tailor data collection approaches to their needs, experiences, and preferences. Regularly solicit feedback and maintain ongoing communication to adapt and improve data collection instruments in collaboration with the community.

Enhancing Federal Data Collections to Address Disability Disparities

To advance the Federal Government's ability to measure and address disparities facing individuals with disabilities, it is crucial to identify and improve existing data collections. Connecting these data is essential for quantifying the quality of disability care and linking it to clinical outcomes. For instance, in the context of HIV, there is broad recognition that social determinants significantly influence health outcomes. [For example, if a person with HIV lacks stable housing, it can hinder their ability to adhere to antiretroviral therapy \(ART\).](#) This underscores the justification for covering services such as housing navigation or emergency housing under the Ryan White HIV/AIDS Program. Below we included six key areas and recommendations for collecting the best data on disabilities:

- **Healthcare Data Collection:**
 - Centers for Disease Control and Prevention (CDC): Enhance the Behavioral Risk Factor Surveillance System (BRFSS) to include more detailed questions on disability status, types, and severity.
 - Centers for Medicare & Medicaid Services (CMS): Improve data collection on disability status in Medicaid and Medicare beneficiary records to better understand healthcare access, utilization, and outcomes among individuals with disabilities.
- **Employment Data Collection:**
 - Bureau of Labor Statistics (BLS): Enhance the Current Population Survey (CPS) and the American Community Survey (ACS) to collect more granular data on employment status, job types, workplace accommodations, and barriers faced by individuals with disabilities.
 - Equal Employment Opportunity Commission (EEOC): Improve data collection on disability in the EEO-1 Report to better track employment practices and outcomes for individuals with disabilities in various sectors.
- **Educational Data Collection:**

- Department of Education (ED): Enhance the National Center for Education Statistics (NCES) surveys, such as the Integrated Postsecondary Education Data System (IPEDS) and the Civil Rights Data Collection (CRDC), to collect more detailed information on disability status, types of disabilities, and educational outcomes.
- Office of Special Education Programs (OSEP): Improve data collection on implementing Individualized Education Programs (IEPs) and 504 plans to better understand the educational experiences and outcomes of students with disabilities.
- **Housing Data Collection:**
 - Department of Housing and Urban Development (HUD): Enhance the American Housing Survey (AHS) to include more detailed questions on housing accessibility, accommodations, and barriers faced by individuals with disabilities.
 - Fair Housing and Equal Opportunity (FHEO): Improve data collection on housing discrimination cases involving individuals with disabilities to understand better and address housing disparities.
- **Transportation Data Collection:**
 - Department of Transportation (DOT): Enhance the National Household Travel Survey (NHTS) to collect more detailed information on transportation access, barriers, and needs of individuals with disabilities.
 - Federal Transit Administration (FTA): Improve data collection on the accessibility and usage of public transportation services by individuals with disabilities.

Identify practices for all Federal agencies engaging in disability data collection to follow to safeguard privacy, security, and civil rights, including regarding appropriate and robust practices of consent for the collection of this data and restrictions on its use or transfer.

To ensure the integrity and protection of disability data, it is imperative for all Federal agencies engaged in data collection to adhere to stringent practices safeguarding privacy, security, and civil rights, encompassing robust consent procedures and strict limitations on data use and transfer. We recognize that the Privacy Act and each agency's rules under its Systems of Records set the baseline for maintaining privacy of federally-collected data, however in our digital age, more can be done, as we outline below.

- **Access to an Informed Consent:** Ensure that consent forms are available in multiple formats and languages (e.g., written, verbal, Braille, large print, digital) to accommodate diverse needs. Obtain explicit and informed consent from individuals before collecting any data. This includes providing clear and accessible information about the data collection's purpose, how it will be used, who will have access to it, and the potential risks and benefits.

- **Rights of Individuals:** Respect and uphold individuals' rights regarding their data, including the rights to access, correct, delete, restrict, or object to certain processing activities. Provide accessible channels for individuals to exercise these rights and address concerns or complaints.
- **Restrictions on Data Use and Transfer:** Implement strict policies governing the use and transfer of data, ensuring it is only shared with authorized parties adhering to the same privacy and security standards. Prohibit data use for discriminatory purposes or activities that could harm individuals or groups.
- **Auditing and Monitoring:** Implement regular audits of data collection systems to ensure they meet accessibility and inclusivity standards, such as 508 compliance. Agencies must consider who will have access, who is centered in decision-making, and who finds the process accessible. Agencies must reflect and report on whose perspectives or positionalities are being centered in the data collected, remaining mindful of the power dynamics and vulnerability of individuals and their health data throughout this assessment.

Thank you for the opportunity to discuss the perspectives and concerns of the health services research community. For further comment, clarification, or inquiry, please email Josh Caplan at Josh.Caplan@AcademyHealth.org.