



July 15, 2024

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White House Office of Science and Technology Policy (OSTP)
1650 Pennsylvania Ave. NW
Washington, DC 20502
[Submitted electronically via Regulations.gov]

Re: Notice of Availability and Request for Information; Federal Evidence Agenda on Disability Equity

To whom it may concern,

The undersigned members of the Consortium for Constituents with Disabilities (CCD) Health Task Force and other CCD members appreciate the opportunity to provide comments on how the federal government can improve its ability to make data-informed policy decisions that advance equity for individuals with disabilities.¹

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 society free from racism, ableism, sexism, and xenophobia, as well as LGBTQ+ based discrimination and religious intolerance.

Our comments on disability data collection center on health care, particularly Medicaid. Millions of people with disabilities depend on Medicaid to provide the services they need to live and thrive in their communities. But even though Medicaid is the nation's biggest payer for home and community-based services (HCBS), our ability to analyze care quality, disparities in access to care, HCBS utilization and expenditures, and especially intersectional inequities, has been hampered by limitations in the collection of demographic data on disability.

¹ Office of Science and Technology Policy, *Notice of Availability and Request for Information; Federal Evidence Agenda on Disability Equity* (May 30, 2024), <https://www.federalregister.gov/documents/2024/05/30/2024-11838/notice-of-availability-and-request-for-information-federal-evidence-agenda-on-disability-equity>.

Describing Disparities

1. What disparities faced by individuals with disabilities are not well-understood through existing Federal statistics and data collection?

First, the current ACS disability questions systematically undercount people with some types of disabilities and need to be updated. While the 6 question set used on the ACS has become the standard for many national surveys, it has numerous well-known limitations. For example, the questions significantly undercount people with disabilities, particularly people who have mental or psychiatric conditions and/or chronic conditions as their primary disability. One recent study of 2100 individuals who reported having a disability found that one in five (19.5%) would have answered no to all six ACS questions.² Individuals whose primary disability was a mental or psychiatric condition (22.7%) or as a chronic illness or disease (31.6%) were even more likely to be missed.³ Another study found widespread undercounting by the ACS among youth with psychiatric and intellectual and developmental disabilities.⁴ The current ACS questions also do not distinguish between people with enduring versus temporary functional difficulties,⁵ as well as other shortcomings.⁶

We recognize that the ACS questions were never intended to identify all persons with disabilities, but the uneven sensitivity to certain types of disability, in addition to the systematic undercounting of disability prevalence, skews the data landscape that informs government policies and resource distribution. Millions of people with disabilities struggle with unmet health and long-term care needs every year. Systematic undercounts can understate the extent of those needs, while overstating the mortality risk of disability.⁷ Those with disabilities more likely to be missed by the survey questions might find it even more difficult to secure needed resources.

² Jean P. Hall et al., *Comparing Measures of Functional Difficulty with Self-Identified Disability: Implications for Health Policy*, 41 HEALTH AFFAIRS 1433 (2022).

³ *Id.*

⁴ Catherine Ipsen et al., *Underrepresentation of Adolescents with Respiratory, Mental Health, and Developmental Disabilities Using American Community Survey (ACS) Questions*, 11 DISABILITY & HEALTH JOURNAL 447 (2018).

⁵ Bryce Ward et al., *Health Status Changes with Transitory Disability Over Time*, 107 AM. J. PUBLIC HEALTH 706 (2017).

⁶ Kristen Miller, J. Brent Vickers & Paul Scanlon, *Collaborating Ctr. for Questionnaire Design and Evaluation Research (CCQDER), National Ctr. for Health Statistics, Comparison of American Community Survey and Washington Group Disability Questions* (Oct. 2022), https://wwwn.cdc.gov/qbank/report/Miller_2020_NCHS_ACS.pdf.

⁷ Scott D. Landes, Bonnielin K. Swenor & Nastassia Vaitsiakhovich, *Disability Documentation in the National Health Interview Survey and Its Consequence: Comparing the American*

There are many disparities that are not fully understood given the fact that some subgroups are simply not measured (e.g., chronic conditions, communication barriers, youth). Ensuring the inclusion of intersectional data, co-concurring conditions, and working to improve current data collection activities through platforms such as Medicaid and the American Community Survey (ACS) are imperative as we look to find ways to improve existing federal statistics and data collection.

Second, recent proposals to shift the ACS to the Washington Group—Short Set would not address many of the shortcomings and gaps in the current ACS questions. Though it does include a question on people with communication disabilities, the WGSS suffers from some of the same limitations as the current ACS-6, particularly in the area of mental or psychiatric conditions and people with chronic conditions. As a measure of disability prevalence, the WGSS standard definition is even more restrictive than the ACS-6. If this were adopted as the federal standard for disability data collection, other national surveys would likely adopt the same questions over time and amplify its shortcomings.

Any recommendations coming out of the development of a Federal Evidence Agenda on Disability Equity should identify more accurate, comprehensive alternatives that do not systemically undercount some types of disabilities.⁸

Third, the DDIWG should improve federal disability data to allow for more nuanced analysis of intersectional or compound disparities. By failing to collect disability health outcomes data comprehensively, we cannot clearly identify compound disparities by people of color with disabilities, for example, black maternal health and maternal health of people with disabilities. We need data collection that facilitates breaking down silos and intentionally includes individuals with co-occurring health conditions.

People with disability and co-occurring health conditions experience unique disparities of under-treatment, under-served, under-supported, with worse health outcomes. People with disabilities are 30% more likely to be obese; 60% more likely to smoke; 2.5 times more likely to develop diabetes; 3 times more likely to have cardiovascular

Community Survey to the Washington Group Disability Measures (2023), <https://www.medrxiv.org/content/10.1101/2023.10.16.23297081v1.full.pdf>.

⁸ Scott D. Landes et al., *A Research Roadmap Toward Improved Measures of Disability*, HEALTH AFFAIRS FOREFRONT (July 9, 2024), <https://www.healthaffairs.org/content/forefront/research-roadmap-toward-improved-measures-disability>.

disease; and 2 times more likely not to see a doctor due to cost.⁹ Over 45% of Medicaid beneficiaries with ID/DD enrolled in HCBS had an additional health condition. Of the physical chronic health conditions examined by GAO: 8-to-26 % had high blood pressure, 6-to-20% had high cholesterol, with diabetes being the third most common chronic health condition. Persons with co-occurring ID/DD and mental health conditions were more common than co-occurring ID/DD and substance use disorders; over 50% of persons with ID/DD in Medicaid “comprehensive” programs had co-occurring behavioral health conditions.¹⁰

Unlike most every medical condition, the system of services and supports focused on persons with IDD, serious mental illness, and SUD are highly siloed. These siloed systems target funding and staffing with condition expertise, but often neglect whole-person needs. State ID/DD agencies reported that 48% of persons with IDD had a co-occurring mental illness, in 2018.¹¹ According to the Christopher and Dana Reeve Foundation, people with disabilities have an overall substance abuse rate 2-to-3 times higher than that of the general population.¹²

People with disabilities have difficulty finding able and willing healthcare providers. Many healthcare providers report that they are unprepared and uncomfortable caring for patients with disabilities.¹³ We know more intersectional data can help identify and address the systematic root causes of disparate impact in order to mitigate inequitable outcomes. More robust intersectional data collection can also help address the health needs of individuals with a range of conditions, such as for individuals who are Deaf and Hard of Hearing. For instance, more robust data could help address issues related

⁹ AAHD National Disability Navigator Resource Collaborative September 30, 2022 newsletter, summarizing Krahn, Walker, and Corraera-DeAraujo “Persons with Disabilities as an Unrecognized Health Disparity Population” in: American Journal of Public Health, February 17, 2015.

¹⁰ U.S. Govt Accountability Office, *Medicaid: Characteristics of and Expenditures for Adults with ID/DD* (Apr. 2023), <https://www.gao.gov/products/gao-23-105457>.

¹¹ NASDDDS and HSRI, *What Do NCI Data Reveal About People Who Are Dual Diagnosed with ID and Mental Illness*, (October 2019), https://legacy.nationalcoreindicators.org/upload/core-indicators/NCI_DualDiagnosisBrief_Oct2019.pdf; *Percentage of Medicare Fee-for-Service Beneficiaries with 21 Selected Chronic Conditions*, CMS to the National Academy of Medicine Behavioral Health Committee on Medicaid and Medicare, August 24, 2023

¹² Disability Policy Consortium. “Urgent Need to Address Substance Abuse Among People with Disabilities in Massachusetts.” November 2017.

¹³ Tara Lagu et al., *“I Am Not the Doctor for You”: Physicians’ Attitudes about Caring for People with Disabilities*, 41 HEALTH AFFAIRS 1387 (2022).

to improving literacy achievement;¹⁴ greater under employment;¹⁵ limited access to hearing healthcare;¹⁶ and higher healthcare costs.¹⁷

As the federal government continues to look at the healthcare disparities faced by people with disabilities the consideration of intersectional and co-concurrent conditions is imperative. This includes the inclusion of youth in any longitudinal data collection initiative.

2. What types of community-based or non-Federal statistics or data collections could help inform the creation of the Federal Evidence Agenda on Disability Equity?

While federal data sources, such as the ACS, are among the most important collections related to people with disabilities, a number of non-federal health data sources contribute to our understanding of health equity for people with disabilities.

¹⁴ Karissa L. LeClair and James E. Saunders, *Meeting the Educational Needs of Children with Hearing Loss* 97 BULL. WORLD HEALTH ORG. 722 (2019), <https://www.ncbi.nlm.nih.gov/pmc/articles/PMC6796661/>; Susan Nittrouer et al. *Emergent Literacy in Kindergartners with Cochlear Implants* 33 EAR HEAR. 683 (2012), <https://pubmed.ncbi.nlm.nih.gov/22572795/>; Ann E. Gears and Heather Hayes, *Reading, Writing, and Phonological Processing Skills of Adolescents with 10 or More Years of Cochlear Implant Experience*, 32 EAR HEAR. 49S (2011), <https://pubmed.ncbi.nlm.nih.gov/21258612/>.

¹⁵ David Jung and Neil Bhattacharyya, *Association of Hearing Loss with Decreased Employment and Income Among Adults in the United States*, 121 ANNALS OF OTOL. RHINOL. LARYNGOL. 771 (2012), <https://pubmed.ncbi.nlm.nih.gov/23342548/>; A. Shan et al., *Hearing Loss and Employment: A Systematic Review of the Association Between Hearing Loss and Employment Among Adults*, 134 J. LARYNGOL. OTOL. 387 (2020), <https://pubmed.ncbi.nlm.nih.gov/32468973/>; Susan D. Emmett, *The Socioeconomic Impact of Hearing Loss in US Adults*, 36 OTOL. NEURITOL. 545 (2015), <https://www.ncbi.nlm.nih.gov/pmc/articles/PMC4466103/>.

¹⁶ DG Blazer and Domnitz S. Liverman, Eds., Committee on Accessible and Affordable Hearing Health Care for Adults, Board on Health Sciences Policy, National Academies of Sciences, Engineering, and Medicine, *Hearing Health Care for Adults: Priorities for Improving Access and Affordability*, Washington, DC: National Academies Press (US). (2016), <https://www.ncbi.nlm.nih.gov/books/NBK385310/>; Arrianna Marie Planey, *Audiologist Availability and Supply in the United States: A Multi-Scale Spatial and Political Economic Analysis* 222 SOC. SCI. MED. 216 (2019), <https://pubmed.ncbi.nlm.nih.gov/30660682/>; Sarah Kingsbury et al., *Barriers to Equity in Pediatric Hearing Hearing, Health Care: A Review of the Evidence* 7 PERSPECT. ASHA SPEC. INTEREST GROUPS 1060 (2022), <https://www.ncbi.nlm.nih.gov/pmc/articles/PMC9585532/>.

¹⁷ Nicholas S. Reed et al., *Trends in Health Care Costs and Utilization Associated with Untreated Hearing Loss over 10 Years*, 145 JAMA OTOLARYNGOL. HEAD NECK SURG. 27 (2019), <https://pubmed.ncbi.nlm.nih.gov/30419131/>.

One such source is the HCBS experience of care surveys that many states collect, including the National Core Indicators – Intellectual and Development Disabilities (NCI–DD), the NCI – Aging and Disability (NCI-AD), the HCBS CAHPS survey, and the Council on Quality and Leadership’s Personal Outcome Measures (POM). These widespread surveys provide (mostly) state-level insights on access to care, care planning, community integration, and autonomy for people with disabilities. The National Association of State Developmental Disability Directors (NASDDDS) and the Human Services Research Institution (HSRI), who help administer NCI, have also published reports on NCI data examining health disparities for people of color with disabilities.¹⁸ These research briefs point toward the need to improve the quality and capacity of stratified reporting on disability data, particularly around race and ethnicity. Since CMS will require states to use these experience of care surveys for each population in their HCBS programs by 2027, these non-federal sources of disability equity data will become even more important. They will be limited by typically smaller sample sizes, which will be even more pronounced for smaller subgroups like race/ethnicity. Also, a significant share of NCI survey responses have missing demographic data that limit our ability to draw conclusions from the comparative results. But if the measure administrators implement best practices to improve responses to demographic questions, these experience of care surveys will be able to identify and track disparities in HCBS access and quality to guide more targeted research and interventions.

A similar area in need of improved disability data collection is state Medicaid administrative data, particularly the data related to community-based services. During the COVID Public Health Emergency, the dearth of data on how COVID affected people with disabilities in congregate non-institutional settings, like group homes and assisted living facilities, was glaring. Federal statistics tracked terrible outcomes for people in nursing facilities, where there is a robust data collection system, but no comparable system existed for people who used Medicaid HCBS. Some studies and state level data suggested that the risks in congregate community-based settings were comparable to nursing facilities, but the lack of consistent, high quality Medicaid data on people with disabilities made it difficult to draw more specific conclusions.¹⁹

¹⁸ Valerie J. Bradley et al., NASDDDS and HSRI, *National Core Indicators® Data Brief: What Do NCI Data Tell Us About Significant Racial & Ethnic Disparities Across Quality of Life & Health Domains?* (Feb. 2021), https://legacy.nationalcoreindicators.org/upload/core-indicators/NCI_DB_RacialEquity_final.pdf.

¹⁹ H. Stephen Kaye & Joseph Caldwell, *Excess Deaths of Medicaid Home and Community-Based Services Recipients During COVID-19*, 42 HEALTH AFFAIRS 115 (2023).

Medicaid data on disability is lacking, and particularly so for measuring intersectional disparities. Incomplete or inaccurate demographic data collection, coupled with the limited ability to collect comprehensive, self-reported disability data through the Medicaid application process, makes it very difficult to quantify and track disparate access to care or care quality for people with disabilities. Medicaid's main claims database, T-MSIS, offers a promising platform to eventually permit a much more nuanced analysis of the barriers to care faced by specific subgroups of people with disabilities, but current limitations, such as an overreliance on eligibility group as a proxy for disability, hinder its usefulness. Ultimately, state Medicaid programs should incorporate disability questions on their applications that help capture the full scope of people with disabilities on the program.

3. Community-based research has indicated that individuals with disabilities experience disparities in a broad range of areas. What factors or criteria should the DDIWG consider when considering policy research priorities?

It is critical that the Federal government take a broad look at disability and consider all types of disabilities, and the various types of disparities experienced by people with disabilities, in its surveys and other research.

The disability community is not monolithic, and instead includes people with all types of physical, mental, and intellectual disabilities. It also ranges from people with less serious functional limitations to those with serious limitations that impact all aspects of life. The impact of disability varies widely among individuals, even for those with the same diagnosis. Factors such as the severity of the condition, availability of support systems, cultural beliefs and attitudes, and personal coping strategies can influence how a disability affects a person's daily life. For example, people with less severe disabilities, especially those disabilities that are considered invisible, may still be struggling to get an accurate diagnosis and may not have the same type of support system as someone with more serious limitations. This is especially true for people with Long COVID or other similar diseases that are still not well understood by the medical community. Therefore, assessments must be individualized to capture the unique experiences and needs of each person and ensure that the Federal government is capturing the full spectrum of experiences for people with disabilities. Standardized tools should be flexible enough to allow for customization based on individual circumstances. This may involve using open-ended questions, incorporating person-reported outcomes, and allowing respondents to provide additional context about their

disabilities. Such open-ended questions must be developed with the input of, and piloted with, individuals from diverse racial/ethnic/cultural/language backgrounds to ensure that they will generate accurate responses across these differences.

Existing Federal statistics often overlook the nuanced disparities faced by individuals with disabilities and the differences between different types of disabilities, particularly in areas such as access to technology, transportation, and specialized health care services. Disparities faced by individuals with disabilities in pain management and mental health services are not well-understood. For example, individuals with invisible disabilities face skepticism and bias, resulting in under-treatment and unnecessary suffering. Similarly, those with physical or intellectual disabilities may face barriers in accessing mental health services due to provider biases or misconceptions about their ability to benefit from such services. Additionally, there is significant room for improvement in gathering long-term outcome data on employment and education for individuals with disabilities, which can provide deeper insights into their ongoing challenges and successes in these critical social determinants of health.

It is particularly important that the Federal government look at the full life cycle of people with disabilities, including the key junctions where people with disabilities face barriers to joining the “mainstream” of American life, and how these experiences are different for people with different types of disabilities. For example, what barriers do people with mental health disorders face in education, employment, marriage, retirement, or access to health care? How are these barriers different across different stages of life or different races/ethnicities? How are these barriers different for people with physical disabilities? Studying these issues needs to be a focus of policy research moving forward, so that people with all types of disabilities and at all stages of life are fully able to participate in their community and society. By undertaking these studies, the Federal government can help ensure accessibility for all.

Informing Data Collections and Public Access

- 1. Disability can be defined and measured in multiple ways. Federal surveys and administrative data collections use different definitions of disability and measure it in different ways depending upon the goal(s) of data collection. What frameworks for defining and measuring disability or specific considerations should the DDIWG be aware of?**

The 2023 Compendium of Disability Data Collection Methods compiled by Mathematica for the Administration for Community Living’s National Institute on Disability,

Independent Living, and Rehabilitation Research (NIDILRR) cites over 600 articles related to measuring disability. Written primarily over the last decade, the range of articles explicitly or implicitly include the following different conceptual frameworks for understanding disability:

- Disability as medical diagnosis;
- Disability as a demographic characteristic that demonstrably accompanies or affects individual outcomes;
- Disability as a demographic characteristic that impacts outcomes both in isolation, and in combination with other demographic characteristics such as race, gender, age, and LGBTQIA+ status;
- Disability itself as a social, health, or other outcome;
- Disability as a pre-condition to eligibility for government benefits;
- Disability as a protected characteristic under civil rights law;
- Disability as a factor that triggers a legal requirement to provide reasonable accommodations and/or policy modifications for equally effective communication, employment, healthcare, and participation in government programs and activities, and the services offered by public accommodations, including equal participation in complaint mechanisms and quality surveys;
- Disability as a specific health condition that requires physical, mental, and/or social support interventions that must be evaluated for evidence of effectiveness, efficiency, and value; and
- Disability as social, cultural and/or political identity, or as a component of such.

Many of the above frameworks are embedded in U.S. law and practice. For example, Section 504 of the Rehabilitation Act of 1973, the Americans with Disabilities Act of 1990, and the Individuals with Disabilities Education Act recognize disability as a protected characteristic because individuals with disabilities experience systemic, harmful stereotypes, denials of equal participation, and discriminatory treatment. The Social Security Act and the Medicaid Act, as well as individual state benefit programs, define disability for the purposes of service eligibility.

Some agencies draw upon the World Health Organization's International Classification of Functioning, Disability and Health (ICF) Framework that attempts to consider disability within a broader social context and wellness perspective. The ICF emphasizes the complex interaction of individual health, contextual, and personal factors that can affect life participation and functioning. This framework accords well with a "social model of disability" that refuses to place disability as purely a medical condition that exists within an individual. This social model necessarily requires broader and more inclusive and collaborative methods of data collection, research and policy-making

because individual and population health depends on understanding the relationship between diverse factors, including a person's own identification as an individual with disabilities and what that means, rather than simply relying on external diagnoses.

There are some key considerations that federal agencies must keep in mind across all the conceptual frameworks. First, the means by which disability is counted cannot be just a secondary consideration of "survey design" after a conceptual framework is adopted. Any tool used to measure disability must be fully accessible to people with a range of different disabilities across the full gamut of cultural, social, and economic characteristics. It is all too easy to entirely miss sub-populations and their experiences of disability by using measures that present physical, communication, social, economic, or other barriers to participation.

Second, all definitions and means of measuring disability can be misused in ways that lead to unintended consequences that result in discrimination or even outright abuse. For example, the identification and accommodation needs of students with disabilities in schools, whether they have an Individualized Education Plan or a Section 504 plan, is an important part of these students' academic and social success in their education. Some of this accommodation information could presumably be useful to individual students in other contexts, such as while they are receiving healthcare or in higher education. It is certainly critical to obtaining data needed for disparate grade and restraint and seclusion analyses. However, this information can also be misused. That same information could be used to unjustifiably link students and people with disabilities to school violence and shooting risks. A common stereotype that we can see in attempts to develop "red flag" laws lays violence at the feet of those with mental health and/or developmental disabilities. We must always be clear about our goals for measuring disability, ensure that we match our conceptual framework of measurement to our goal, guard against the sloppy use of disability statistics and data, and always ensure that people with disabilities and disability advocates are included in goal-setting and the ongoing evaluation of whether those goals are being achieved.

We support the urgent need for a National Academies of Science, Engineering, and Medicine (NAEM) report to build consensus for the best approaches to collect data on disability across federal programs and surveys.

This process should engage a diverse committee representing expertise across the range of disabilities and the racial/ethnic/language/cultural backgrounds of individuals with disabilities. They should review current standards and make recommendations on updating them to more accurately capture the disability demographic and to promote

intersectional analyses that allow for better understandings of the specific challenges people with disabilities face in getting access to needed services.

This administration has taken important steps to improve demographic data collection and reporting, and as CMS and other federal agencies look toward future improvements, we urge to keep two major principles in mind:

- Do no harm -- weigh potential consequences for people with disabilities in the areas of data collection and research and resource allocation, with the intent to minimize any potential negative outcomes; and
- “Nothing about us, without us” – continue to adhere to a transparent, inclusive public process that engages the range of people with disabilities, the parents of minors with disabilities, disability researchers, and advocates to build consensus around a gold standard for disability data collection going forward.

2. In some instances, there are multiple surveys or data collection tools that could be used to collect data about a particular disparity faced by the disability community. In addition to factors like sample size, timeliness of the data, and geographic specificity of related data products, what other factors should be considered when determining which survey or data collection tool would best generate the relevant data? Which surveys or data collection tools would be uniquely valuable in improving the Federal Government’s ability to make data-informed decisions that advance equity for the disability community, and why?

Person-centeredness and self-determination are core elements and principles in the disability community. Increasingly, the entire health care delivery systems and the disability serving organizations are developing, gathering, and trying to analyze and publicly report data on lived experience for people with disabilities. The health care arena currently refers to these data as “Patient-Reported Outcomes” (PROs) and “Patient-Reported Outcomes – Performance Measures” (PRO-PMs). The disability movement uses more individualized and less medically-oriented terminology – person, beneficiary, participant.²⁰

²⁰ In a 2014 report, NQF observed: “One single term cannot apply to all individuals in all situations; in actuality, an individual with many needs may self-identify as a person, client, or patient at a single point in time...The task force agreed to use the word ‘person’ as an overarching term to encompass the health and healthcare needs of all individuals, regardless of age, setting, or health status.” National Quality Forum, *Finding Common Ground for Healthcare Priorities: Families of Measures for Assessing Affordability, Population Health, and Person-and-*

Capturing the person-reported experience as a Routine Health Care Data Collection Element has been the topic of two 2024 AHRQ webinars for the CAHPS (Consumer Assessment of Health Care Providers and Systems) community.²¹ As mentioned above, the HCBS experience of care surveys collected in many states represent an important data source for person-reported outcomes. These surveys include the NCI–IDD, the NCI–AD, the HCBS CAHPS survey, and CQL’s POM. They provide useful state-level data on access to care, care planning, community integration, health and welfare, and autonomy for people with disabilities.

Since CMS will require states to use these experience of care surveys for each population in their HCBS programs by 2027, these non-federal sources of disability equity data will become even more important. They are limited by typically smaller sample sizes, often not more than 400 individuals, which limits the ability to look at health outcomes for subgroups, such as individuals in particular types of settings, people of color with disabilities, or even differences between geographic regions. Some states conduct experience of care surveys with larger sample sizes that permit a more nuanced look at survey outcomes.²²

CMS has also been developing experience of care surveys that focus on mental health services. On June 19, 2024, AHRQ announced its first CAHPS outpatient mental health survey and its revised version 3 ECHO (The Experience of Care and Health Outcomes) for mental illness survey. AHRQ is still working on its inpatient psychiatric hospital experience of care survey.

Congress recently required state Medicaid and CHIP programs to report core quality measures for children and for adult behavioral health. CMS has published a core set of Medicaid HCBS quality measures, which will become required over the next several

Family-Centered Care, 21 (May 30, 2014),

<http://www.qualityforum.org/WorkArea/linkit.aspx?LinkIdentifier=id&ItemID=77001>.

²¹ At its May 8, 2024 webinar, AHRQ CAHPS focused on effective approaches to [“Listening to the Voice of the Patient.”](#) At its February 27, 2024 webinar, [Integrating Patient-Reported Outcomes into Practice: Benefits, Challenges, and Recommendations for Action](#), AHRQ discussed: (1) “Establishing Digital Infrastructure for Monitoring PROs as Quality Measures” and (2) “Can We Extract PRO Data from Structural EHR Data?”

²² For example, California’s NCI-IDD Adult Family Survey sample exceeded 7700 responses in 2021-22. This allows for more precision in looking at performance across subpopulations, geographic areas, and HCBS programs within the state. See National Core Indicators, *2021-22 CA Adult Family Survey State Report*, <https://idd.nationalcoreindicators.org/wp-content/uploads/2023/10/CA-Adult-Family-Survey-21-22-State-Report.pdf>.

years. This is commendable and could become an important source of state-level quality data on these essential disability services. However, the HCBS measure set will not address disparities that people with disabilities may encounter trying to access acute care or mental/behavioral health services that are included in the child and adult Medicaid core sets. CMS should find more reliable ways to flag disability such that adult and child core quality measures could be reported stratified by disability. This is particularly important given that people with disabilities experience high rates of co-occurring conditions, as described above.

3. Are there any Federal surveys or administrative data collection tools for which you would recommend the Federal Government should not explore collecting disability data due to privacy risk, the creation of barriers to participation in Federal programs, or other reasons? Which collections or type of collections are they, and why would you make this recommendation?

Surveys that do not include accessibility accommodations should not be used to collect data on disability. While we do not have recommendations on specific survey tools not to use, we note that tool design should pay special attention to who answers the survey tool, as it is very common that someone else – a parent or guardian or case manager, will fill out survey forms on behalf of an individual with a disability they work with. This does not necessarily invalidate the data collected, but it is essential information to guide the analysis of responses.

Studies of the ACS, for example, have shown that answers to the disability questions differ when someone answers the question for themselves versus when another household member answers for them.²³ If a survey form does not specify who filled out the answers, the data drawn from the survey can mislead. For example, when Michigan designed a beneficiary survey related to its HCBS settings compliance work, the researchers added a question at the beginning of the document asking who filled out the survey. They found that 94% of the 700+ responding beneficiaries had received assistance from their supports coordinator or case manager to fill out the form. Of those, only 41% of the assistance givers reported they had actually consulted with the beneficiary to fill out the survey!²⁴ Again, this does not necessarily invalidate the data

²³ Kristen Miller, J. Brent Vickers & Paul Scanlon, COLLABORATING CTR. FOR QUESTIONNAIRE DESIGN AND EVALUATION RESEARCH (CCQDER), NATIONAL CTR. FOR HEALTH STATISTICS, *Comparison of American Community Survey and Washington Group Disability Questions* (Oct., 2022), https://wwwn.cdc.gov/qbank/report/Miller_2020_NCHS_ACS.pdf.

²⁴ David Machledt, personal communication with survey designers, (Oct. 2015).

collected, but it provides crucial context to understand the responses provided. In this case, the revelation from the added questions led to a state letter to HCBS program and plan leaders admonishing them to ensure that the individuals responding to these surveys were “active participants” in the process.²⁵

4. How can Federal agencies increase public response rates to questions about disability in order to improve sample sizes and population coverage?

There are best practices related to this on Race/ethnicity data, such as informing people about why the data is important, how it will be used to address health inequities, and reassuring people the privacy protections for their responses. Another effective technique requires someone to provide a response to demographic questions, but including “prefer not to say” as an option. This remains consistent with the requirement that providing demographic data must be optional, but does not allow someone to simply skip that question.

5. What barriers may individuals with disabilities face when participating in surveys or filling out administrative forms?

Some of the barriers individuals with disabilities may face when participating in surveys or filling out administrative forms include lack of interoperability when reporting disability status (i.e., no standard mechanism in place to obtain such data or report it in a person’s electronic health records, vital records, etc.) This means that people with disabilities often need to reshare the same information repeatedly, which can become frustrating and tiresome. Then, depending on the collection mechanism, that information may not be consistent, transferrable, or updated from a centralized location. In addition to inaccessible formats and communication demands, there may be concerns regarding self-disclosure of disability (e.g., fears of discrimination) and cultural norms that may not provide a welcoming context to share personal information.

The mitigation of such barriers to support a more equitable healthcare space would go far to increase completion rates for those participating in surveys and filling out administrative forms.

²⁵ Thomas Renwick, Mich. DHHS, *Letter to Exec. Dirs. of PIHPs, Comm. Mental Health Programs, and HCBS Leads* (Oct. 17, 2017), https://www.michigan.gov/mdhhs/-/media/Project/Websites/mdhhs/Folder3/Folder73/Folder2/Folder173/Folder1/Folder273/HCBS_Surveys_Memo_101717.pdf.

6. Disaggregated data—data about groups separated out by disability, race/ethnicity, gender identity, sexual orientation, geography, income level, veteran status, rural/urban location, and other factors—are essential for identifying and remediating disparities in how the government serves American communities. Which data disaggregated by disability that are currently collected by Federal agencies are useful? Which data disaggregated by disability are not currently collected by Federal agencies and would be useful, and why?

While it has its limitations in terms of disability populations and ages represented, the CDC'S [Disability and Health Data System](#) (DHDS) does allow for surveillance via selection of: 1) various indicators (disability estimates, demographics, health risks and behaviors, prevention and screenings, barriers and cost of care, general health conditions, chronic conditions, mental and emotional health); and 2) various disability responses (any disability, cognitive, hearing, mobility, vision, self-care, independent living disability, no disability) by state and by year, which assists in tracking trends that can influence their health status, health outcomes and health disparities.

Regarding data that is currently not being collected, but may be useful: The primary federal disability data collection sources (e.g., ACS, CPS, SIPP, DHDS, BRFSS, MEPS) use the HHS standard set of six disability questions. These six yes/no questions ask about difficulty seeing, hearing, mobility, cognition, self-care and independent living. However, this set does not include a communication-focused question that addresses speech, language or voice function and access needs. While function and access related to hearing and cognition are two domains that professionals in the fields of audiology and speech-language pathology address, omission of a communication question as part of a standardized measure of disability data leaves out a significant portion of the population that we serve--those who have speech, language and voice disabilities outside of (or in conjunction with) any hearing or cognitive difficulties. That means there is no way to account for the millions of people who have speech, language, and voice disabilities when communication is at the center of our daily functioning, activities and life participation. People with chronic illnesses, mental health disabilities, and intellectual and developmental disabilities are also not specifically included. In addition, it is unclear how categories like cognitive disabilities are being defined and parsed. For example, developmental cognitive challenges can be quite different from acquired or progressive cognitive challenges, as are their associated needs and services.

Having disability data that helps track the incidence and prevalence of specific populations with communication disabilities and identify characteristics or social

determinants that can influence their health status, health outcomes and health disparities can be used to support policies, programs and funding within federal, state and local agencies to reduce barriers to health promotion and care. They can also be used to support the implementation and coverage of evidence-based interventions to ensure people with communication disabilities have access to quality care at both the systems and individual levels. Finally, it can help us better identify the effects of communication disabilities on the population's health and participation in society, for example, who has chronic conditions, who is eligible for or enrolled in certain services, who is using/needs assistive technologies or certain accommodations and community supports, who is forgoing medical care, or who is experiencing adverse preventable events that may be attributed in part to lack of effective communication access. Including the disability groups mentioned above when collecting disability data and documenting access barriers is imperative in recognizing and addressing health disparities and improving equitable, quality care. This disability data is also necessary for designing, targeting, and measuring outcomes of systems-based initiatives and establishing policies to improve the health and healthcare of people with disabilities.

7. How can Federal agencies best raise public awareness about the existence of sources of disability data? How can Federal agencies best communicate with the public about methodological constraints to collecting data or publishing disability statistics?

The Federal government needs to ensure that it is engaging the public in its work on disability, and should work to raise public awareness about disability data, as well as any methodological constraints to that data.

Engaging with CCD and other groups of people with disabilities should be a key priority for the Federal government in building a long-term stakeholder engagement process. While this RFI is an important step towards raising awareness of disability data, it is critical that the Federal government continue to receive the input of people with disabilities. The Federal government should form a committee of outside experts, including persons with disabilities and their families to examine best practices in data collection and test and implement those statistical methods. The Federal government should invite CCD and other disability groups to nominate people to this committee, and the committee should get the input of these groups throughout their process. This input should be from people with all different types of disabilities and at different stages of life. "Nothing about us without us" is a key tenet of the disability movement, and the Federal government needs to recognize the key role that people with disabilities can play in the process of collecting and publishing data.

Public service announcements and social media campaigns can also help raise public awareness of the need to collect disability data, but the Federal government needs to ensure that these communication methods are accessible for all people with disabilities.

Communicating methodological constraints can be done through transparent reporting, public forums, and educational materials that explain the limitations and efforts to improve data collection methods. By being open to public ideas and engagement, and transparent about their work and its limitations, the Federal government can help ensure that people with disabilities are more open to participating in research and surveys. Decades of discrimination and unfair practices have led many in the disability community to distrust the Federal government, so working with the disability community will be a long, but important, process for the Federal government. A key part of this process must include being as open and transparent as possible.

8. How do individuals and organizations external to the Federal Government utilize data from Federal surveys and administrative data collections? Which practices employed by Federal agencies facilitate access to and use of these data? Are there additional practices that would be beneficial?

There are myriad potential uses for federal disability data. Here we focus on promising practices for Medicaid data, which is a crucial program for people with disabilities. We support recent efforts to increase the transparency of state-reported data in Medicaid. Requirements in the recent Access rule to prioritize publicly posted quality data in a centralized web site and to phase in stratified reporting of Medicaid quality data on HCBS measures will greatly facilitate the use of these important data. Individuals and organizations external to the Federal Government frequently use available data, and would welcome higher quality and enhanced data, in efforts to improve the systems and services for individuals with disabilities.

There are also substantial barriers to accessing Medicaid data on people with disabilities. We endorse comments from researchers at the Community Living Policy Center at Brandeis University who note the extremely high cost of accessing claims data from the Transformed Medicaid Statistical Information System (T-MSIS).²⁶ The costs are prohibitive for most researchers and force them to rely on the tables and data that CMS

²⁶ Joe Caldwell, Community Living Policy Center at Brandeis University, *Comments re:Docket No. 2024-11838; Federal Evidence Agenda on Disability Equity Request for Information* (Submitted June 24, 2024).

analyzes and releases on its own. Finding ways to make that data more financially accessible for independent researchers would greatly expand the capacity of disability equity research.

Privacy, Security, and Civil Rights

1. What specific privacy and confidentiality considerations should the DDIWG keep in mind when determining promising practices for the Federal collection of data for administrative purposes, such as applications for programs or benefits, compliance forms, and human resources and restrictions on their use or transfer?

A July 2024 report in the New York Times discusses how administrative and private data sources are being used by federal agencies to supplement traditional federal survey data, at least in the area of financial/economic data, as survey response rates fail to rebound fully from their pandemic low points and agency budgets continue to be reduced:

Statistical agencies and outside experts agree that federal statistics will ultimately need to incorporate more data from private sources and administrative records alongside traditional surveys. That process has already begun: The Census Bureau, for example, uses data from the private-sector aggregators Circana and Nielsen to supplement survey data for its monthly retail sales report.²⁷

However, the use of administrative and private data to supplement granular data about who has disabilities is probably not happening because few administrative and private data sources collect data on disability status beyond the existence of a specific diagnosis. This is true even in electronic health records, though the requirements will be changing over the next few years.²⁸ This lost opportunity is unfortunate because granular information about disability status in administrative records would be very helpful for the disability community.

²⁷ Ben Casselman, *Reliability of U.S. Economic Data Is in Jeopardy, Study Finds*, THE NEW YORK TIMES (July 9, 2024), https://www.nytimes.com/2024/07/09/business/economy/economic-data-response-rates.html?campaign_id=57&emc=edit_ne_20240709&instance_id=128331&nl=the-evening®i_id=90809238&segment_id=171710&te=1&user_id=e2823957f7d56c77a27f8c7360af905e.

²⁸ See United States Core Data for Interoperability (USCDI) v. 3, Disability Status, at <https://www.healthit.gov/isp/uscdi-data-class/health-status-assessments#uscdi-v3>.

If demographic disability data were collected in administrative records, and that data in turn was aggregated with traditional federal survey data, it could potentially produce an overall larger pool of disaggregated data that will provide more reliable results and provide less potential for reverse engineering from small sample sizes to identify individual respondents. Another reason to improve the collection of demographic disability data in administrative records is to meet two strong needs of the disability community. First, such demographic data can provide evidence of disparities linked to the presence of disability (without a presumption that negative health outcomes are “caused” by disability). Second, specific functional limitation data can pave the way for electronic health records including the kinds of reasonable accommodations and policy modifications that many people with disabilities need to receive equally effective healthcare required by federal disability rights laws such as Section 504 and the ADA.

The federal collection of disability data simultaneously encourages and benefits from the broader collection of demographic disability data in administrative and other data sources. But the DDIWG must also appreciate and guard against the reality that ableism and negative consequences in education, housing, employment, healthcare, and so forth follow disclosures of disability, whether the disability is a health condition that employers stereotypically fear will lead to lost productivity and time, or a mental health condition that landlords or campus security automatically assume label someone as a public risk. The fact that Big Data use is common, largely unregulated, and easily used to impute disability to individuals, when better systemic data that could be used for accurate population estimates, disparities analyses, and individual accommodations needs is not readily available, leaves the disability community in a precarious position.²⁹

²⁹ Mary Lou Breslin & Silvia Yee, DISABILITY RIGHTS EDUCATION & DEFENSE FUND, RACE FORWARD, MOVEMENT ADVANCEMENT PROJECT, NATIONAL HEALTH LAW PROGRAM, AND JUSTICE IN AGING, *This Data Not That Data: Big Data, Privacy, and the Impact on People with Disabilities* (Mar., 2023), <https://healthlaw.org/resource/risks-and-rewards-of-demographic-data-collection-how-effective-data-privacy-can-promote-health-equity/>.

2. Unique risks may exist when collecting disability data in the context of both surveys and administrative forms. Please tell us about specific risks Federal agencies should think about when considering whether to collect these data in surveys or administrative contexts.

While the Health Insurance Portability and Accountability Act (HIPAA) protects information collected and used by covered entities, not all entities that collect, handle, use, or distribute health-related information are covered by HIPAA. People with disabilities must have strong protections relating to their health-related information, and this is perhaps particularly important for people with non-visible disabilities. It is easy to imagine a scenario wherein the exercise of one's civil rights can become, in itself, a flag of disability that can be used against an individual. For example, someone who regularly uses the wheelchair accessible or companion seats at a stadium when they buy tickets for sports or music events will not necessarily have that information protected as "health information," yet it is not difficult for disability to be imputed to the person or the household that purchases those tickets.³⁰ If privacy and security protections for "administrative forms" and uses of data are relaxed to allow certain uses of shared information by federal or state agencies, great care must be taken to ensure that this relaxation is not extended beyond uses that clearly meet the not for profit, socially beneficial needs of government, civil rights, consumer protection, and public health data collection.

3. Once disability data have been collected for administrative or statistical purposes, what considerations should Federal agencies be aware of concerning retention of these data? Please tell us how privacy or confidentiality protections could mitigate or change these concerns.

Sometimes privacy and data collection can be seen as competing interests. That is, the more one asks people questions and look for data, the greater the potential for data breaches that will, in turn, disincentivize people from providing information in future. However, the relationship between privacy and data collection can be more nuanced. When fewer people respond, due to lack of trust or fear that their personal information isn't safe, the reliability of what data there is lowers in quality and reliability. The very inaccuracy of the data will further fuel suspicions of bad motive, bias, and reluctance to provide information via traditional survey methods, even though direct personal answers tend to be more accurate.

³⁰ This scenario was posited by a law student at UC Berkeley Law who wrote an excellent paper on the subject for a 2003 fall disability rights class.

A large part of DDIWG's work in collecting better disability information must be to ensure strong protections, education, and clear enforcement in practice for such information. People with disabilities must be assured that they can safely and securely provide their information. Data privacy and data security are deeply intertwined, and both are critical to the substantive collection of accurate, good, maximal data which relies on population trust in both the process and the use of harvested data. *Tell* people with disabilities what the data is for, *show* them the benefits of the data in practice, and *include* people with disabilities when determining how data should be used setting priorities for how agencies determine and meet community needs.

DDIWG must develop and robustly enforce privacy and security protections for disability data because ableism and civil rights violations make it highly likely that people with disabilities will be subjected to discrimination in housing, employment, and other social drivers of health upon any data breach, particularly if these breaches occur in conjunction with information about other personal characteristics. The key is to ensure that the best data about disability, derived whenever possible from the source which is people with disabilities themselves, is obtained, protected, and available to combat erroneous information.

4. Where administrative data are used to enforce civil rights protections, such as in employment, credit applications, healthcare settings, or education settings, what considerations should the DDIWG keep in mind when determining promising practices for the collection of these data and restrictions on its use or transfer?

One critical additional component that DDIWG must consider when thinking about how data is used to enforce civil rights proceedings is the impact of Big Data practices and the ascendant use of AI to both generate "new" sources of information and inform decision-making upon digesting large sources of information. Federal agencies that have any involvement in civil rights enforcement should recognize that the collection, transfer, and use of enormous banks of data to train AI means that:

- The training data inevitably includes ableism and systemic bias against people with disabilities;
- General population data will tend to obscure both those who are significantly disabled and whose existence can be masked because of much lower prevalence numbers, and those with chronic disabilities and conditions because they may not be recognized as being disabled with support and accommodation needs;

- The specific nuances of disability rights law, and particularly the obligation of covered entities to extend reasonable accommodations and policy modifications and assess the capacity/eligibility of people with disabilities *after* accommodations have been made, are likely lost. That is, AI will equally absorb and weigh instances where people with disabilities have encountered denials of their civil rights as much as instances where their civil rights have been observed.

The result is that disability bias in AI use is likely to be both common and difficult to discern. DDIWG must carefully consider how to counter the above factors to ensure that people with disabilities can reap the alleged efficiencies and benefits of AI use without constantly being confronted by repeating stereotypes and biases perpetuated by AI generated data and decision-making.

Thank you for the opportunity to share our views and resources on improving data collection and reporting on disability data across the federal government. If you have any questions about our comments, please contact David Machledt (machledt@healthlaw.org).

Sincerely,

American Association on Health and Disability
American Council of the Blind
American Music Therapy Association
American Network of Community Options and Resources (ANCOR)
American Speech-Language-Hearing Association
American Therapeutic Recreation Association
The Arc of the United States
Association of People Supporting Employment First (APSE)
Association of University Centers on Disabilities
Autistic Self Advocacy Network
CommunicationFIRST
Disability Rights Education and Defense Fund (DREDF)
Epilepsy Foundation
IEC (Institute for Exceptional Care)
Justice in Aging
Lakeshore Foundation

Muscular Dystrophy Association
National Association of Councils on Developmental Disabilities
National Center for Parent Leadership, Advocacy, and Community Empowerment
(National PLACE)
National Disability Rights Network (NDRN)
National Down Syndrome Congress
National Health Law Program
Perkins School for the Blind
Tourette Association of America
United Spinal Association