LAKESHORE

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Submitted via regulations.gov

Re: Notice of Availability and Request for Information; Federal Evidence Agenda on Disability Equity; FR Doc. 2024-11838

The American Association on Health and Disability and the Lakeshore Foundation appreciate the opportunity to provide comments.

The American Association on Health and Disability (AAHD) (www.aahd.us) is a national non-profit organization of public health professionals, both practitioners and academics, with a primary concern for persons with disabilities. The AAHD mission is to advance health promotion and wellness initiatives for persons with disabilities. AAHD is specifically dedicated to integrating public health and disability into the overall public health agenda.

The Lakeshore Foundation (www.lakeshore.org) mission is to enable people with physical disability and chronic health conditions to lead healthy, active, and independent lifestyles through physical activity, sport, recreation and research. Lakeshore is a U.S. Olympic and Paralympic Training Site; the UAB/Lakeshore Research Collaborative is a world-class research program in physical activity, health promotion and disability linking Lakeshore's programs with the University of Alabama, Birmingham's research expertise.

AAHD and the Lakeshore Foundation were actively engaged in drafting the submission comments of the **Consortium for Constituents with Disabilities (CCD)** and we signed and endorsed the CCD comments. CCD addresses a wide variety of questions and topics. AAHD also is a member of the **Disability and Rehabilitation Research Coalition (DRRC)** and the **National Health Council,** each of whom are submitting comments. We fully support the larger disability and health community array of interests and concerns, while focusing in this letter on three areas.

AAHD and the Lakeshore Foundation address here several high priority data equity related issues:
1. **Co-Occurring Conditions: RFI What Is Not Understood Question Response**
2. **Person-Reported Experience as a Data Challenge: RFI Federal Data That Could Help Inform a Federal Disability Equity Agenda Question Response.**
3. **Medicaid Administrative Data and Disability (including the relation between Medicaid core quality measures and Medicaid HCBS core quality measures): RFI Federal Data That Could Help Inform a Federal Disability Equity Agenda Question Response.**

RFI Question One: What disparities faced by individuals with disabilities are not well-understood through existing Federal statistics and data collection?

We concur and reinforce the introductory overview provided by the **Urban Institute**: "There is a need for more and better research on: (1) how to measure disability; (2) whether people with disabilities who are eligible for federal programs are getting the services relative to their needs; and (3) where there are gaps in federal data that make it difficult to measure outcomes for individuals with disabilities."

Co-Occurring Conditions: RFI What Is Not Understood Question Response

People with disability and co-occurring health conditions experience unique disparities of under-treatment, under-served, under-supported, with worse health outcomes.

Our AAHD and Lakeshore Foundation comments discuss the following populations overview:
Co-occurring Disability and Health Conditions
Siloed systems for persons with IDD, SMI, SUD
Co-occurring IDD and MI
Co-occurring MI and Chronic Medical Conditions
Co-occurring MI and SUD
Co-occurring Disability and SUD
Co-occurring IDD and Health Conditions
Definitions of Disability and Major Bodily Functions

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 disease; and 2 times more likely not to see a doctor due to cost. {Source: AAHD National Disability Navigator Resource Collaborative September 30, 2022 newsletter, summarizing Krahn, Walker, and Correra-DeAraujo "Persons with Disabilities as an Unrecognized Health Disparity Population" in: American Journal of Public Health, February 17, 2015.]

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, while targeting funding and staffing condition expertise, are not designed for addressing whole-person needs. Integration of services and supports a priority. State ID/DD agencies reported that 48% of **persons with IDD had a co-occurring mental illness**, in 2018. The percentage of state respondents with such a

dual diagnosis ranged from 34% to 64%. [Source: NASDDDS and HSRI: "What Do NCI Data Reveal About People Who Are Dual Diagnosed with ID and Mental Illness," October 2019; National Core Indicators.]

Percentage of Medicare FFS Beneficiaries – **Mental Illness and Co-Occurring Health Conditions**: 6% had depression with 23% of these persons having one-to-two co-occurring health conditions and 28% having three-to-four co-occurring conditions. 9% had schizophrenia or other psychotic conditions with 22% of these persons having one-to-two co-occurring health conditions and 24% having three-to-four co-occurring conditions. 4% had a drug abuse or substance abuse condition with 20% having one-to-two co-occurring conditions and 26% having three-to-four co-occurring conditions. 4% had an alcohol abuse condition with 20% having one-to-two co-occurring conditions and 28% having three-to-four. [Sources: 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; and, Medicare Service Utilization by Specialty: Disability-Behavioral Health-SDOH-Non/Metro Area (proposed CMS PFS rules, Table 107, August 2023).

While 61.2 million adults had either a mental illness or substance abuse disorder in 2019, 9.5 million had both a **mental illness and co-occurring SUD**. [Source: National Quality Forum (NQF), CMS funded, June 17, 2022 report "Addressing Opioid-Related Outcomes Among Individuals with Co-Occurring Behavioral Health Conditions."]

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. [Source: Disability Policy Consortium. "Urgent Need To Address Substance Abuse Among People with Disabilities in Massachusetts." November 2017.]

Adults with ID/DD and Co-Occurring Health Conditions. Over 45% of Medicaid beneficiaries with ID/DD enrolled in HCBS (Home-and-Community-Based Services) had an additional health condition in 2019. 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. [Source: April 2023 GAO report on Medicaid Characteristics and Expenditures for Adults with ID/DD.]

Compared to their peers without disabilities, adults with ID/DD were 5 times more likely to have diabetes, 3 times more likely to have arthritis, more than twice as likely to have cardiovascular disease, and more than twice as likely to have asthma. People with disabilities have difficulty finding able and willing healthcare providers and many providers do not take the time to listen or respect. Healthcare providers report that they are unprepared and uncomfortable caring for patients with disabilities. [Source: ID/DD and Co-Occurring Health Conditions – December 8, 2021 Ohio State University presentation to the National Academy of Medicine workshop on Optimizing Care Systems for Persons with ID/DD.]

We concur and support the comments of our colleague organization – **National Partnership for Women and Families (NPWF)** have submitted:
"A lot of current questions about functional limitations fail to incorporate all disabilities covered under the Americans with Disabilities Act (ADA), or the legal definition of disability, as well. The ADA more broadly defines disability as "(A) a physical or mental impairment that substantially limits one or more major life activities of such individual; (B) a record of such an impairment; or (C) being regarded as having such an impairment." [Source: 42 USC 12101 (1) (2023]. Congress explicitly expanded the definition of disability in the Americans with Disabilities Act Amendments Act of 2008 (ADAAA) to include "major bodily functions," such as gastrointestinal, immunological, endocrine and other functions. [42 USC 12102 (2) (B) (2023)]. Disabled people with conditions such as Crohn's Disease, diabetes or endometriosis, for example – which are covered under the ADAAA – may not be counted currently in data sets that do not adopt a similar definition. Chronic pain or chronic conditions covered under the ADAAA are also often not captured."

RFI Question Two: 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?

Person-Reported Experience as a Data Challenge

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 the individual's lived experience. The health care arena

currently calls this "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.

In its CMS authorized, report to the CMS, the National Quality Forum (NQF) observed: "Patient and family engagement is increasingly acknowledged as a key component of a comprehensive strategy, (along with performance improvement and accountability), to achieve a high-quality, affordable health system. Emerging evidence affirms that patients who are engaged in their care tend to experience better outcomes." [Source: National Quality Forum. "Patient-Reported Outcomes (PROs) in Performance Measurement." January 10, 2013, page 3.]

In its CMS authorized, report to the CMS, 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 over-arching term to encompass the health and healthcare needs of all individuals, regardless of age, setting, or health status." [Source National Quality Forum. "Finding Common Ground for Healthcare Priorities: Families of Measures for Assessing Affordability, Population Health, and Person-and-Family-Centered Care." May 30, 2014, page 21.]

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. At its May 8, 2024 webinar, AHRQ CAHPS focused on effective approaches to "Listening To The Voice of the Patient" and "Capturing the Voice of the Customer." At its February 27, 2024 webinar, AHRQ discussed: (1) "Establishing Digital Infrastructure for Monitoring PROs as Quality Measures" and (2) "Can We Extract PRO Data From Structural EHR Data?"

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.

CMS is moving state Medicaid agencies toward an evolving home-and-community-based services (HCBS) experience-based measures that states build using **CAHPS (Consumer Assessment of Healthcare Providers and Systems) HCBH; National Core Indicators (NCI)-IDD; National Core Indicators**

(NCI)-AD; and Personal Outcome Measures (POM). [Source: CMS Informational Bulletin. "2024 Home-and-Community-Based-Services (HCBS) Quality Measures Set." April 11, 2024.]

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 Institute (HSRI), who help administer NCI, have also published reports on NCI data examining health disparities for people of color with disabilities. [Source: NASDDDS and HSRI. "National Core Indicators Data Brief: What Do NCI Data Tell Us About Significant Racial and Ethnic Disparities Across the Life and Health Domains. February 2021.] 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.

While the HCBS measures cited above include persons with mental illness, 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. [Source. AHRQ. CAHPS Mental Health Surveys." June 19, 2024.] AHRQ is still working on its inpatient psychiatric hospital experience of care survey. SUD experience measures are well behind the evolution of mental illness measures.

Missing from the current array of HCBS measures are standardized and complete public transparency of state-specified outcomes data and segmentation by disability categories and other demographic factors.

RFI Question Two, Continued: 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?

Medicaid Administrative Data and Disability

From the CCD submission: 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. [Source: Kaye and Caldwell. "Excess Deaths of Medicaid Home-and-Community-Based Services Recipients During COVID-10." In: Health Affairs, 115, 2023.]

From the CCD submission: **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.

CMS recently required state Medicaid and CHIP programs to report core quality measures for children and for adults. [Source: CMS SHO #2024-001. "2025 Updates To The Child and Adult Core Adult Health Quality Measure Set and Mandatory Reporting Guidance." May 30, 2024.] CMS has published a core set of Medicaid HCBS quality measures, which will become required over the next several years. [Source: CMS Informational Bulletin. "2024 Home-and-Community-Based-Services (HCBS) Quality Measures Set." April 11, 2024.]

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.

Further: CMS requires a core quality measure set for Medicaid and CHIP. CMS requires an evolving core Medicaid HCBS quality measure set. HCBS beneficiaries are NOT subject to the Medicaid core measures. CMS should consider eventual integration of the Medicaid core quality measure set and the HCBS core quality measure set to promote and document whole person health measures for Medicaid HCBS beneficiaries. Currently – by excluding HCBS beneficiaries from the Medicaid core QM set, they are only subject to HCBS-specific services and their general health conditions are ignored. Over time, the two requirements and systems should be integrated, in name of whole-person health. Services should be coordinated and communicated between Medicaid general health, Medicaid primary care, and Medicaid HCBS: and, service plans and services delivered should be documented and shared between general health Medicaid and Medicaid HCBS.

Thank you for the opportunity to comment. If you have any questions please contact Clarke Ross at clarkeross10@comcast.net.

Sincerely,

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