American Association on Health & Disability

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AAHD - *Dedicated to better health for people with disabilities through health promotion and wellness*

LAKESHORE

April 9, 2026

Re: Disability Status as demographic element in the United States Core Data for Interoperability (USCDI)

The American Association on Health and Disability and the Lakeshore Foundation appreciate the opportunity to provide comments to the Office of the National Coordinator for Health Information Technology.

The American Association on Health & Disability (AAHD) (www.aahd.us) is a national nonprofit organization committed to advancing health equity, community inclusion, and wellness for people with disabilities through research, policy, and knowledge translation. AAHD is focused on addressing systemic barriers to health inequity, strengthening disability data infrastructure, and advancing a human rights–based approach to disability across research and healthcare systems. 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.

We appreciate the opportunity to provide comment and strongly urge the Assistant Secretary for Technology Policy/Office of the National Coordinator for Health Information Technology (ASTP/ONC) to adopt the recommendations of the PACIO Project to improve the representation of disability within the United States Core Data for Interoperability (USCDI).

Specifically, AAHD supports the following actions:

- Renaming the existing "Disability Status" data element under the Health Status Assessments data class to "Disability Assessment," with a clarified definition and updated examples.

- Adding a new “Disability Status” data element under the Patient Demographics/Information data class, consistent with the HHS Data Council’s Implementation Guidance and the intent of Section 4302 of the Affordable Care Act.

AAHD strongly urges ASTP/ONC to adopt the recommendations of the PACIO Project that include making this important distinction. This distinction is foundational to the disability community and from our organizational commitment to improving the quality, equity, and utility of disability data and ensuring that data systems accurately reflect the lived experiences of people with disabilities. Improving the quality and consistency of disability data is essential to delivering equitable healthcare, particularly in light of the well-documented disparities experienced by people with disabilities across healthcare access, quality, and outcomes. When healthcare systems systematically collect and use accurate disability data, they are better equipped to identify unmet needs, tailor care, allocate resources effectively, and monitor progress toward reducing these disparities.

Disability status is a patient-reported demographic characteristic, not a clinical determination. The Federal Evidence Agenda on Disability clearly states, “Physical examinations are never appropriate for identity documentation.” (p. 43, 2025). Additionally, research shows that disability self-identification remains notably misaligned with the prevalence of health conditions, reflecting a gap shaped by a range of social, cultural, and structural factors that are well-studied and understood by the disability community (i.e., Bogart et al., 2017; Hall et al., 2022). Meaning, even with the presence of health conditions, many individuals do not report disability on their own. Additionally, asking individuals to self-report disability identification is different than asking individuals to self-report functional limitations—which is what the widely used American Community Survey (ACS) 6 questions do. Many use measures such as the ACS-6 as a proxy for self-reported disability, however, researchers are working to explore better ways of asking those questions since functional limitations are not always the same as how much a disability is a part of a person's identity (See Landes et al, 2025). Until the measurement science catches up, however, the widely adopted ACS-6 questions would provide a helpful and unique data element under the patient demographics/information data class.

The combination of self-reported functional limitations from patient demographics AND clinical assessment of disability from clinicians gives a more complete picture of individuals with disabilities. Clinical diagnoses identify specific medical conditions based on standardized criteria, while self-report about functional limitations reflects how individuals experience functional limitations and participation in daily life—often shaped by social and environmental barriers that clinical measures may miss. Because disability is both a medical and lived, contextual experience, relying on only one approach provides an incomplete picture. We need both to ensure accurate data, equitable policy, and research that truly reflects the realities of disabled people’s lives. It should be noted that self-reported disability identity status is a different type of question that is not currently reflected in the proposed changes.

In reality, there may be alignment between both clinical assessment and self-report of functional limitations, as these individuals have a documented condition and also acknowledge the limitations presented because of that disability and may embrace disability as part of their identity. Though, there may also be examples from the disability community and supported by research that shows misalignment: For example, individuals may meet the criteria of disability based on clinical assessment but do not self-report functional limitations. This could be due to stigma, cultural factors, using assistive devices that minimize the impacts on functional limitations, age—late onset or individuals aging into disability are less likely to self-report functional limitations. There may also be individuals who self-report functional limitations but do not have a clinical assessment that corroborates, this often occurs for hard to diagnose conditions, as one example, or fluctuating conditions that make clinical assessment at a specific moment in time challenging, yet these individuals may experience functional limitations, chronic conditions, or disabling environments even in the absence of a formal diagnosis.

As such, if policy relies only on clinical diagnosis, it may miss people who are functionally impacted or are undiagnosed. If it relies only on self-reported functional limitations, it may miss those who qualify clinically but based on their environmental set up or assistive devices used they may not report functional limitations, as an example. Using both approaches helps create a more complete understanding of disability across populations. Therefore, we urge ASTP/ONC to recognize that disability status and clinical impairment are not interchangeable and that there is a need to better develop strategies for capturing data during clinical encounters to improve healthcare delivery that addresses the unique and evolving needs of people with and without disabilities.

Thank you for the opportunity to comment. If you have any questions please contact Anjali Forber-Pratt at aforberpratt@aahd.us

Sincerely,

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