Comment for Draft USCDI V7 Disability Status

from the PACIO Community

Health Status Assessments Data Class — Disability Status Data Element (V3)

Version 2.5

Executive Summary

Independent capture of Disability Status as a Patient Demographic in the United States Core Data for Interoperability (USCDI), separated from rather than included along with disability assessments, is a foundational step toward equal health treatment for the more than one in four American adults who report living with a disability. [11] Based on the consensus of the PACIO Disability Status Work Group — comprising clinicians, EHR vendors, health systems, disability advocates, and federal agency participants — the PACIO Community respectfully urges the Assistant Secretary for Technology Policy (ASTP) to:

(1) Rename the existing "Disability Status" data element under the Health Status Assessments data class to "Disability Assessment" and provide a refined definition and updated examples for the data element.

(2) Add a Disability Status data element under the Patient Demographics/Information data class, consistent with the HHS Data Council's own Implementation Guidance and with the intent of Section 4302 of the Affordable Care Act (ACA). A corresponding ONDEC submission is forthcoming.

These recommendations aim to disambiguate between demographic and clinical uses of disability-related data by clarifying that (1) the Health Status Assessments element captures clinician-collected health assessment data and (2) the new Patient Demographics/Information element captures self-reported disability status as a demographic characteristic.

This comment documents the benefits that proper capture of “Disability Status” as a demographic will enable: closing persistent gaps in health surveillance, unlocking cross-system interoperability for demographics across federal agencies and post-acute care settings, reducing conflation of demographics with clinical assessment, and advancing patient autonomy. It also addresses the functional framing of the American Community Survey six-question set (ACS-6) on disability and demonstrates that this framing is immaterial to its classification as a demographic data element.

Recommendations

Data Class	Health Status Assessments
Data Element	Disability Status → Disability Assessment
Recommendation	Recommend renaming this data element “Disability Assessment” and removing the American Community Survey from the list of examples in the definition.
Rationale Summary	This recommendation is provided in concert with the proposal of a new Disability Status data element to properly capture patient demographic information.

	Definition: *Assessment of a patient's physical, cognitive, or psychiatric disabilities.* *Examples include but are not limited to the Veterans RAND Health Survey (VR-12) and Patient-Reported Outcomes Measurement Information System (PROMIS).* The data element name change, and example update clarify the use of this data element for health assessments and the clinical data that it will cover.

Data Class	Patient Demographics/Information
Data Element	Disability Status (new ONDEC submission)
Recommendation	Recommend the creation of the Disability Status data element under the Patient Demographics/Information data class.
Rationale Summary	Disability Status, as defined by the HHS ACS-6 standard, is a demographic characteristic collected for population-level health surveillance. The collection of this data element will fulfill the data capture as described in the HHS Implementation Guidance to ensure that disability status is collected alongside race, ethnicity, sex, and primary language as a standardized demographic characteristic, enabling the identification, monitoring, and equal health access for people with disabilities. Definition: *A self-reported status that identifies individuals with disabilities or conditions that impact major life activities, used to ensure equal access and may inform accommodation needs.* *Examples include but are not limited to the required responses for the American Community Survey six-question set (ACS-6) and optional capture of other surveys such as the Washington Group Short Set on Functioning (WG-SS).* Please see the ONDEC submission for a full rationale and USCDI Leveling Criteria review.

Three-Domain Framework Synopsis

The PACIO Disability Status Work Group was convened to delineate different types of disability-related data. This work group includes clinicians, EHR vendors (Epic, PointClickCare), health systems (University of Pittsburgh Medical Center, Kaiser Permanente, Mass General Brigham), subject matter experts (participants from the World Health Organization's Functioning and Disability Reference Group/Bradley University, Centers for Medicare & Medicaid Services, National Institutes of Health), a disability advocacy organization (DEC), and federal benefits agency (Social Security Administration). The federal benefits agency was included to ensure that the recommendation reflects the full landscape of disability-related data and provides the clearest possible case for how disability data are used across the various systems that impact patients.

In their deliberations, the work group identified that the current USCDI "Disability Status" data element commingles patient-reported demographic data with clinician-gathered health assessment data. [1] Ultimately, they reached consensus on conceptualizing disability data across three distinct domains:

Domain 1: Demographic Data (Patient Self-Report): Disability status as a patient-reported demographic attribute, collected alongside race, ethnicity, sex, and primary language as required under ACA Section 4302 [2] and the HHS Data Council's Implementation Guidance. [3]

- This information is used for population identification, health access tracking, and accommodation triggers. The primary instrument is the ACS-6, which the work group recommends expanding to include a communication disability question. A person's self-reported disability status is demographic data, not a clinical finding.

Domain 2: Health Assessment Data (Clinician-Collected): Clinical assessments of functioning and impairment, administered or ordered by licensed healthcare providers, utilize health assessment instruments like the VR-12 and PROMIS.

- These assessments involve episode-specific, clinician-collected measures, such as the VR-12 and PROMIS. Data gathered via these measures are used for clinical decision-making, treatment planning, and outcomes measurement.

Domain 3: Benefits Eligibility Data (Benefits Agency-Determined): Disability determination conducted by federal agencies (e.g., Social Security Administration, Veterans Benefits Administration) under separate statutory authority. [6,7]

- This domain relates to evaluations based on stringent criteria for benefits determination specific to a federal agency. These findings do not require a USCDI data element; the healthcare system's role is to produce and share high-quality health assessment data that supports the determination process.

Implications for USCDI

The Disability Status Work Group reached strong agreement that patient-reported disability status, represented by the ACS-6, should be separated out from disability assessments and nested within the Patient Demographics/Information data class. The group also agreed that disability-related health assessments, separate from disability status, should remain under the Health Status Assessments data class, with example assessments being the VR-12 and PROMIS. The group agreed that no USCDI data element is needed for the benefits eligibility domain. [8]

Rationale

The Lack of Concordance of What "Disability Status" Currently Encompasses

The current USCDI data element "Disability Status" is classified under the Health Status Assessments data class and lists the ACS-6, VR-12, and PROMIS as equivalent examples under a single “Disability Status” element [1] The ACS-6 is a demographic self-report instrument developed by a federal interagency committee for population-level identification—the same category of data collection as the race, ethnicity, sex, and primary language standards established under the same statute. [2,3] The VR-12 and PROMIS measures are clinical health assessment and screening instruments that assess functioning and health-related quality of life. These measures serve fundamentally different purposes, are collected by different actors, at different points in the care process, under different legal authority – this signals the lack of concordance of what this data element encompasses and the need to bifurcate it to have conceptually-aligned data elements, one data element for demographics and another for assessments.

Alignment with Federal Policy and Congressional Intent

Current regulations clearly delineate disability demographic data as its own type of data, indicating the need to keep it separate from health assessment data.

- **Section 4302 of the Affordable Care Act** explicitly groups disability status with race, ethnicity, sex, and primary language as demographic data collection standards. [2]
- **The HHS Data Council’s Implementation Guidance** (October 2011), authored by the Office of the Assistant Secretary for Planning and Evaluation (ASPE), implements this statutory requirement by establishing the ACS-6 as the disability standard within the same framework used for the other four demographic variables. [3]
- **A U.S. Government Accountability Office** report (December 2025; GAO-26-107120) found that HHS established the ACS-6 as its demographic data standard for disability status. [10]

Classifying disability status as its own data element, separate from disability assessment and nested under Patient Demographics/Information, directly aligns with the intent of these regulations.

To support cross-agency data harmonization and health data interoperability, it is important for USCDI to align its disability status data element with this federal guidance. The Disability Status data element within USCDI should therefore be created to separate it out from disability assessments and included under the Patient Demographics/Information data class, consistent with how race, ethnicity, sex, and primary language are already classified as per federal regulations.

Data Standards Represent Minimum not Maximum

The data standards described in the HHS Implementation Guidance represent minimum standards and are not intended to limit the collection of needed data. “Agencies desiring more granularity or additional data are permitted and encouraged to collect additional data as needed as long as: the minimum standard is included; […]. For the disability data standard, although survey questions and answer categories included in the standard cannot be changed, **additional disability questions may be included.**” [3]

Begin Responsible Data Collection Immediately

Just as continued research is necessary to improve the quality of other data collections, the federal government should continuously strive to improve its disability data collection methods.

However, in most circumstances, agencies have enough knowledge about appropriate disability questions and data collection approaches to responsibly begin collecting disability data now. [9]

Addressing the Functional Framing of the ACS Disability Status Questions

While the ACS-6 disability status question set adopted by HHS employs functional language, asking respondents whether they experience “serious difficulty” with various abilities and activities, the *purpose* of this question set is to capture information about disability prevalence to support equal access to healthcare. This indicates that these disability questions are conceptualized as a demographic, not as a functional assessment. The PACIO Community therefore recommends capturing disability status data as an independent data element separated from disability assessment data.

Recommendation.

For these reasons, the PACIO Community maintains that the functional framing of the ACS-6 questions is immaterial to their classification. The purpose of these questions is not to assess function—it is to identify a demographic population. That the questions use functional language is a methodological choice about how to reliably identify individuals with disabilities, not an indication that the resulting data belongs in a distinct data element. Disability status is collected via the ACS-6 to identify support population-based health statistics and policy accountability, thus its capture within USCDI should reflect that purpose.

** The PACIO (Post-Acute Care Interoperability) Project, established February 2019, is a collaborative effort between industry, government, and other stakeholders, that aims to advance interoperable health information exchange between post-acute care (PAC) providers, patients, and other key stakeholders across health care.*

References

1. Draft USCDI V7 Disability Status data element and Accommodation data element, ASTP/ONC (healthit.gov).
2. ACA Section 4302 (2010).
3. U.S. Department of Health and Human Services Implementation Guidance on Data Collection Standards for Race, Ethnicity, Sex, Primary Language, and Disability Status. ASPE, Office of Health Policy (October 2011).
4. Federal Register Vol. 79, No. 38 (February 26, 2014). HHS request for public comment on potential addition of a communication disability question to the ACS-6 standard.
5. Washington Group Short Set on Functioning Questions (WG-SS). Washington Group on Disability Statistics (October 2022).
6. Social Security Act, Titles II and XVI — disability determination for benefits eligibility.
7. VA disability rating system — service-connected disability rating schedule (0–100%).
8. PACIO Community’s Previous Comment on Disability Status (submitted 2025-09-12).
9. Federal Evidence Agenda on Disability, A Report by the Disability Data Interagency Working Group of the National Science and Technology Council. January 2025.
10. U.S. Government Accountability Office. GAO-26-107120 (December 2025).
11. U.S. Centers for Disease Control and Prevention, Disability Impacts All of Us Infographic (April 14, 2025).

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