

Disability

This document was developed by the Data Standardization Work Group (DSWG) of the Council of State and Territorial Epidemiologists (CSTE) Surveillance Practice and Implementation Subcommittee (SPIS) as a part of a larger data harmonization effort. It will be published and maintained in a repository on the CSTE website.

More information about the DSWG and data harmonization can be found here: [link to DSWG Core Surveillance Project Brief (pending)].

Background

Public health agencies rely on accurate disability data in order to better understand the prevalence of disabilities and subsequent requirements of certain populations as well as to gauge the impact of reportable and emerging conditions on populations with specific disability types. A disability can be defined as any condition of the body or mind that makes it more difficult for the person with the condition to do certain activities and interact with the world around them. Given that a wide range of disabilities exists which result in varying service requirements, data elements need to be able to support and capture the variability.

The current standard for the collection of disability status data consists of a six-item set of questions that has been accepted by the US Department of Health and Human Services (HHS) as the minimum requirement, although additional information on disability may be collected. These questions were developed by a federal interagency committee with the goal of capturing information on functional limitations across several domains and have been vetted and validated through several rounds of field testing. They are now used in multiple federal data collection systems, including the American Community Survey (ACS) conducted by the US Census Bureau.

The ACS questions currently cover six disability types with the approved response set for each question being "Yes" or "No" (Table 1). Specific age thresholds apply to each question: five years and older for the first five questions and 15 years and older for the last question.

Table 1. Disability-Related Questions from American Community Survey (ACS)

Disability Type	Question	Responses
Hearing	Are you deaf, or do you have serious difficulty hearing?	1. Yes 2. No
Vision	Are you blind, or do you have serious difficulty seeing, even when wearing glasses?	
Cognition	Because of a physical, mental, or emotional condition, do you have serious difficulty concentrating, remembering, or making decisions?	
Ambulatory	Do you have serious difficulty walking or climbing stairs?	
Self-care	Do you have difficulty dressing or bathing?	
Independent Living	Because of a physical, mental, or emotional condition, do you have difficulty doing errands alone such as visiting a physician's office or shopping?	

Although the ACS is one of the most widely used and adopted standards for the collection of disability data in the United States, the Washington Group on Disability Statistics created the Washington Group Short Set on Functioning (WG-SS) to support this effort internationally. This set includes six internationally validated questions on functioning for use in national censuses and surveys (Table 2). Instead of the dichotomous (Yes/No) responses used in the ACS, the range of options in the WG-SS allows for more detailed and flexible analysis. Typically, any response of “3. A lot of difficulty” or “4. Cannot do at all” is interpreted as presence of a disability.

Table 2. Washington Group Short Set on Functioning

Disability Type	Question	Responses
Vision	Do you have difficulty seeing, even if wearing glasses? Would you say...	1. No difficulty 2. Some difficulty 3. A lot of difficulty 4. Cannot do at all 7. Refused 9. Don't know
Hearing	Do you have difficulty hearing, even if using a hearing aid(s)? Would you say...	
Mobility	Do you have difficulty walking or climbing steps? Would you say...	
Cognition (Remembering)	Do you have difficulty remembering or concentrating? Would you say...	
Self-care	Do you have difficulty with self-care, such as washing all over or dressing? Would you say...	
Communication	Using your usual language, do you have difficulty communicating, for example understanding or being understood? Would you say...	

The ACS and WG-SS are largely similar in the types of disability that are addressed in each set of six questions, and neither survey identifies people with intellectual or developmental disabilities. In addition to direct questions posed to an individual, disability status can also be ascertained through certain diagnoses or underlying health conditions known to be associated with disability. A scientific panel of subject matter experts, including people with lived experience with disability, is being convened by CDC and ASTHO to identify such conditions in clinical terms in order to support the querying of electronic health records to identify people with disabilities.

The only Message Mapping Guide (MMG) that currently captures disability information for transmission to CDC via routine case notifications is the COVID-19 MMG. The Risk Factor Repeating Group value set includes a concept of “Disability” which is paired with a Risk Factor Indicator value of “Yes” or “No” to indicate the presence or absence of a disability. “Type of Disability” (LOINC code 95377-8) is a free text data element directly following this repeating group which allows the sender to further specify the type of disability.

Table 3. Disability Data Elements from the COVID-19 MMG

Data Element (DE) Name	DE Identifier Sent in HL7 Message	Data Element Description	Value Set Name (VADS Hyperlink)
START: Risk Factor Repeating Group			
Patient Epidemiological Risk Factors	INV1117	Underlying medical conditions or risk behaviors for the case patient. Please provide a response for each underlying medical condition and risk.	Risk Factor (COVID-19)
Patient Epidemiological Risk Factors Indicator	INV1118	Provide a response for each value in the risk factors value set	Yes No Unknown (YNU)
END: Risk Factor Repeating Group			
Type of Disability	95377-8	If disability indicated as a risk factor, indicate type of disability (neurologic, neurodevelopmental, intellectual, physical, vision or hearing impairment)	N/A

Core Surveillance Disability Data Elements for Routine Case Notifications

The DSWG came to consensus that disability should be considered a core surveillance data element for case notification to CDC. The value set associated with this data element (Table 4) outlines the categories of disability which the group determined to be the minimum core disability categories for case notifications.

Because the ACS questions are the minimum standard for collection of disability information for HHS, DSWG discussions focused primarily on two topics:

1. Determining whether categories other than the primary six ACS questions should be included in the disability category value set.
2. Deciding whether or not a “No” or “Unknown” value was necessary for each disability category to ensure the data being sent to CDC was meaningful and potentially comparable across jurisdictions.

In addition to the HHS minimum dataset, the final value set (Table 5) incorporated a communications category similar to that from the WG-SS and an intellectual disability category. The group also established the need for each disability category to have a Yes/No/Unknown answer as it is important to be able to distinguish between a negative screening and a lack of information. A two-element repeating block is required for an HL7 formatted case notification, as a repeating element would not suffice. (Table 4) If a repeating block is not used, it would be imperative that each value in Table 5 be converted into its own individual data element.

Table 4. Core Surveillance Data Element for Routine CDC Case Notification – Disability Type

Disability Type	
Definition	Type of disability (vision, hearing, mobility, cognition, self-care, independent living, communication, or intellectual/developmental).
Standard Code for Transmission to CDC	Utilizing the repeating group format, disability type would be transmitted as two data elements: - Disability Type- LOINC: 95377-8 Problem associated signs and symptoms - Disability Type Indicator- TBD
Value Set or Coding System for Transmission to CDC	Value Labels (SNOMED-CT code) - Impaired cognition (finding) (386806002) - Decreased hearing (finding) (103276001) - Impaired mobility (finding) (82971005) - Abnormal vision (finding) (7973008) - Difficulty performing personal care activity (finding) (284778005) - Functionally dependent (finding) (718705001) - Difficulty communicating (finding) (288579009) - Intellectual disability (disorder) (110359009)
Abstracted/ Derived/ Created	Abstracted
Derived from (examples)	N/A
Recommendations for Input Data Source(s)	- Case Investigation - eCR
Notes	N/A
Data Source Details*	
eCR CDA	Within Disability Status Observation template (observation templateId root: 2.16.840.1.113883.10.20.15.2.3.47): - Disability Type: ClinicalDocument/component/Social History Section (V3)/observation/code - Response: ClinicalDocument/component/Social History Section (V3)/observation/value
eCR FHIR	Resource Profile: US Public Health Disability Status Observation.value[x]
ELR	N/A
USCDI v4	Health Status Assessments data class: Disability Status: Assessments of a patient’s physical, cognitive, intellectual, or psychiatric disabilities. Examples include but are not limited to vision, hearing, memory, and activities of daily living. Functional Status: Assessment of a person’s ability to perform activities of daily living and activities across other situations and settings. Examples include but are not limited to bathing, ambulation, and preparing a light meal. Mental/Cognitive Status: Assessment or screening for the presence of a mental or behavioral problem. Examples include but are not limited to alertness, orientation, comprehension, concentration, and immediate memory for simple commands.

USCDI+ Public Health: Case Reporting Use Case	Health Status Assessments data class: • Disability Status: Assessments of a patient’s physical, cognitive, intellectual, or psychiatric disabilities. Examples include but are not limited to vision, hearing, memory, and activities of daily living.
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* Additional information on input data sources for disability data can be found in Appendix A.

Table 5. Disability Type data element – Value Set Descriptions

Value Label	Value Description
Impaired cognition	Cognitive (serious difficulties such as concentrating, remembering, or making decisions due to a physical, mental, or emotional condition)
Decreased hearing	Hearing (serious difficulty hearing or deafness)
Impaired mobility	Mobility (serious difficulty walking or climbing stairs)
Abnormal vision	Vision (serious difficulty seeing or blindness, even when wearing glasses)
Difficulty performing personal care activity	Self-care (difficulty dressing or bathing)
Functionally dependent	Independent Living (difficulty doing errands alone)
Difficulty communicating	Communication (difficulty communicating, understanding others, or being understood, using your usual language)
Intellectual disability synonym: Intellectual developmental disorder	Intellectual disability, Autism Spectrum Disorder or other developmental disabilities

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Appendix A. Input Data Sources for Disability Data

Electronic Case Reporting (eCR)

The Disability Status Observation template is defined in the CDA implementation guide for eCR as an optional template that can be included zero or more times within the Social History section of an eICR, where each iteration of the template represents a response to one of the six ACS questions. The template includes a “code” element, which is equal to one of the six LOINC codes that indicates the type of disability being reported (Table 7). Additional elements for “value” and “effectiveTime” provide the actual result (i.e., “true” or “false”) and the time of the observation, respectively.

In addition to disability information that is specifically transmitted using this template, any diagnoses that are included in the CDA document may also inform the recipient of a disabling condition that a person may have.

Table 6. Disability Status Assessment Value Set

<https://vsac.nlm.nih.gov/valueset/2.16.840.1.113762.1.4.1099.49/expansion>

LOINC Code	Question
69856-3	Are you deaf, or do you have serious difficulty hearing?
69857-1	Are you blind, or do you have serious difficulty seeing, even when wearing glasses?
69858-9	Because of a physical, mental, or emotional condition, do you have serious difficulty concentrating, remembering, or making decisions?
69859-7	Do you have serious difficulty walking or climbing stairs?
69860-5	Do you have difficulty dressing or bathing?
69861-3	Because of a physical, mental, or emotional condition, do you have difficulty doing errands alone such as visiting a physician's office or shopping?

The US Public Health Disability Status profile in the eCR FHIR specification largely aligns with the CDA Disability Status Observation template in terms of how the data elements are defined and used.

Electronic Laboratory Reporting (ELR)

ELR does not contain defined data elements related to disability status.

USCDI and USCDI+

USCDI has included a data element for Disability Status in the Health Status Assessments data class since version 3. The current definition states “Assessments of a patient’s physical, cognitive, intellectual, or psychiatric disabilities. Examples include but are not limited to vision, hearing, memory, and activities of daily living.” An additional data element in the same data class, called Functional Status, is relevant to the ambulatory and self-care disability types referenced in the ACS survey and is defined as “Assessment of a person’s ability to perform activities of daily living and activities across other situations and settings. Examples include but are not limited to bathing, ambulation, and preparing a light meal.”

The Public Health domain of USCDI+ has adopted the Disability Status data element, with the same definition and data class as above, for the Case Reporting use case.

Several disability-related data elements have been submitted for inclusion in USCDI but still remain at Level 0, meaning that they are currently only being captured and applicable for exchange in a limited number of health care settings. The submissions include the following data elements that are intended to directly represent the six questions used on the ACS and other major surveys to measure disability:

- HHS Disability Status - Activities of Daily Living
- HHS Disability Status - Cognitive
- HHS Disability Status - Hearing
- HHS Disability Status - Independence
- HHS Disability Status - Mobility
- HHS Disability Status - Vision