



Core Case Notification Data Element Recommendations: 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.

The DSWG identified and standardized the data elements to utilize in the transmission of core surveillance case data to the Centers for Disease Control and Prevention (CDC). Core surveillance data classes and data elements are those that apply across many conditions and, in general, are not specific to any single condition or condition family. In each recommendation document, the DSWG provides common definitions, value sets/code sets, structure, and interpretation notes for each identified data element that is designated as core. The DSWG does not provide questions which would be used to populate the recommended data elements. More information about the DSWG and data harmonization can be found [here](#).

The structure of this document is as follows:

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Background

Public health agencies rely on accurate disability data to better understand the prevalence of disabilities within populations and the specific requirements of communities. Data is needed 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. It is essential that data elements can support a wide range of disabilities by capturing the variability that exists across conditions.

The current standard for the collection of disability status data consists of a six-item set of questions developed by a federal interagency committee with the goal of capturing information on functional limitations across several domains. These questions have been vetted and validated through several rounds of field testing and, at the time these recommendations were developed by the DSWG, were accepted by the US Department of Health and Human Services (HHS) as the minimum required data. Current federal uses include the 2025 American Community Survey (ACS) conducted by the US Census Bureau. This question set will be referred to for the remainder of this document as the ACS questions or as the ACS.

The ACS questions 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.

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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” indicates the 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 5. Refused 6. 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, though 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. Additional work is needed to support the querying of electronic health records to more accurately identify people with disabilities.

Currently, the COVID-19 Message Mapping Guide (MMG) is the only MMG for routine case notifications to CDC that captures disability information. 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) (e.g. Disability (21134002))
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 minimum core disability categories for case notification identified by the group.

Data elements related to disability are not currently collected across conditions in a standardized way, and often not collected at all. Despite this, the DSWG came to consensus that, when this information is available, there should be a mechanism for transmitting this data for all conditions. Including disability information as core data means that a standard method of collecting these data will exist for use when known or applicable. The decision to rely on ACS and WG-SS categories for disability types is an effort to a) utilize the subject matter expertise behind development of those existing question sets, and b) facilitate public health collection of these data by leveraging existing definitions used in possible primary data sources.

Because the ACS questions were the minimum standard for collection of disability information for HHS at the time of discussion, the DSWG used these as the base standard and 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; and
2. Deciding whether a “No” or “Unknown” value was necessary for each disability category to ensure the data being sent to CDC were meaningful and potentially comparable across jurisdictions.

The final disability value set (Table 5) incorporates a “Difficulty communicating” category, similar to that from the WG-SS, as well as an “Intellectual disability” category, in addition to the ACS questions. The DSWG membership also expressed the need for each disability category to have Yes/No/Unknown response options, rather than simply a “Yes” or identifying which of the disability types were experienced by the individual, as it is important to be able to distinguish between a negative response and lack of information. To this end, if incorporating disability into a repeating group in an HL7 v2-format for case notifications, another data element (Disability Type Indicator) is recommended to be paired with the



disability value set to capture these answers (Table 4). If not using a repeating group, each value in Table 5 should 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) For <u>Disability Type</u> : - 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) For <u>Disability Type Indicator</u> : - Yes/No/Unknown
Abstracted/ Derived/ Created	Abstracted
Derived from (examples)	N/A
Recommendations for Input Data Source(s)	- Case Investigation - eCR
Notes	Disability information transmitted via this mechanism is intended to reflect a person's baseline level of abilities prior to any impacts from the condition. If, for example, an illness from the condition results in any changes to a person's cognitive abilities, this new status would not be captured and transmitted using this data element.
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 v6	Health Status Assessments data class: Disability Status: Assessments of a patient's physical, cognitive, or psychiatric disabilities. Examples include but are not limited to American Community Survey, Veterans RAND Health Survey, and

	Patient-Reported Outcomes Measurement Information System (PROMIS). • 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 Functional Assessment Standardized Items (FASI) and Timed Up and Go (TUG). • Mental/Cognitive Status: Assessment or screening for the presence of a mental or behavioral problem. Examples include but are not limited to Confusion Assessment Method (CAM) and Patient Health Questionnaire (PHQ).
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.

* Additional information on input data sources for disability data can be found in Appendix A.

Table 5. Disability Type data element – Value Set Labels and 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 (blindness or serious difficulty seeing, even when wearing glasses)
Difficulty performing personal care activity	Self-care (difficulty dressing, bathing, or toileting)
Functionally dependent	Independent Living (difficulty doing errands alone, e.g., shopping or visiting doctor's office)
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

Appendix A. Input Data Standards and 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 (Table 7). 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. The Public Health domain of USCDI+ has adopted the Disability Status data element, with the same definition but different examples, 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 are intended to directly represent the six questions used on the ACS and other major surveys to measure disability.

Table 7. Disability-related data elements in USCDI or USCDI+ Public Health Domain

Data Element	Description	USCDI Level	USCDI+ Use Case
Disability Status	Assessment of a patient's physical, cognitive, or psychiatric disabilities. <i>USCDI:</i> Examples include but are not limited to American Community Survey, Veterans RAND Health Survey, and Patient-Reported Outcomes Measurement Information System (PROMIS).	Included since Version 3	Case Reporting

	USCDI+: 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 Functional Assessment Standardized Items (FASI) and Timed Up and Go (TUG).	Included since Version 3	Not Present in the Public Health Domain
HHS Disability Status - Activities of Daily Living	According to the HHS implementation guide there are six-item set of questions used on ACS and other major surveys to gauge disability is the data standard for survey questions on disability. (HHS Implementation Guidance on Data Collection Standards for Race, Ethnicity, Sex, Primary Language, and Disability Status ASPE). The prompt for this data element should be consistent with HHS implementation guide: "Do you have difficulty dressing or bathing?"	Level 0	N/A
HHS Disability Status - Cognitive	According to the HHS implementation guide there are six-item set of questions used on ACS and other major surveys to gauge disability is the data standard for survey questions on disability. (HHS Implementation Guidance on Data Collection Standards for Race, Ethnicity, Sex, Primary Language, and Disability Status ASPE). The prompt for this data element should be consistent with HHS implementation guide: "Because of a physical, mental, or emotional condition, do you have serious difficulty concentrating, remembering, or making decisions?"	Level 0	N/A
HHS Disability Status - Hearing	According to the HHS implementation guide there are six-item set of questions used on ACS and other major surveys to gauge disability is the data standard for survey questions on disability. (HHS Implementation Guidance on Data Collection Standards for Race, Ethnicity, Sex, Primary Language, and Disability Status ASPE).	Level 0	N/A
HHS Disability Status - Independence	According to the HHS implementation guide there are six-item set of questions used on ACS and other major surveys to gauge disability is the data standard for survey questions on disability. (HHS Implementation Guidance on Data Collection Standards for Race, Ethnicity, Sex, Primary Language, and Disability Status ASPE). The prompt for this data element should be consistent with HHS implementation guide: "Because of a physical, mental, or emotional condition, do you have difficulty doing errands alone such as visiting a doctor's office or shopping?"	Level 0	N/A
HHS Disability Status - Mobility	According to the HHS implementation guide there are six-item set of questions used on ACS and other major surveys to gauge disability is the data standard for survey questions on disability. (HHS Implementation Guidance on Data Collection Standards for Race, Ethnicity, Sex, Primary Language, and Disability Status	Level 0	N/A

	ASPE). The prompt for this data element should be consistent with HHS implementation guide: “Do you have serious difficulty walking or climbing stairs?”		
HHS Disability Status - Vision	According to the HHS implementation guide there are six-item set of questions used on ACS and other major surveys to gauge disability is the data standard for survey questions on disability. (HHS Implementation Guidance on Data Collection Standards for Race, Ethnicity, Sex, Primary Language, and Disability Status ASPE). The prompt for this data element should be consistent with HHS implementation guide: “Are you blind or do you have serious difficulty seeing, even when wearing glasses?”	Level 0	N/A