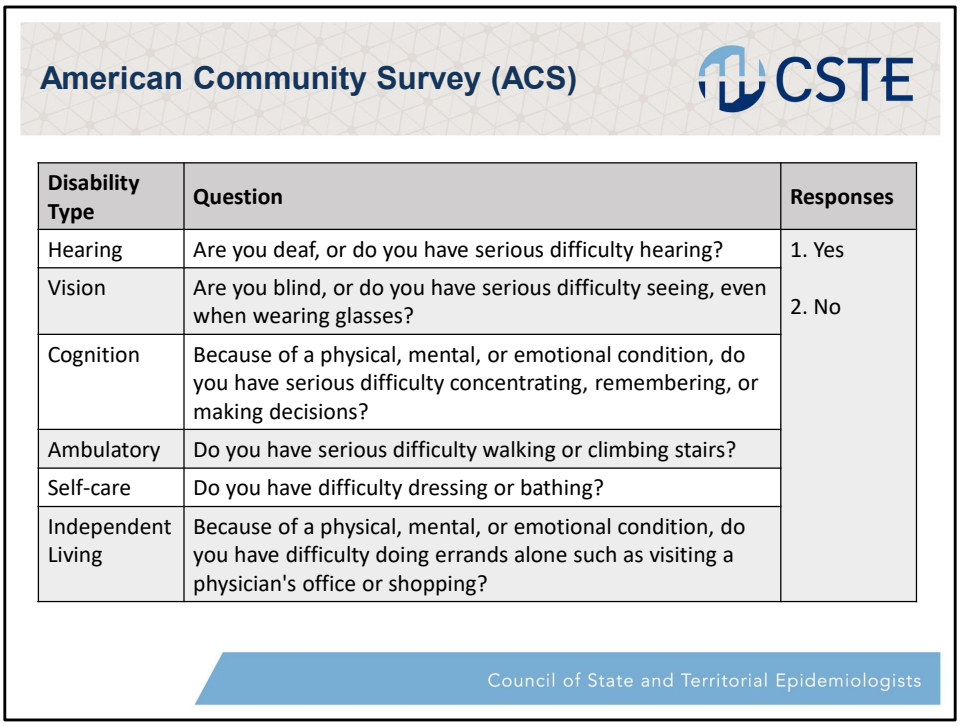
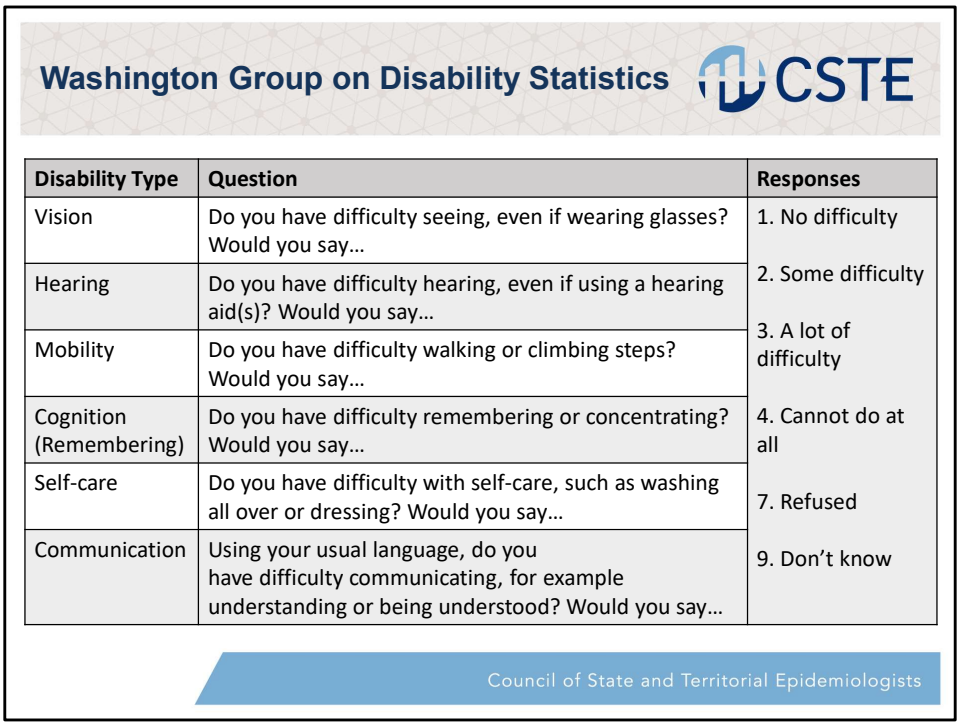
Welcome to the recording of background information related to the Disability data class. The intended audience for this presentation are members of the Data Standardization Workgroup who indicated interest in participating in the Disability data-element specific team.

During this presentation, we will take a look at how various standards and working groups have defined data elements related to Disability. Using a functional definition, a disability is 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. Although the phrase “people with disabilities” is sometimes used to indicate a single population, in reality, it refers to a diverse group of people with a wide range of needs. As such, data collection systems need a data element that captures this variability.



To understand this diverse population, a federal interagency committee developed a set of six questions for use in the American Community Survey and other major surveys. These 6 questions, which going forward we will refer to as the ACS, capture information on functional limitations across domains of hearing, vision, cognition, ambulatory, self-care, and independent living. Each question has a yes/no response, and disability is defined by an answer of 'yes' to any of these 6 questions. The first five questions have age thresholds of five years and older and the final question has an age threshold of 15 years and older.

This question set went through several rounds of cognitive and field testing and has been adopted in many federal data collection systems. OMB has encouraged the use of this question set by other federal agencies. HHS includes the ACS questions as part of the published standards for data collection on race, ethnicity, sex, primary language, and disability status. The ACS is used as the minimum data standard to collect data under the Affordable Care Act and is used in Bureau of Census surveys



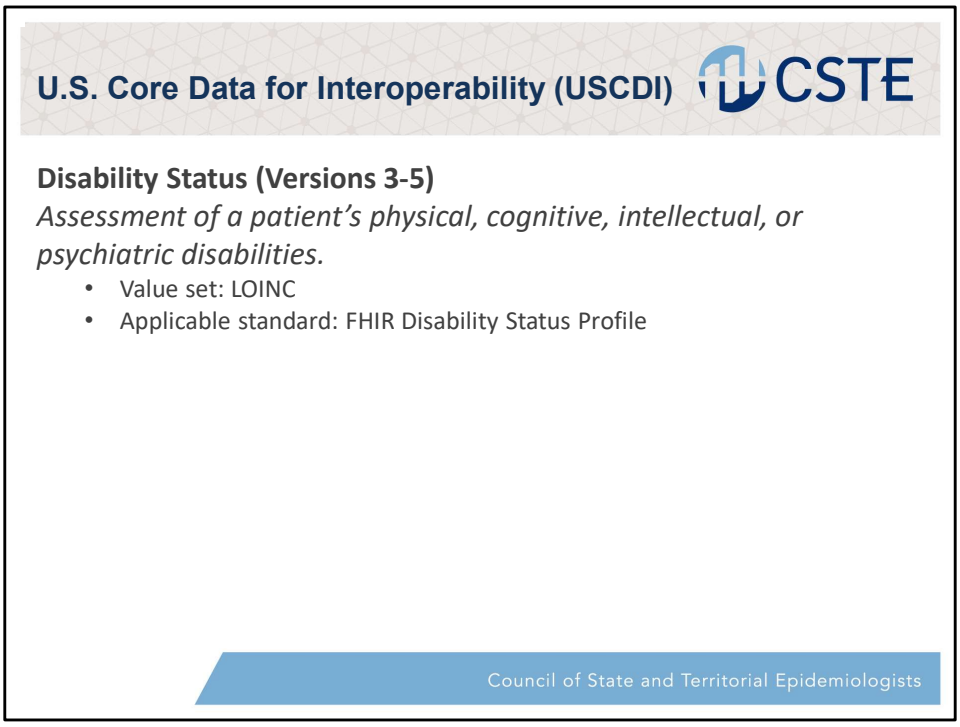
Similarly, the Washington Group on Disability Statistics developed, tested, and adopted the Washington Group Short Set of six questions on functioning for use on national censuses and surveys worldwide. The intent of these questions is to address whether persons with certain defined disabilities participate to the same extent as persons without disabilities in activities such as education, employment, or family/civic life. Domains were selected using the criteria of simplicity, brevity, universality and comparability. This methodology has been internationally validated and cognitively tested in low-, middle-, and high-income countries and has been used in censuses or surveys in over 75 countries. In contrast, the ACS were designed for and are used within the United States.

Rather than a dichotomous (Yes/No) response, options of no difficultly/some difficulty/a lot of difficulty/cannot do at all are used for each question. While this allows more flexibility in analysis, typically anyone with a response of "a lot of difficulty" or "cannot do at all" is considered to have a disability.

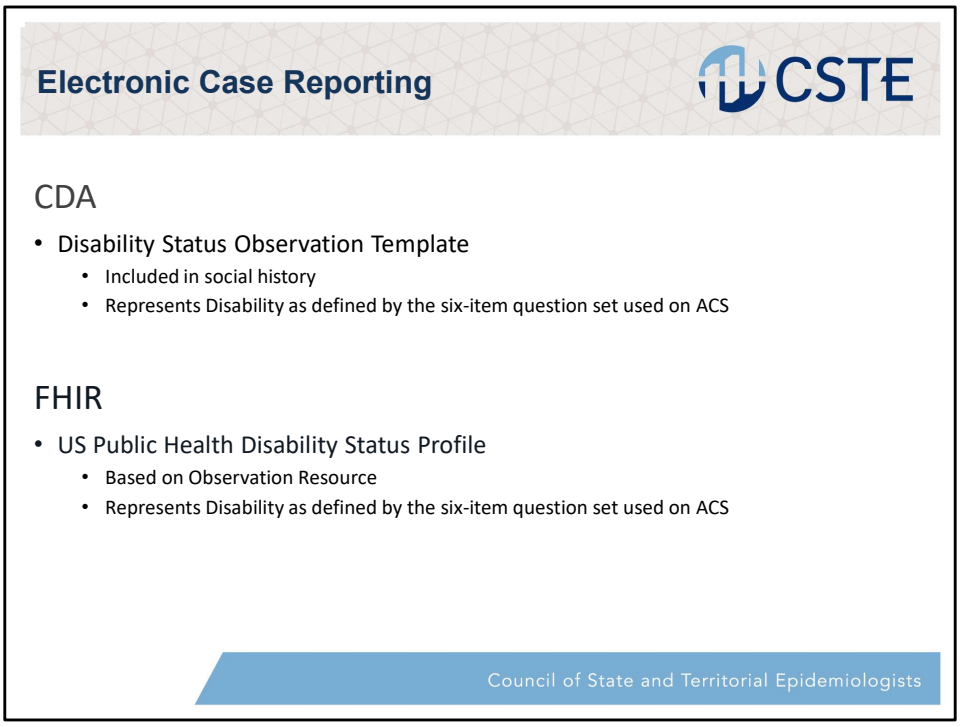
Other differences between the Washington Group and ACS questions, are inclusion of "communication" as a domain in the Washington Group short set and "Independent Living" in the ACS questions.

Both the Washington group short set and ACS have age restrictions on some or all of the questions and neither identifies people with intellectual or developmental disabilities.

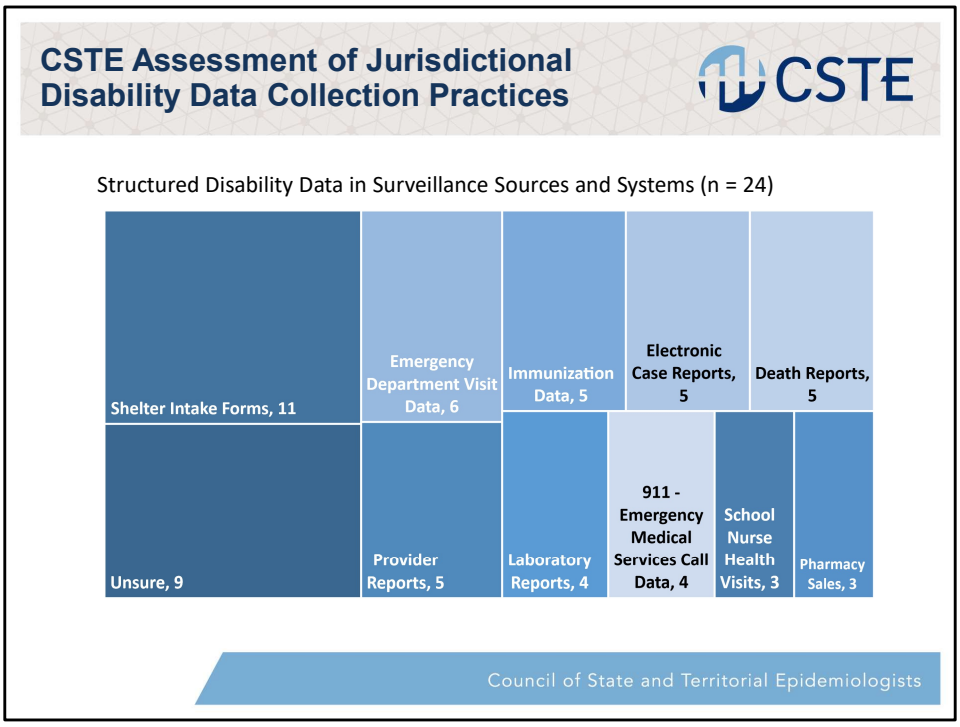
It is important to note that disability status can be identified by means other than a set of questions asked of the patient. For instance, CDC and ASTHO are working to convene a scientific panel of subject experts, including people with lived experience with disability, to identify the underlying health conditions that are associated with “disability” in clinical terms to support querying electronic health records for clinical terms to identify visits by people with disabilities and their reasons for seeking care.



Disability status has been included in USCDI in the Health Status Assessments data class since version 3. The description of this data element is "Assessments of a patient's physical, cognitive, intellectual, or psychiatric disabilities." LOINC provides the value set and the data element submission references the FHIR Disability Status profile, which is based on the ACS 6 question set.

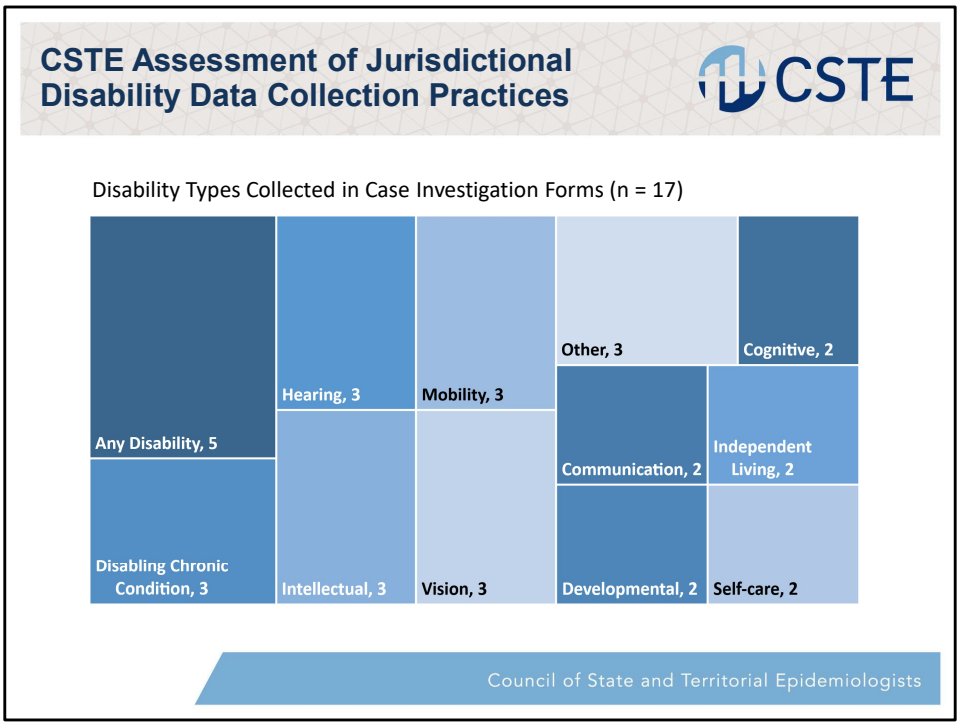


- Disability status is not routinely captured in electronic lab reports. However, it can be captured in electronic case reports in both CDA and FHIR. The eCR CDA profile uses the disability status observation template and FHIR uses the US public health disability status profile. Both are structured as true/false answers to the 6 ACS questions.



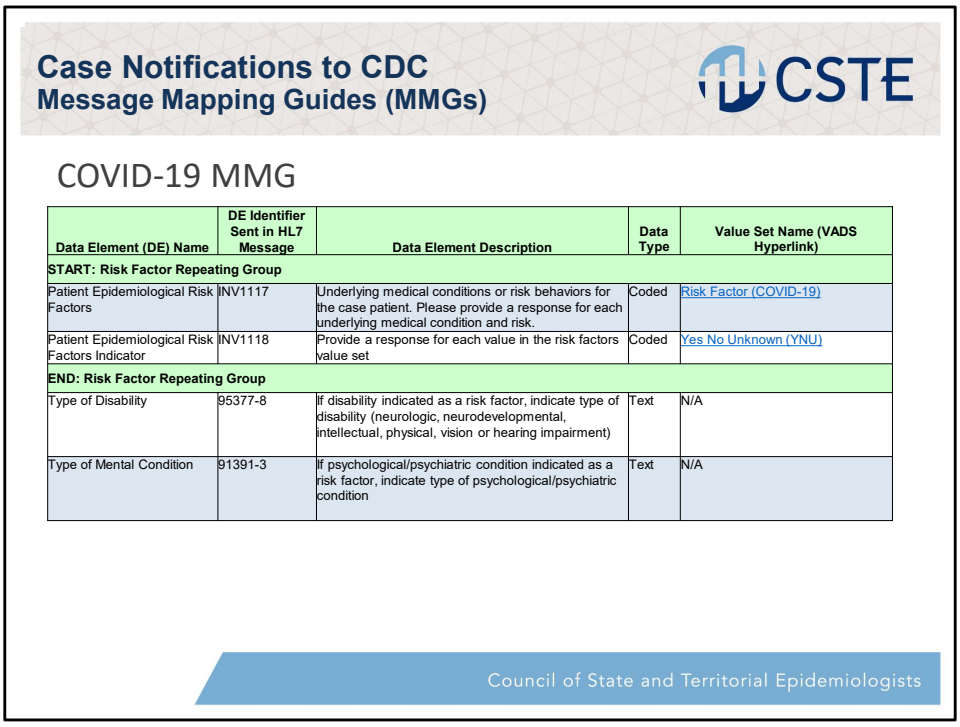
Within public health departments, data on disability status can be collected from multiple sources. The *CSTE Assessment of Jurisdictional Disability Data Collection Practices on the Impacts of Emergencies on People with Disabilities* aimed to understand if and how state and territorial jurisdictions collect data on people with disabilities and to what extent they report those data to agency and jurisdictional leadership during emergencies. A total of 34 jurisdictions responded, with at least one response per HHS region. Overall, 53% of jurisdictions were aware of disability data being captured in a structured way in surveillance data sources and systems, and 26% were unsure.

The figure presented here summarizes the surveillance data sources and systems that participants use to collect disability data in a structured way. As you can see, the data sources and systems are numerous and varied and include things such as shelter intake forms, all manner of provider/facility reporting, eCR and vital records, among other things.



In addition, the CSTE Assessment of Jurisdictional Disability Data Collection Practices found that exactly half of jurisdictions captured data on specific disability types through case investigations during emergency responses such as COVID-19, Mpox, or heat-wave related mortality. The figure shown here summarizes the distribution of disability types captured during emergency response case investigations.

“Any disability” was the most common category captured. Other categories included all 6 ACS domains, as well as additional domains such as intellectual disability, developmental disability, and disabling chronic conditions.



Case Notifications to CDC
Message Mapping Guides (MMGs)

CSTE

COVID-19 MMG

Data Element (DE) Name	DE Identifier Sent in HL7 Message	Data Element Description	Data Type	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.	Coded	Risk Factor (COVID-19)
Patient Epidemiological Risk Factors Indicator	INV1118	Provide a response for each value in the risk factors value set	Coded	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)	Text	N/A
Type of Mental Condition	91391-3	If psychological/psychiatric condition indicated as a risk factor, indicate type of psychological/psychiatric condition	Text	N/A

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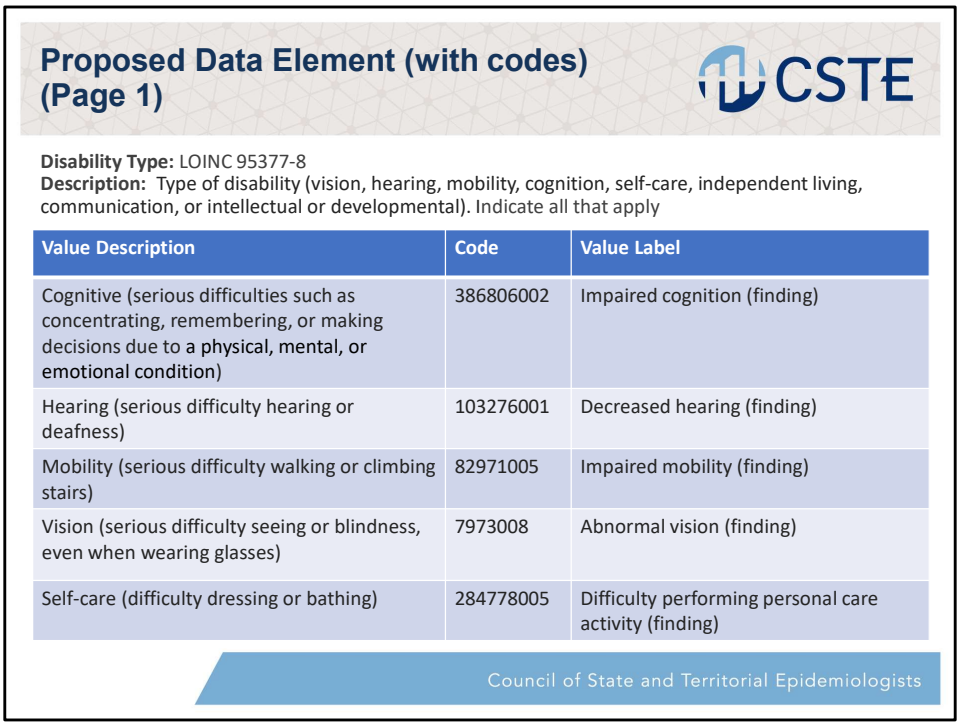
In NNDSS, the only message mapping guide that currently captures disability is the COVID MMG. It includes a risk factor repeating group with a value of “disability”. If this disability value is marked as Yes, the sender can further specify the type of disability in a follow-up free text field where categories suggested include, but are not limited to neurological, neurodevelopmental, intellectual, physical, vision or hearing impairment.



Proposed Data Element (with codes) (Page 1)

CSTE

Disability Type: LOINC 95377-8
Description: Type of disability (vision, hearing, mobility, cognition, self-care, independent living, communication, or intellectual or developmental). Indicate all that apply

Value Description	Code	Value Label
Cognitive (serious difficulties such as concentrating, remembering, or making decisions due to a physical, mental, or emotional condition)	386806002	Impaired cognition (finding)
Hearing (serious difficulty hearing or deafness)	103276001	Decreased hearing (finding)
Mobility (serious difficulty walking or climbing stairs)	82971005	Impaired mobility (finding)
Vision (serious difficulty seeing or blindness, even when wearing glasses)	7973008	Abnormal vision (finding)
Self-care (difficulty dressing or bathing)	284778005	Difficulty performing personal care activity (finding)

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The proposed data element is what has been referred to previously as a repeating element.

This follows a standard format of using a LOINC code to ask a question and provides SNOMED CT concepts to use as a select all answer values set.

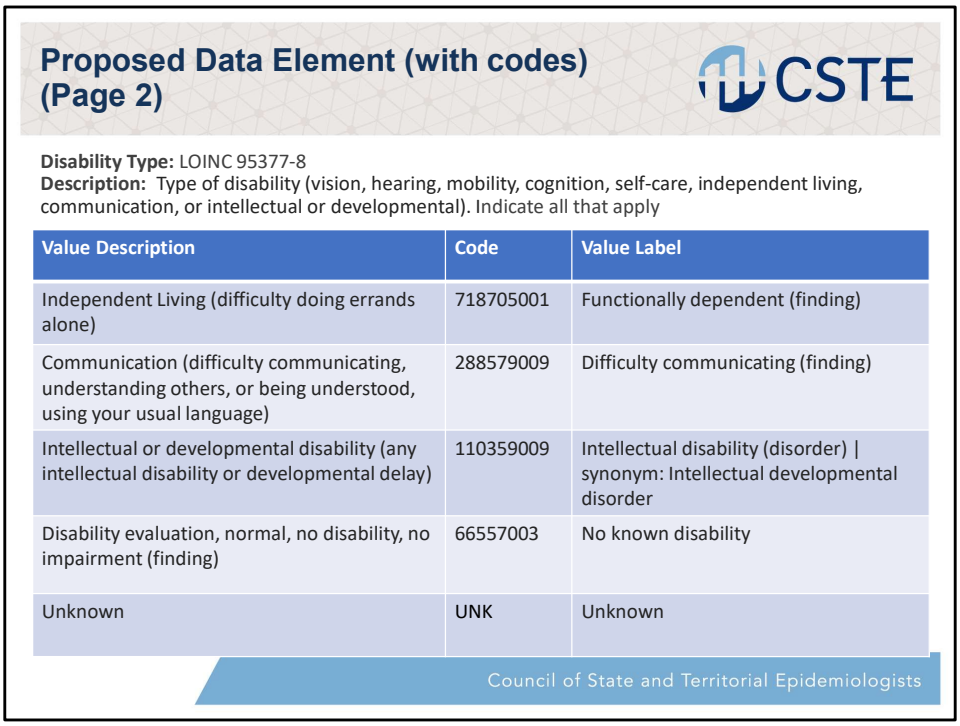
The suggested value set includes concepts which align with the ACS, the minimum required by HHS, and adds some additional concepts to cover variables currently collected by some jurisidictions. Because of its size, the value set is split across two slides and I will move to the other half of the value set on the next slide in a moment.

These have been written as concepts instead of questions in order to convey that this information may come from many sources.

A catch all concept of “any disability” was intentionally left out due to it’s difficulty of being implemented or defined in a way that is meaningful for data analysis.

Rationale:
- Not saying all states should ask about all of these, but we do want to be able to receive the information that states are collecting
- Started with ACS disability status domains as initial values as those are gold-standard requirement within HHS (HHS does say minimum is to align with ACS, but can extend beyond that)
- Chose concepts, rather than questions as value set because information on disability can come from many sources, and still want to capture data that extends beyond what is capturing using ACS questions.
- Added communication because states are capturing it and because it is included in Washington Group
- Adding Intellectual or development disability because some states are capturing it and it is an important disability domain
- "any disability" explicitly left off because of difficulty in implementing/defining it, and to avoid confusion about how to answer when a specific disability is being documented
- chronic conditions were excluded because they are not included in the functional disability model and

Questions to ask DEST:
- What to do if someone is screened and has no known disability. Does this happen that states would identify and record someone as not having a disability? How is captured/stored/represeten in states? Is there value in including this? Right now we have "Screened negative for disability", other options include "no known disability", "screened negative for any disability", "screener completed, no disability noted".
- Approval of proposed DE as core?



Proposed Data Element (with codes) (Page 2)

Disability Type: LOINC 95377-8
Description: Type of disability (vision, hearing, mobility, cognition, self-care, independent living, communication, or intellectual or developmental). Indicate all that apply

Value Description	Code	Value Label
Independent Living (difficulty doing errands alone)	718705001	Functionally dependent (finding)
Communication (difficulty communicating, understanding others, or being understood, using your usual language)	288579009	Difficulty communicating (finding)
Intellectual or developmental disability (any intellectual disability or developmental delay)	110359009	Intellectual disability (disorder) | synonym: Intellectual developmental disorder
Disability evaluation, normal, no disability, no impairment (finding)	66557003	No known disability
Unknown	UNK	Unknown

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Here are the rest of the concepts.

For the call, we would like participants to be ready to discuss several ideas:

1. whether or not a disability data element should be included as core surveillance
2. how to approach negative disability screens in a variable jurisidictional surveillance landscape where different jurisdictions are collecting different things.
3. And whether or not we need to be able to assess a No or Unknown for any or all concepts.

This concludes the background information presentation for the disability DEST. Please be ready to discuss on May 10 at 1 PM Eastern.