Meeting: CSTE Data Standardization – Disability -Data Element-Specific Team Meeting
Date: May 10, 2024
Attendees: 53

CSTE (3)	PHAs (28)	CDC (17)
Becky Lampkins Rebecca Ruvane Shaily Krishan **JMC (4)** Erin Kough Laura Lane Sam Spoto Sara Sanford **Unknown (1)** MKennedy	<u>DSWG Co-Chairs</u> Laura Erhart (AZ) <u>DEST Members</u> Alina Paegle | UT Caleb Lyu | LA County Cher Levenson | WA Cristin Larder | Ingham Ed Hartwick | MI Elizabeth Kessler | NV Elizabeth Schiffman | MD Eman Addish | Philadelphia Eric Grosso | WI Erica Ruud | NV Hanna Chakoian | MN Jennifer Kwon | LA County Judie Hyun | MD Kacee Redden | SD Karene Thomas-Watts | CO Kayleigh Nerhood | GA Krista Mevoli | KY Kyra Veatch | IN Lea Moser| NV Luis Vela | ID Orlando Velazco | CT Rachel Klos | WI Sam Hawkins | OR Stephanie Moberg | NM Steven "Ike" Eichner | TX Suzanne Gibbons-Burgener | WI Theron Huntamer | NV	Alejandro Pérez Amanda Deering Doris McGinness Erin Miller Hailey Vest Keaton Hughes Kristie Clarke Luis Hernandez | GDIT Marci Pitasi Myrna del Mar Gonzalez | GDIT Jennita Reefhuis Peter Boersma Rachelle Oseni Robyn Cree Sandy Price Sara Johnston Shawn Arshad | GDIT

**SOME INDIVIDUALS DIALED IN; THE NAMES ARE UNKNOWN, AND THEY ARE LEFT OFF OF THE ATTENDANCE*

HIGH-LEVEL MEETING NOTES (*REFER TO MEETING SLIDES FOR MORE DETAIL AS NEEDED*):

Disability Data Elements

DEST Opportunities for Participation

- DEST sign-ups are ongoing.
- **[Action Requested]** Please sign up for upcoming data elements on the DEST Sign-Up here.
- Upcoming data elements
    - Identifiers – first call 5/17
    - Medication/Treatment – possible topic on 6/28 DSWG
    - Laboratory
    - Race/Ethnicity/Tribal Affiliation
    - Reporting Source
    - Social Determinants of Health
- DEST member expectations—members are not expected to write documents, lead meetings, or prepare slides. The goal is to keep members engaged in conversations about content during and between meetings.
- Active participation in polling, document review, discussion, and other input during and between meetings is expected.

DSWG Reminders

- DEST members will soon receive draft recommendations for feedback, including
    - Exposures, Risk Factors, and Underlying Conditions
    - Signs, Symptoms, and Clinical Manifestations

Meeting Ground Rules

- We welcome everyone's opinions and active participation from jurisdictions, CDC programs, CSTE membership, etc.
- As we work through data elements/classes, we strive for 80/20 consensus.

In-Scope vs Out-of-Scope

- Focus on core data for surveillance and transmission to the CDC within selected data classes.
- We will work to identify standard definitions and value sets within that definition of core data.
- This is not a discussion of how to collect this data, frame questions in surveys or interviews, or implement these data standards. This is also not meant to impose limitations on how jurisdictions collect data.

Disability Data Elements

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, 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.

American Community Survey (ACS)

- This slide shows the American Community Survey disability questions.
- These are a set of six questions developed by a federal interagency committee for use in major surveys.
    - These will be referred to as the ACS.
    - These six questions capture information on functional limitations across hearing, vision, cognition, ambulatory, self-care, and independent living domains.
    - Each question has a yes/no response, and disability is defined by an answer of ‘yes’ to any of these six 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.
- Currently, these six questions are the minimum data standard to collect data under the Affordable Care Act and are used in Bureau of Census surveys. HHS includes the ACS questions as part of the published standards for data collection on race, ethnicity, sex, primary language, and disability status.

Washington Group on Disability Status

- Here, we see the Washington Group Short Set of six questions on functioning, which were developed for use on national censuses and surveys worldwide. These questions intend to address whether persons with a disability 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 difficulty/some difficulty/a lot of difficulty/cannot do 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 disabled.

Electronic Case Reporting

- 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.

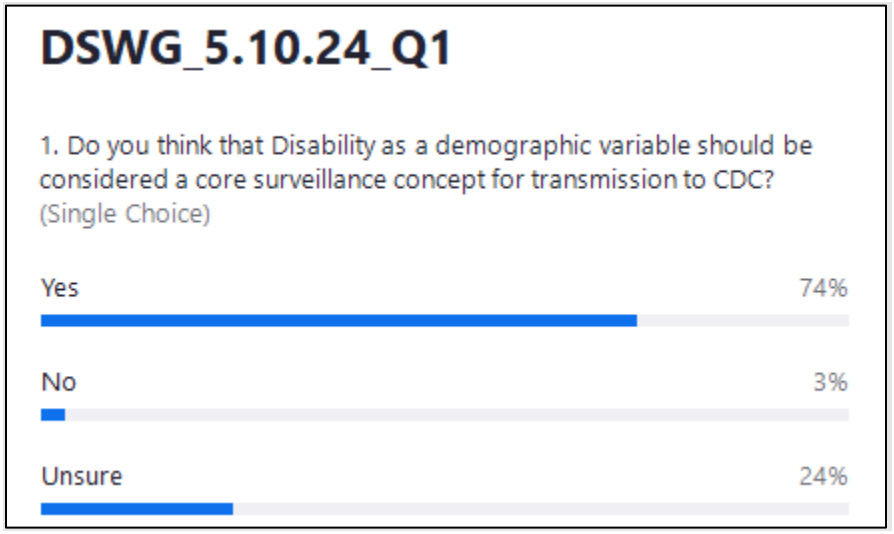
Proposed Data Element (with codes) (Page 1)

- 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 value set. There are a total of 10 concepts included in the value set, and to make them readable, they are split across two slides.
- These have been written as concepts instead of questions to convey that this information may come from many sources, including electronic medical data sources.
- Overall, the suggested value set was put together using some of the following rationale. Most importantly, this value set includes concepts that align with the six ACS questions. As mentioned earlier, these six questions are the minimum standard required by HHS, and these are the concepts required for data reporting for the ACA and used by the Bureau of Census, which is important as it relates to potential denominator data.
- A catch-all concept of "any disability" was intentionally left out due to its difficulty in being implemented or defined meaningfully for data analysis.
- Rationale:
    - Started with ACS disability status domains as initial values as those are gold-standard requirements within HHS (HHS does say the minimum is to align with ACS, but can extend beyond that)
    - Added communication because states are capturing it and because it is included in the Washington Group
    - Adding Intellectual or developmental 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

Proposed Data Element (with codes) (Page 2)

Poll 1 (n= 34) –Disability as Core?

- It seemed important to start our conversations with the most basic question related to this concept, which is:
  Do you think that Disability as a demographic variable should be considered a core surveillance concept for transmission to the CDC? You are not agreeing to the proposed value set by voting yes here. Instead, you are just saying that, yes, some sort of disability demographic data element should be sent to the CDC as part of core surveillance.

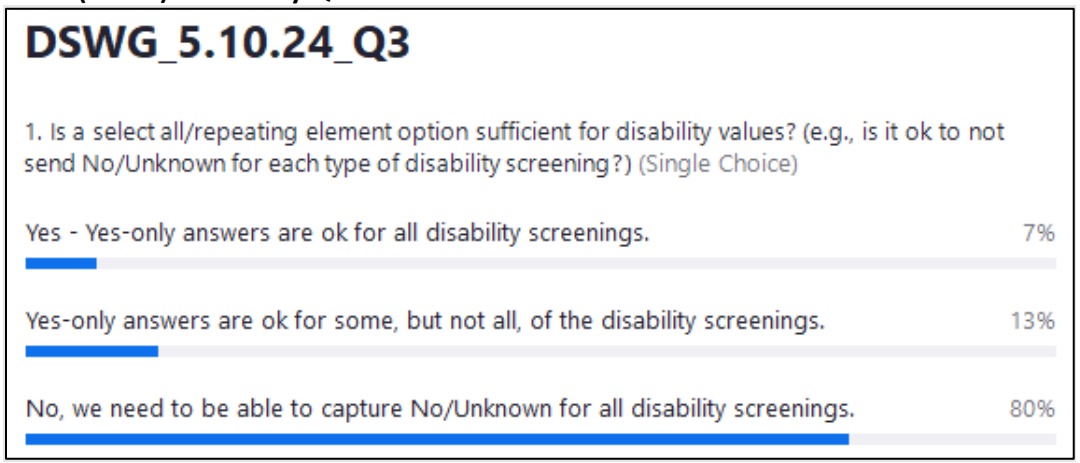


Discussion

- Steve Eichner commented that one thing we didn't chat about or mention is the fact that if you're looking at associated diagnoses, diagnoses that are included in a CDA would also provide information about a disabling condition that a particular patient may have. So that's another aspect of sharing information about disabilities.
- Kristie Clarke noted limitations encountered when using ICD codes for diagnosis and disability analysis during the pandemic. She explained that their team used ICD codes as a temporary measure by analyzing data from a chronic disease warehouse with input from several clinicians. However, she highlighted issues such as potential miscoding, omission of unrelated conditions (e.g., a disability not considered related to a COVID visit), and biases towards coding more visually obvious disabilities.
    - Erin Kough: Commented that this is important to remember and noted that this should be considered during implementation discussions. The focus of today's conversation is the definitions of the value set.
- Steve Eichner added that ONC recently tasked High Tech with providing recommendations regarding the USCDI version 5 draft. One of the task force's recommendations was adding a device-used data element to the medical device data class, which includes a wide range of assisted devices. That's another component that is part of the value set that's included or potentially included in the USDCI draft or final version 5, which is expected to be released sometime in the June or July timeframe for implementation a couple of years out.
- Kristie Clarke noted that there are other ways to capture disability, so that is something to keep in mind as we vote on as core.

- Erin Kough shifted gears to gauge people's feelings about whether it is ok only to indicate a positive result for a disability concept and not transmit no or unknown values. As currently proposed, the data element would allow jurisdictions to indicate which disability categories a person is positive for without requiring a No or Unknown to be sent for all the concepts. With such an element, jurisdictions could effectively ignore those concepts that their surveillance process did not currently screen for and request input.
    - Steve Eichner commented that depending on the person's view, there are not necessarily six dimensions of disability, but four dimensions of disability and two dimensions of severity. As you look at self-care and independent living, these are often considered, at least by the disabled community, as measures of severity and not disabilities unto themselves.
    - Kristie Clarke noted that she led the disproportionally affected populations team, which covered disability for the CDC during the COVID-19 response, and one of the big challenges when we were trying to work with our disability SMEs was that we weren't sure if a blank for the disability variable within any data set we were trying to use meant that the person had screened negative or that it meant that this part had been skipped. Therefore, it was difficult to draw epidemiologic conclusions because of the lack of a denominator.
    - Sam Hawkins noted their support for including no or unknown to differentiate between the two responses.
        - Several participants agreed with the value of including no or unknown options.
    - Steven Eichner urged that this would be a required yes/no/unknown, so missing values can't be sent.
    - Peter Boersma noted that he would like to hear the state-level reaction to his comment but would like "no" to be considered part of the responses. This would then likely turn this into a repeating group, and to capture all the no's would be at least six instances. Would that be a reasonable request? Or maybe there are other ways of capturing no.
        - Ed Hartwick commented that, from a data housing standpoint, the concern is the cost space-wise. It often doesn't make a lot of difference for us. From an informatics standpoint, we're here to support the Epi work. At the least, we can transmit to the CDC that the lack of a positive indication is unknown and does not require much effort. For those that need no/unknown, it doesn't weigh heavily and would not cause a lot of burden from an informaticist's standpoint.

Poll 2 (n = 30) –Disability Question Structure



Proposed Data Element (with codes) (Page 1)

- Currently, this is written as one data element, but for this discussion, we need to flex that concept and think of these as individual items to be considered. Essentially, each one of these would be yes/no/unknown. It might be easier to tackle this in groupings. First, we'll discuss the minimum base from the ACS questions: cognitive, hearing, mobility, vision, self-care, and independent living. These are the concepts aligning with the ACS questions. She requested to hear major concerns, including those, but also with the understanding that these are the minimum data sets that must be included.

  Discussion

  - Steven Eichner pointed out issues with categorizing disabilities, particularly in communication. He noted that using sign language shouldn't be considered a disability from a communication perspective and that conditions like autism might be excluded from some definitions, depending on cognitive criteria. He emphasized the importance of ensuring that all individuals with disabilities can submit relevant information unless there's a deliberate decision to focus only on specific types of disabilities.
    - Erin Kough thanked Steve for his comment and noted that this would also be discussed later in today's meeting.
    - Steven Eichner followed up with a comment noting that from a mobility standpoint, this definition includes walking and climbing stairs. Other definitions for mobility include reaching and other types of activities. So again, do not try to distinguish or solve it here and now. The question is, what are we trying to do with the data on the back end? What are we trying to represent? What questions are we trying to answer?
  - Suzanne Gibbons-Burgener requested clarification on whether these are all-inclusive since the definition of mobility, for example, is vast.
    - Erin Kough noted that this is a good question for consideration.

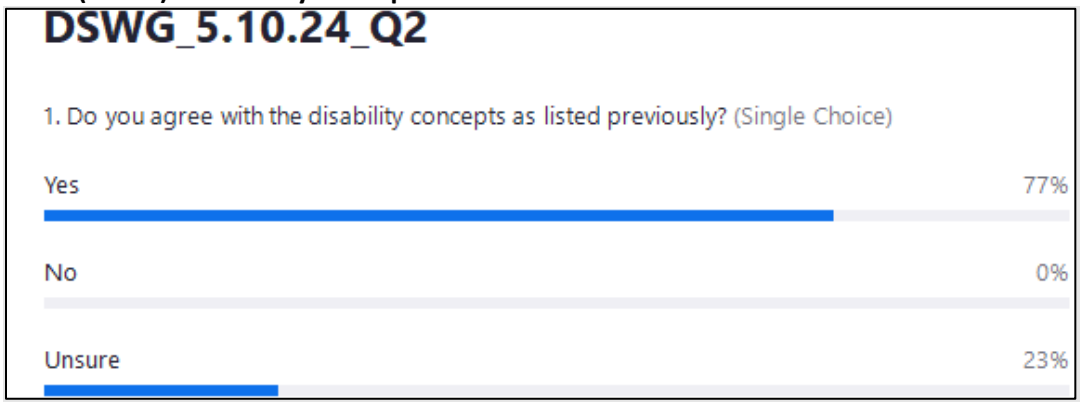
- Sam Hawkins also noted that the value set does not include mental health disabilities and wanted to voice support, based on some experience in Oregon, for this to be included.
    - Erin Kough made a note that will also be considered.
    - Robyn Cree supported adding mental health to the data set, a topic discussed extensively. She is the technical lead on a project to develop a diagnostic code-based definition for identifying emergency department visits by people with disabilities. Her group has engaged with a scientific panel of people with disabilities and syndromic surveillance experts. Mental health was considered both a disabling condition and an outcome disproportionately affecting people with disabilities. Ultimately, it was excluded from their definition of syndromic surveillance because a separate mental health definition already exists and can be combined. Robyn suggests further discussion on including mental health in the proposed data elements, considering its significant impact on people with disabilities.
    - Steven Eichner noted that it is important to distinguish between the cause of a disability and the functional aspect of the disability. What aspect of mental health is the disabling condition?
- Laura Erhart advocated using established and well-defined definitions and value sets from other sources. She acknowledged her lack of expertise in this area, a sentiment likely shared by many completing the forms and stressed the importance of having a standardized reference to avoid inconsistencies. Additionally, she highlighted the need to properly map these values when information is transmitted through systems like FHIR or ECR.
    - Erin Kough agreed this is an important point
- Suzanne Gibbons-Burgener wondered if this had already been covered but pondered if disability had been defined as relatively permanent and not transient. For example, a broken leg is technically disabled, but this is not a permanent condition.
    - Erin Kough noted no time component in the current definition.
    - Steven Eichner replied that it depends on what program you're speaking to. As an example, SSDI expects the condition to last a minimum of a year if not permanent. For disabled placards, many states or jurisdictions offer temporary red permits for up to six months and permanent tags that last six months or longer.

Proposed Data Element (with codes) (Page 2)

- The discussion shifted away from ACS and focused on input received before the meeting with a request to discuss intellectual or developmental disability. An alternative from a DEST member who was unable to attend the call was proposed for the section to expand this to include intellectual disability, Autism Spectrum Disorder, or other developmental disabilities. In addition, it was mentioned that developmental delay is a term generally only used for children under 10. The idea is that currently, a lot of disability data sets do not capture people who qualify for intellectual and developmental disability special services. She pointed out that this information would be very helpful for public health response, and this is a vulnerable population. She offered this as support for inclusion with this expanded definition. Are there any thoughts about this?
- ***Discussion***

- Steven Eichner commented that looking at the definition from a LOINC perspective, the value label is not consistent with either the CDCs or other aspects of the Federal Government's definition of developmental disabilities, which includes a wide range of physical disabilities or conditions as well as issues on the brain and mental health functioning. So, it's a wide, ranging subject.
    - Erin Kough noted that it is felt that the thought is how can this be captured because public health does not currently capture this information, particularly for individuals where services are provided.
    - There was continued discussion from several participants indicating that they felt autism, for example, would already be included within the intellectual or developmental disability category.
- Steven Eichner also noted that some disabilities, though categorized as a disability at the Federal level, do not mean it is always categorized the same way at the state level, making the issue even more complex.
- Robyn Cree acknowledged the complexity of measuring disability, emphasizing that functionality often depends on access to appropriate supports and services. She noted that someone might not have functional limitations but could still face discrimination due to their disability. She highlighted the importance of including intellectual and developmental disabilities (IDD) in assessments despite its current absence from the ACS or Washington Group Short Set. Robyn mentioned an ongoing three-year CDC project aimed at improving the identification of adults with IDD at the point of care and suggested including a placeholder for IDD in current assessments to accommodate future developments from their project.
    - Erin Kough acknowledged the importance of this comment.
- Laura Erhart also noted that this is a very complex topic overall and noted that the discussion could continue with the next poll.
    - She agreed with removing the last two items based on the previous polling.
    - She asked the group to consider how to implement the definitions they developed, even though implementation is scheduled for a later time. She emphasized the importance of capturing the richness and scope of the group's ideas in a way that can be applied across different jurisdictions, ensuring that the resulting data sets are meaningful and useful for public health purposes.
- Erin Kough asked one final question before moving on to polling about the wording change for developmental or intellectual disability to add the wording that had been placed in the chat.
    - Robyn and Steven agreed that there is no issue with adding autism.
    - Erin Kough updated the slides during the call.
- Steven Eichner requested that the definition of mobility include the most recent definition, which includes movement and reaching. Validate which definition to use and ensure you use the most current definition. Reliant questions need to be used and presented to the patient.
    - ACTION: JMC (Erin), be sure to use the most recent ACS question and descriptor for mobility.

Poll 4 (n = 26) – Disability Concepts



Next Steps

- Look out for the next steps for this DEST via email.
- Upcoming team meetings
    - 5/17, 1-2 ET- Identifiers
    - The 6/14 and 6/21 meetings were cancelled due to the CSTE Conference
- The next large DSWG call will be on June 28, 2024.