

# Disability data elements

CSTE DSWG Data Element Specific Team

05/10/2024



Council of State and Territorial Epidemiologists

***Please mute phone/ headset/ computer audio!***

## Agenda

- Welcome & Announcements
- Disability data element discussion and polling
- Next Steps
- Wrap-Up & Adjourn

# DEST Opportunities for Participation



- The Data-element Specific Team (DEST) Interest Sign-Up sheet has been updated to include known future data classes:
  - Identifiers
    - First call 5/17
  - Medication/Treatment
    - Possible topic on 6/28 DSWG
  - Laboratory
  - Race/Ethnicity/Tribal Affiliation
  - Reporting Source
  - Social Determinants of Health

Link to Sign-Up sheet:

<https://app.smartsheet.com/b/form/3da89d48bda94fc7a33c4a8a505fe54a>

If you have signed up previously but feel you are not getting the emails/meeting invites that you expected to get, please reach out directly to [llane@jmmichael consulting.com](mailto:llane@jmmichael consulting.com).

# DSWG Reminders



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

# Meeting ground rules



- Discussion Guidelines
  - "Raise" your hand
  - Use the chat to provide feedback and ask questions
  - When called, state your name and affiliation
  - Stay on point, be brief, and within the context of the discussion in progress
  - 80/20 consensus
  - Co-Chairs/moderators' prerogative to move the discussion forward as needed
    - [Post-meeting survey](#) provided for additional input
  - Be courteous and be open to new ideas

## **Active participation encouraged for all!**

- Chats, voting, comments, etc.
- Includes STLT jurisdictions + CDC Programs + CSTE, etc.

# In-scope vs Out-of-scope



## What this is:

- Discussion about data elements/classes which are:
  - collected at the jurisdiction and sent to CDC for surveillance purposes
  - Abstracted, calculated, or derived from a combination of electronic sources, patient interviews and chart abstractions
- Collaborative consensus building about the best ways to approach the transmission of public health data in a standardized way

## What this is not:

- Discussion of data elements for research studies
- Recommendations for public facing surveys
- Limitations on what can be collected for a data element within a jurisdiction
- Recommendations for how to ask about data elements in a case interview
- Implementation guidance

# Disability Data Elements



# American Community Survey (ACS)



| Disability Type    | Question                                                                                                                                             | Responses           |
|--------------------|------------------------------------------------------------------------------------------------------------------------------------------------------|---------------------|
| Hearing            | Are you deaf, or do you have serious difficulty hearing?                                                                                             | 1. Yes<br><br>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? |                     |

| Disability Type         | Question                                                                                                                         | Responses                                                                                                                                  |
|-------------------------|----------------------------------------------------------------------------------------------------------------------------------|--------------------------------------------------------------------------------------------------------------------------------------------|
| Vision                  | Do you have difficulty seeing, even if wearing glasses?<br>Would you say...                                                      | 1. No difficulty<br><br>2. Some difficulty<br><br>3. A lot of difficulty<br><br>4. Cannot do at all<br><br>7. Refused<br><br>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?<br>Would you say...                                                            |                                                                                                                                            |
| Cognition (Remembering) | Do you have difficulty remembering or concentrating?<br>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... |                                                                                                                                            |

## CDA

- Disability Status Observation Template
  - Included in social history
  - Represents Disability as defined by the six-item question set used on ACS
    - Yes/No

## FHIR

- US Public Health Disability Status Profile
  - Based on Observation Resource
  - Represents Disability as defined by the six-item question set used on ACS

# Proposed Data Element (with codes)

## (Page 1)



**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) |

# 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/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)  <br>synonym: Intellectual developmental disorder |
| Disability evaluation, normal, no disability, no impairment (finding)                                          | 66557003  | No known disability                                                                  |
| Unknown                                                                                                        | UNK       | Unknown                                                                              |

# Poll 1 – Disability as Core?



- Do you think that Disability as a demographic variable should be considered a core surveillance concept for transmission to CDC?
  - Yes
  - No
  - Unsure

# Discussion Points



- Current proposal only allows for a positive indication for each class of disability (Cognitive, Hearing, Mobility, Vision, Self-care, Independent Living, Communication, Intellectual/developmental)?
- Are No or Unknown answers important for each class of disability?

# Poll 2 – Disability Question Structure



- Is a select all/repeating element option sufficient for disability values?
  - i.e. Is it ok to not send No/Unknown for each type of disability screening?
- Yes, Yes-only answers are ok for all disability screenings.
- Yes-only answers are ok for *some, but not all*, of the disability screenings.
- No, we need to be able to capture No/Unknown for all disability screenings

# Discussion Points



- Within a select all or repeating element style question, will the inclusion of “No known disability” be meaningful if different jurisdictions screen for a subset of the disability types, instead of all.
  - e.g.

State A screens only for Cognitive, Hearing and Vision.

State B screens only for Hearing, Vision, Intellectual/developmental.

*Would values of “No known disability” be comparable across the two states?*

# Proposed Data Element (with codes)

## (Page 1)



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# 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/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 disability, Autism Spectrum Disorder or other developmental disabilities                          | 110359009 | Intellectual disability (disorder)   synonym: Intellectual developmental disorder |

# Poll 4 – Disability Concepts



- Do you agree with the disability concepts as listed previously?
  - Yes
  - No
  - Unsure

# Next Steps



- Look out for next steps via email.
- Upcoming team meetings:
  - 5/17 1-2pm ET– Identifiers (Outbreak identifiers, Linkage of maternal/infant cases, Identifiers to link labs and cases)
  - 6/14 and 6/21 meetings cancelled due to CSTE Conference
  - [Link to Sign Up](#)
- The next large DSWG call will be on 28 June 2024.