Collecting and Reporting Data on the Impacts of Emergencies on People with Disabilities

A Summary Report for a 2023–2024 CSTE Project: Advancing Equity in Emergency Preparedness to Understand Current Practices and Develop Educational Resources

July 2024

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Contents

Acronyms

Acronym	Term
BRFSS	Behavioral Risk Factor Surveillance System
CSTE	Council of State and Territorial Epidemiologists
CDC	Centers for Disease Control and Prevention
AFN	Access and Functional Needs
EPRR	Emergency Preparedness, Response, and Recovery
HHS	U.S. Department of Health and Human Services
REALD	Race, Ethnicity, Language, and Disability
SitRep	Situational Report
SPIS	Surveillance Practice & Implementation Subcommittee
STLT	State, Tribal, Local, and Territorial

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Introduction

Although more than one in four U.S. adults has a disability[1] and most people will experience disability at some point in their lifetime, the emergency-related needs of people with disabilities are often overlooked by public health agencies.[2] People with disabilities experience significant inequities in health outcomes, healthcare access, and other social determinants of health, compared to people without disabilities. The impacts of these inequities are magnified during emergencies such as pandemics and disasters, placing people with disabilities at increased risk for illness, injury, hospitalization, or death if emergency preparedness, response, and recovery (EPRR) efforts do not meet the needs of people with disabilities. For example, shelters may not be fully accessible; people with disabilities may experience greater barriers due to disruptions in transportation and support services; and accessible emergency communications may not be consistently provided. People with disabilities may also experience discrimination, including a lack of access to life-saving care, despite federal laws protecting the rights of people with disabilities. Public health and social issues (e.g., ableism, racism, and poverty) are intersectional and contribute to severe impacts of emergencies on various populations. Therefore, public health jurisdictions need to maintain robust situational awareness of people with disabilities as they prepare, respond, and recover from public health emergencies.

To support public health jurisdictions in these efforts, CSTE undertook a project to improve data collection and response efforts for people with disabilities during emergencies with funding from the CDC and project implementation support from Ross Strategic. In summer 2023, CSTE and Ross Strategic conducted an online Assessment of Jurisdictional Disability Data Collection Practices on the Impacts of Emergencies on People with Disabilities ("Jurisdictional Assessment") to first understand current practices, gaps, and opportunities. In spring 2024, CSTE and Ross Strategic conducted focus groups with jurisdictional staff, individuals with disabilities, and disability subject matter expertise and engaged with CSTE Disaster Epidemiology Subcommittee members. Through these engagements, the team unpacked the results of the Jurisdictional Assessment and gathered input on educational resources that could help increase awareness and capacity of public health jurisdictions to collect, utilize, and report data on people with disabilities for EPRR. The resulting suite of products include the following, which are available on CSTE's Disaster Epidemiology page:

- *Disability Data: Situational Report Template* is a resource for public health departments to incorporate data elements into their existing SitRep form to assess the health impact of emergencies on people with disabilities.
- *Population-level Publicly Available Disability Data Sources for Public Health Agencies* summarizes population-level data sets that could be used to fill in some components of the SitRep template.
- *Collecting Data to Support People with Disabilities in Emergency Preparedness, Response, and Recovery* describes jurisdictional practices for collecting data on people with disabilities, partnering with disability organizations, and conducting education and outreach activities.
- A webinar recording that provides an overview of this project, the results, and the products listed above, as well as spotlighting jurisdictions' ongoing work to improve collection and reporting of disability data for EPRR.

[1] Centers for Disease Control and Prevention, National Center on Birth Defects and Developmental Disabilities, Division of Human Development and Disability. Disability and Health Data System (DHDS) Data [online]. [accessed Jul 10, 2024]. URL: https://dhds.cdc.gov
[2] National Council on Independent Living - Disability Equity During Disasters Toolkit

This report summarizes the methods and results of the Jurisdictional Assessment, as well as engagement with CSTE Subcommittees and focus groups to develop and refine the final SitRep template and educational resources.

Jurisdictional Assessment

The aim of the Jurisdictional Assessment was to better understand the extent to which state and territorial jurisdictions collect data on people with disabilities and if, how, and to what extent they report those data to agency and jurisdictional leadership during emergencies. The findings from this Jurisdictional Assessment helped to inform the development of a disability data SitRep template and two educational resources. The following section describes key results and summarizes the methods for development, administration, and results processing. Additional details about the results can be found in Appendix A. Detailed Jurisdictional Assessment Results and the instructions and questions can be found in Appendix B. Jurisdictional Assessment Form.

Jurisdictional Assessment Development and Administration

CSTE National Office staff and Ross Strategic developed the questions for the Jurisdictional Assessment with technical assistance from CDC and input and feedback from CSTE's SPIS and Disaster Epidemiology Subcommittee. CSTE Subcommittee members were engaged to refine questions included in the Jurisdictional Assessment, followed by pilot testing with six jurisdictions before finalizing and launching the Jurisdictional Assessment. This work was deemed a 'non-research activity' according to the CDC's interpretation of federal regulations defining research,[3] and thus exempt from CDC Institutional Review Board approval.

CSTE Subcommittee Meetings and Pilot Testing

In April and May 2023, Ross Strategic, CSTE, and CDC engaged with the Disaster Epidemiology Subcommittee and SPIS Subcommittee. Subcommittee members were presented with an overview of the importance of leveraging data on people with disabilities for emergency-related activities and the draft Jurisdictional Assessment and asked to reflect on the scope, target audiences, and definitions included in the Jurisdictional Assessment. Ross Strategic and CSTE used this feedback to finalize the Jurisdictional Assessment and transition into a pilot testing process.

Once developed, six jurisdictions pilot-tested the Jurisdictional Assessment in July 2023 (District of Columbia, Massachusetts, Minnesota, Ohio, Oregon, and Tennessee). Pilot testers generally reported that the Jurisdictional Assessment was easy to understand, although finding the answers to the Jurisdictional Assessment questions required time and coordination with colleagues. After pilot-testing, Ross Strategic and CSTE revised the Jurisdictional Assessment and CSTE broadly distributed via email in August 2023. The e-mail included a link to the online Jurisdictional Assessment instrument in Qualtrics, a PDF attachment of the Jurisdictional Assessment, as well as a supplemental document with additional background information for respondents. CSTE staff sent several reminders to jurisdictions to complete the Jurisdictional Assessment, including direct emails to state epidemiologists for non-responding jurisdictions. The Jurisdictional Assessment was then closed in October 2023.

[3] U.S. Centers for Disease Control and Prevention. 2021. Protection of Human Subjects in Research and Clinical Investigation. Available at https://www.cdc.gov/os/integrity/docs/CDC-Human-Subjects-Protections-Policy.pdf (Accessed July 17, 2024).

Key Terms

The following terms were used in the Jurisdictional Assessment:

- **Disability**: There are many different definitions of disability. CDC defines disability as any condition of the body or mind (impairment) that makes it more difficult for the person with the condition to do certain activities (activity limitation) and interact with the world around them (participation restrictions).
- **Situational Report**: The reporting format used to keep your agency and jurisdictional response leadership informed of changing circumstances during an emergency. It should be shared through an established forum, such as your agency's Incident Command System, jurisdiction's information sharing network, or a secure website.
- **Situational Awareness**: The ability to identify, process, and comprehend the critical information about an incident. More simply, it is knowing what is going on around you. Situational Awareness requires continuous monitoring of relevant sources of information regarding the health and mental health impacts of actual incidents and developing hazards.
- **Structured Data**: Standardized and stored in a predefined format, where unstructured data could be many varied types of data that are stored in their native formats (e.g., free text field).
    - Example of structured data format: What is your ethnicity?
        - Hispanic or Latino
        - Not Hispanic or Latino
- **Individual-, Residential Facility-, and Population-level Data**: See below for examples of data elements related to people with disabilities during emergencies.

Table 1: Examples of Individual-, Residential Facility-, and Population-Level Data Elements

Term	Description	Examples of Data Sources
Individual-level	Individual-level data on disabilities collected as part of an existing surveillance system, or one set up at time of an emergency. Individual level-data may or may not include personal identifying information.	Reportable disease surveillance data sources and systems, including provider and lab-based reporting as well as electronic case reports; Syndromic surveillance (emergency department visits, outpatient visits); Vital Registries (death certificates).
Residential Facility-level	List of residential facilities within the jurisdiction for persons with disabilities (e.g., group homes, supportive housing).	Centers for Medicare & Medicaid Services; Community-level disability service organizations; Jurisdictional agencies that support/regulate residential facilities for persons with disabilities.
Population-level	Population-level data on the number and/or percentage of population within the jurisdiction of persons with disabilities – overall or by disability type (ideally available state or territory wide, as well as at county level).	Jurisdiction-level surveys, U.S. Department of HHS emPOWER, Census Bureau, Disability Claims Services, American Community Survey, Behavioral Risk Factor Surveillance System (BRFSS), Community Reception Center Simulation Program for Leveraging and Evaluating Resources.

Disability Types

The following disability types were included in the Jurisdictional Assessment:

- Intellectual (characterized by limitations in intellectual functioning and adaptive behavior originating before age 18) or Developmental (broad range of conditions due to an impairment in physical, learning, language, or behavior areas originating before age 22)
- Cognitive (difficulties such as concentrating, remembering, or making decisions)
- Hearing (serious difficulty hearing or deafness)
- Mobility (serious difficulty walking or climbing stairs)
- Vision (serious difficulty seeing or blindness)
- Self-care (difficulty dressing or bathing)
- Independent Living (difficulty doing errands alone)
- Communication (difficulty communicating, understanding others, or being understood)
- Disabling chronic condition
- Any disability – no distinction in the type of disability

Jurisdictional Assessment Limitations

The Jurisdictional Assessment response rate for states was 66%, and the total response rate (including the District of Columbia and territories) was 62.5%. This means that approximately one-third of the eligible jurisdictions' disability data collection and reporting practices are not included in the analysis. Furthermore, this Jurisdictional Assessment required coordination between staff involved with surveillance, epidemiology, infectious diseases, equity, disability and aging, informatics, populations with disability and access and functional needs (AFN), and emergency preparedness and response. Thus, the accuracy and completeness of the results varied across responses and depended on the extent to which jurisdictions were able to internally coordinate. For example, there were several instances in which respondents selected "unsure" or skipped questions, but it was not clear whether this was because the questions were not applicable to them, or the respondent was unsure of the answer. Some Jurisdictional Assessment questions were more subjective in nature; therefore, answers may have varied depending on the individual respondent's assessment of their health department.

Summary of Responses and Key Jurisdictional Assessment Findings by Topic

CSTE distributed the Jurisdictional Assessment to State and Territorial Epidemiologists, Deputy State Epidemiologists, the CSTE Executive Board, and CDC's Disability and Health state programs on August 9th, 2023. The response deadline was originally September 1st and extended until October 20th. A total of 35 jurisdictions responded to the Jurisdictional Assessment, including 33 states and two territories (Puerto Rico and District of Columbia), with at least one response per HHS region. Jurisdictions responding to the survey also represented a wide variety of health department governance classifications, with the majority (49% or 17 total) from decentralized jurisdictions, followed by centralized (20% or seven total) and mixed (11% or four total) jurisdictions.

Routine Disability Data Collection

- Almost half of responding jurisdictions (46%) do not use a set definition for disability.
- More jurisdictions collect disability data at the population-level (60%) than at residential facility- (40%) or individual- (37%) levels.

- More jurisdictions have access to disability data at the population-level (77%) than at residential facility- (34%) or individual- (23%) levels.

Individual-Level Data Practices

- More than half of jurisdictions (54%) are aware of disability data being captured in a structured way in surveillance data sources and systems, with 24% of jurisdictions being unsure.
- Only one jurisdiction (Oregon) uses discrete structure variables on disabilities in case investigation forms as mandated by a recently passed law.
- Slightly over half of jurisdictions capture data on specific disability types during individual case investigations conducted as part of surveillance activities during emergency responses.

Residential Facility-Level Data Practices

- Over half of jurisdictions (57%) have access to information (facility name, address, and contact information) on all residential facilities for people with disabilities (e.g., group homes, intermediate care facilities, supportive housing, etc.) in their jurisdictions.

Population-Level Data Practices

- Most jurisdictions (89%) use some form of population-level data for EPRR that includes disability status and/or type of disability.
- The most common population-level data sources used are the Census Bureau, HHS emPOWER, Social Vulnerability Index, BRFSS, or CDC's Disability and Health Data System.

Public Health Emergency Preparedness, Response, and Recovery During Emergencies

- Only a third of jurisdictions (34%) conduct or have plans to conduct a rapid needs assessment of individual households that includes questions on disability as part of public health responses during emergencies.
- Jurisdictions cite limited resources (funding, staff capacity, and staff expertise) as the main reason for not conducting rapid needs assessments of individual households as part of their public health response during emergencies.
- Only 19% of all jurisdictions report that their SitReps include data on people with disabilities during emergency response, though most respondents (66%) chose not to answer this question or were unsure.
- For the 14% of jurisdictions that do not report data on people with disabilities in their SitReps, the majority cite that these types of data are not consistently collected.

Educational Resources for Agency Staff

- Jurisdictions would like materials specifically designed to train surveillance and emergency response staff in collecting and using data on people with disabilities.
- Several jurisdictions desire a 'grant-funded mandate' or a 'national standard' for reporting data on people with disabilities during an emergency to which jurisdictions would be held accountable.

Engaging Public Health Jurisdictions and Disability Subject Matter Experts

Throughout the project, Ross Strategic engaged with public health jurisdictions and disability subject matter experts (including people with disabilities) through focus groups and meetings. After analyzing the Jurisdictional Assessment results, the project team engaged with jurisdictional staff and disability subject matter experts to unpack the Jurisdictional Assessment's results and further explore current practices, challenges, and opportunities to address challenges and gaps in utilizing data on the impacts of emergencies on people with disabilities for EPRR. Insights from these meetings and focus groups were utilized to inform the development of educational materials, including a disability data SitRep template. Although not all feedback was appropriate for inclusion in the final educational resources and SitRep template given the scope of those documents, the perspectives and ideas shared throughout this process were valuable and could inform ongoing efforts. As such, the following sections summarize insights and takeaways from the entire engagement process. The final educational resources and SitRep template are available on the CSTE Disaster Epidemiology webpage.

CSTE Subcommittee Meeting

In March 2024, Ross Strategic attended a Disaster Epidemiology Subcommittee meeting to discuss members' reflections on Jurisdictional Assessment results and elements proposed for a SitRep template with an emphasis on opportunities and challenges associated with accessing and using residential facility-level data to address needs of people with disabilities during EPRR activities. Subcommittee members shared that residential-level disability data could be used to understand (1) the needs of people with disabilities during emergencies and (2) how to best provide services and supplies during emergencies, but also shared numerous challenges with collecting and accessing residential-level disability data to inform emergency-related activities. Additionally, people with disabilities are a diverse population with varying needs, which can complicate jurisdictions' EPRR efforts. Insights from the Subcommittee meeting were integrated into the development of educational resources and SitRep template.

Focus Groups

In January 2024, focus group participants were recruited via an online form distributed by CSTE. In February 2024, Ross Strategic conducted two focus groups with staff from state jurisdictions with an emphasis on opportunities and challenges for using individual-level disability data to inform EPRR activities. In May 2024, one focus group was conducted with disability subject matter experts, including people with disabilities, working on disability inclusion and EPRR (refer to Table 2 for a full list of participants). Participants were provided with a summary of results from the Jurisdictional Assessment and discussion questions before their focus group. Objectives of focus group discussions were to (1) ground truth and gather feedback on Jurisdictional Assessment findings, particularly around individual-level disability data practices and related Jurisdictional Assessment findings; (2) collect feedback on proposed components and format for reporting disability data in SitReps used during emergency activations; and (3) gather input on specific topics and audiences for educational resources to be developed through this project.

Table 2: Focus Group Participants

Focus Group #1	State jurisdictions including Iowa Department of Health and Human Services and Oregon Health Authority.
Focus Group #2	State jurisdictions including Hawaii Department of Health, Iowa Department of Health and Human Services, and Massachusetts Department of Public Health.
Focus Group #3	Disability subject matter experts, including people with disabilities, from the following organizations: The Partnership for Inclusive Disaster Strategies, Disaster Health Services, The University of Montana, Ohio Disability and Health Program, and North Intertribal Vocational Rehabilitation Program

Focus group participants suggested that educational resources developed through this project should provide guidance on (1) the importance of collecting data on people with disabilities for emergencies; (2) ways that jurisdictions can collaborate with disability organizations to support data-related activities; and (3) jurisdictions' success stories with supporting people with disabilities in EPRR activities.

Although most jurisdictional focus group participants had not collaborated with disability organizations to date, they recognized the importance of engaging with these organizations. They also acknowledged that disability organizations may have competing priorities and limited capacity to engage with the public health staff. State jurisdictions have many layers of contact separating them from community-based organizations which hinders consistent communication at the local level. Focus group participants were interested in building and strengthening partnerships with disability organizations to support emergency-related activities (e.g., improve dissemination of assistive technology and establish temporary shelters during emergencies). Focus group participants speculated that local jurisdictions may have more involvement with disability organizations or other community-based organizations and raised the importance of engaging with disability organizations during periods of non-emergency.

The project team convened disability subject matter experts, including people with disabilities, who work on disability inclusion and emergency preparedness to get their input on the development of the SitRep template and educational resources and to discuss promising practices for inclusive EPRR activities (see Table 2 for participants). Disability subject matter experts shared input on core data elements for inclusion in the SitRep template and described collaborations between disability organizations and public health jurisdictions. Focus group participants suggested several key points which were incorporated into the final SitRep template, including specific data sources and the importance of gathering data around the needs of individuals who identify as having disabilities as well as individuals who do not identify as having disabilities but do identify as having AFN. In terms of collaborating with jurisdictions, focus group participants shared challenges related to miscommunication, limited capacity, and destigmatizing disabilities and provided recommendations which were incorporated into the final educational materials.

Developing a Disability Data SitRep Template and Educational Resources

Situational Report Template Drafting and Review Cycles

Based on the initial results of the Jurisdictional Assessment and subsequent input from the Disaster Epidemiology Subcommittee meeting and three focus groups, Ross Strategic collaborated with CSTE and CDC to develop a SitRep template to capture data on people with disabilities in emergency-related activities. This SitRep template is intended for use by jurisdictions during an emergency response to facilitate reporting data on people with disabilities and can also inform emergency preparedness activities such as developing needed collaborations and data pipelines. The SitRep template includes recommendations for core data elements that can be collected and reported in SitReps to

assess the health impact of emergencies on people with disabilities, along with instructions and guidance for capturing data for all-hazards and hazard-specific emergencies (e.g., communicable disease outbreak, extreme weather/natural disaster, and radiological/nuclear/chemical incident).

The SitRep template was refined with feedback from CDC and CSTE over multiple review cycles, discussion during the CSTE Annual Conference project session on this topic (see call out box below, "CSTE Annual Conference Session"), volunteer pilot testers from Florida Department of Health and Michigan Department of Health and Human Services from the CSTE Disaster Subcommittee, and disability subject matter experts who conducted an in-depth review of the draft SitRep template. They provided detailed feedback on the structure, content, and feasibility of completing the SitRep template which resulted in clarifications to instructions, examples, context for how/why the data can be utilized, and additional data sources.

Educational Resources Drafting and Review Cycles

Based on the Jurisdictional Assessment, CSTE Subcommittees member input, and focus group takeaways, the Ross Strategic team compiled a list of the following topics proposed for educational resources that could help address challenges and gaps identified based on the initial results of the Jurisdictional Assessment, input from the Disaster Epidemiology Subcommittee meeting, and three focus groups:

- The importance of collecting data on people with disabilities for emergency-related activities.
- Ways to engage with people with disabilities and disability organizations to support data collection, analysis, and messaging.
- Readily available disability data sources and guidance on how jurisdictions can use population-level disability data sources for EPRR.
- Success stories on how jurisdictions have used disability data to support people with disabilities in emergency-related activities.

After reviewing the full list of potential topics, Ross Strategic, CSTE, and CDC prioritized topics in alignment with the original project scope and available resources. The final educational resources provided guidance on (1) the importance of collecting data on people with disabilities; (2) ways to engage with people with disabilities and disability organizations to support data-related activities; and (3) readily available disability data sources for jurisdictions. These topics are relevant to all jurisdictions regardless of their progress with using data on people with disabilities for EPRR. Furthermore, these topics provide flexibility with creating concise, user-friendly educational resources that are accessible to different types of jurisdictions without being overly complicated with technical information.

Practices and recommendations shared by focus group participants on collecting data, partnering with disability organizations, and conducting education and outreach activities were included in the educational resource on *Collecting Data to Support People with Disabilities in Emergency Preparedness, Response, and Recovery*. This resource is designed for jurisdictions to learn about various strategies that can improve the representation of people with disabilities in public health data systems for emergencies. These strategies specifically focus on ways that data collection and use, education and outreach, and partnerships can be leveraged by jurisdictions to better represent people with disabilities.

Another resource on *Population-level Publicly Available Disability Data Sources for Public Health Agencies* summarizes data sources and trainings/how-to materials that can be used during emergencies to estimate the number of people with disabilities who are impacted and in need of support. These data sources can also inform decision-making and be used to mobilize resources for people with disabilities during emergencies. The educational

resources were refined with feedback from CDC and CSTE over multiple review cycles. Participants from the focus group with individuals with disabilities and disability subject matter expertise were provided with preliminary drafts of the educational resources for their optional review. One focus group participant provided feedback on more explicitly stating ways to include people with disabilities and disability organizations in this work with jurisdictions. The focus group participant also provided additional data sources on people with disabilities or AFN.

CSTE Annual Conference Session

In June 2024, CDC and Ross Strategic facilitated a discussion session during the CSTE Annual Conference. The session emphasized the importance of disability data to guide EPRR and previewed the draft SitRep template to support jurisdictions with reporting data on the impact of emergencies on people with disabilities for situational awareness. During the discussion session, attendees provided their reflections on the Jurisdictional Assessment results, SitRep template, and ways in which their jurisdictions collect and use disability data for EPRR. Key takeaways from the discussion session were incorporated into the educational resources, SitRep template, and planning efforts for a rollout webinar. For example, educational materials and SitRep template were updated to include the following based on session discussion:

- Notable limitations of population-level data sources (e.g., data are not collected in real-time and may not be disaggregated).
- Additional details on whether children are included in publicly available population-level data sources.
- Other publicly available population-level data sources (e.g., BRFSS) and opportunities for data sharing agreements with Veterans Affairs, Social Security Disability Insurance, and others.
- An emphasis on jurisdictions partnering with various types of disability organizations to collaboratively identify emergency-related problems and solutions.
- Specific methods to improve data collection efforts (e.g., data use agreements between disability organizations and jurisdictions).

Session attendees shared their jurisdictions' work with emPOWER, BRFSS, AFN trainings, and emergency planning at the local level. One state's success story was showcased during a July 2024 rollout webinar available on the CSTE Disaster Epidemiology webpage.

Looking Ahead

The results of the Jurisdictional Assessment and development of the suite of resources for public health jurisdictions provide meaningful information about current practices as well as opportunities to improve data collection and reporting for EPRR to better address the needs of people with disabilities during and after emergencies. These resources not only raise awareness of the importance, but also advance the practice of disability data collection and sharing during emergency response, with the ultimate aim of addressing inequitable outcomes and increasing the safety and well-being of people with disabilities both during and after an emergency. That said, throughout the engagement process for this project, public health staff and disability subject matter experts suggested more can and should be done. They raised numerous ideas and opportunities to continue to improve data collection and reporting on the impact of emergencies on people with disabilities

that went beyond the scope of this project. Suggestions for future consideration if funding were available included:

- **Additional Pilot Testing:** Pilot test the Disability Data SitRep template with community organizations, iterating based on feedback over time.
- **Expanding the SitRep Template:** Explore opportunities to expand the SitRep template beyond the current "core" variables, which are the minimum standards for collecting and reporting disability data for EPRR. This includes considering short-term disability status, which could affect an individual's AFN during an emergency, potentially requiring novel data sources and methods.
- **Developing Tools and Guidance:** Create a suite of tools or guidance for use by state, Tribal, local, and territorial (STLT) public health jurisdictions. This could include a toolkit with model data use agreement language for partnering with disability data stewards.
- **Integrating Disability Data into Rapid Needs Assessments:** Further integrate disability data collection to help ensure funded programs are inclusive of people with disabilities, improve this population's health monitoring, and identify health disparities between people with and without disabilities.
- **Forming National Partnerships:** CDC could further develop strong partnerships with disability data stewards such as the National Organization for Rare Disorders, AARP, Social Security Administration, Social Security Disability Insurance, and Veterans Affairs and jointly consider possibilities for future data sharing to STLT public health jurisdictions for emergency preparedness.

Appendix A. Detailed Jurisdictional Assessment Results

Response Rates and Program Areas in the Jurisdictional Assessment

CSTE distributed the Jurisdictional Assessment to state epidemiologists in each of the 50 states plus the U.S. territories (American Samoa, Guam, Northern Mariana Islands, Puerto Rico, and the U.S. Virgin Islands) and the District of Columbia. There were 35 responses to the Jurisdictional Assessment, from 33 states plus the District of Columbia and Puerto Rico.

Figure 1 highlights states that completed the Jurisdictional Assessment in blue: Alaska, Arkansas, California, Colorado, Connecticut, Delaware, Florida, Hawai'i, Iowa, Illinois, Indiana, Louisiana, Maryland, Michigan, Minnesota, Mississippi, North Carolina, North Dakota, New Hampshire, New Mexico, Nevada, New York, Ohio, Oklahoma, Oregon, Pennsylvania, South Dakota, Tennessee, Utah, Vermont, Washington, Wisconsin, and West Virginia.

The Jurisdictional Assessment response rate for states is 66%, and the total Jurisdictional Assessment response rate (including the District of Columbia and territories) was 62.5%.

Figure 1: Completion of Jurisdictional Assessment

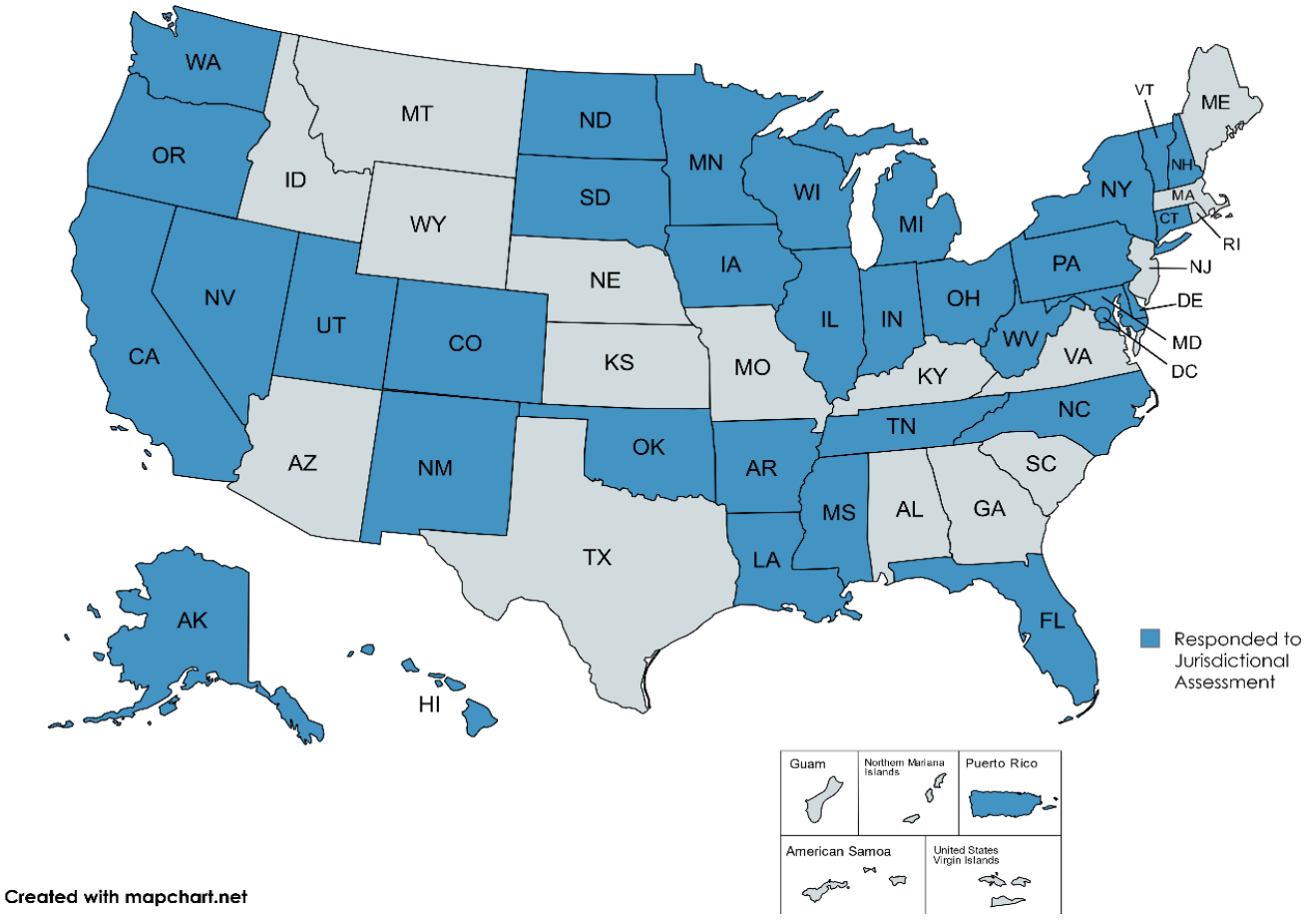


Table 3: Jurisdictional Assessment Participation by U.S. Department of Health and Human Services (HHS) Region

U.S. Department of Health and Human Services (HHS) Regions and States	Total Responses (% of HHS region)
Region 1 - Boston: Connecticut, Maine, Massachusetts, New Hampshire, Rhode Island, and Vermont	3 (50%)
Region 2 - New York: New Jersey, New York, Puerto Rico, and the Virgin Islands	2 (50%)
Region 3 - Philadelphia: Delaware, District of Columbia (DC), Maryland, Pennsylvania, Virginia, and West Virginia	5 (83.33%)
Region 4 - Atlanta: Alabama, Florida, Georgia, Kentucky, Mississippi, North Carolina, South Carolina, and Tennessee	4 (50%)
Region 5 - Chicago: Illinois, Indiana, Michigan, Minnesota, Ohio, and Wisconsin	6 (100%)
Region 6 - Dallas: Arkansas, Louisiana, New Mexico, Oklahoma, and Texas	4 (80%)
Region 7 - Kansas City: Iowa, Kansas, Missouri, and Nebraska	1 (25%)
Region 8 - Denver: Colorado, Montana, North Dakota, South Dakota, Utah, and Wyoming	4 (66.67%)
Region 9 - San Francisco: Arizona, California, Hawaii, Nevada, American Samoa, Commonwealth of the Northern Mariana Islands, Federated States of Micronesia, Guam, Marshall Islands, and Republic of Palau	3 (30%)
Region 10 - Seattle: Alaska, Idaho, Oregon, and Washington	3 (75%)

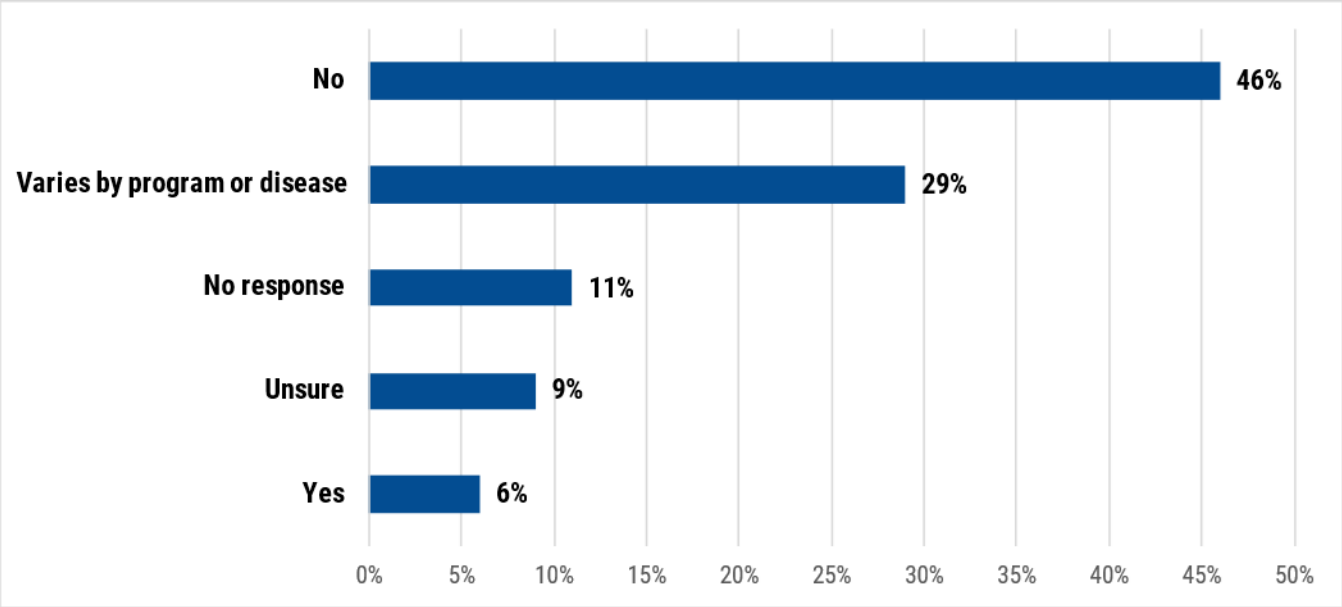
Routine Disability Data Collection

The Jurisdictional Assessment background information included CDC's definition of disability, which is based on the World Health Organization's International Classification of Functioning Framework: "*A disability is any condition of the body or mind (impairment) that makes it more difficult for the person with the condition to do certain activities (activity limitation) and interact with the world around them (participation restrictions)*." Jurisdictions were then asked what definition of disability they use. Almost half of responding jurisdictions do not use a set definition for "disability" for data collection activities as part of disease surveillance activities. (Question 1). A common theme from these responses was that there was not a consistent definition used for disability across departments, rather there are several elements collected to determine disability status.

"We do not actually have a definition for disability. We have questions that are related to a person's functional status and limitations but do not have a set definition for 'disability'."

"Numerous state entities refer to disability and the varying conditions of disability differently. Most of the time this is by a condition or functional-based definition - that is, a medical model of definition (often looking at disabilities as chronic health conditions). There are very few use cases based on sociological, supportive definitions."

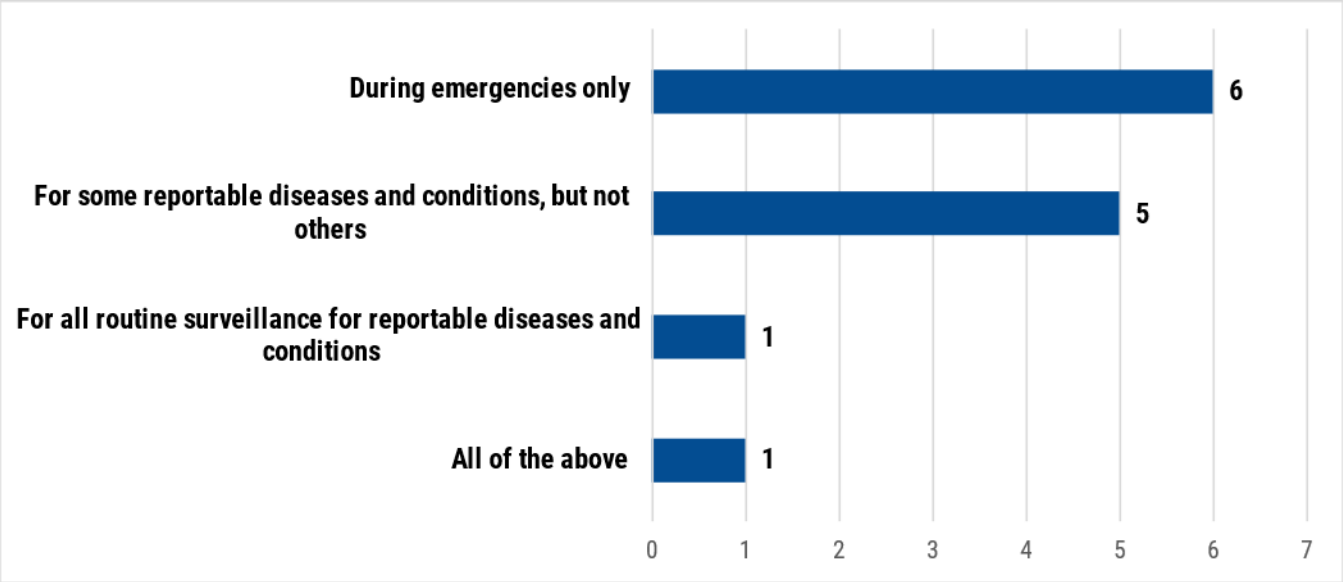
Figure 2: Definition for Disability – Question 1 (n = 35)



The Jurisdictional Assessment also sought to determine at which levels jurisdictions collect and/or have access to disability data. Table 1 provides examples of individual, residential facility, and population-level data elements and data sources. More jurisdictions collect disability data at the population-level (60%) than at residential facility- (40%) or individual- (37%) levels (Question 2). Similarly, more jurisdictions have access to disability data at the population-level (77%) than at residential facility- (34%) or individual- (23%) levels (Question 3). Only one jurisdiction that completed the Jurisdictional Assessment does not collect or have access to disability data. For the thirteen responding jurisdictions that do collect disability data at the individual-level, the majority (54%) only collect disability data during emergencies (Question 2A).

"Disabilities are generally collected as underlying health conditions and collected via medical record reviews or patient interviews. These enhanced surveillance activities are only conducted for specific conditions due to severity and/or funding."

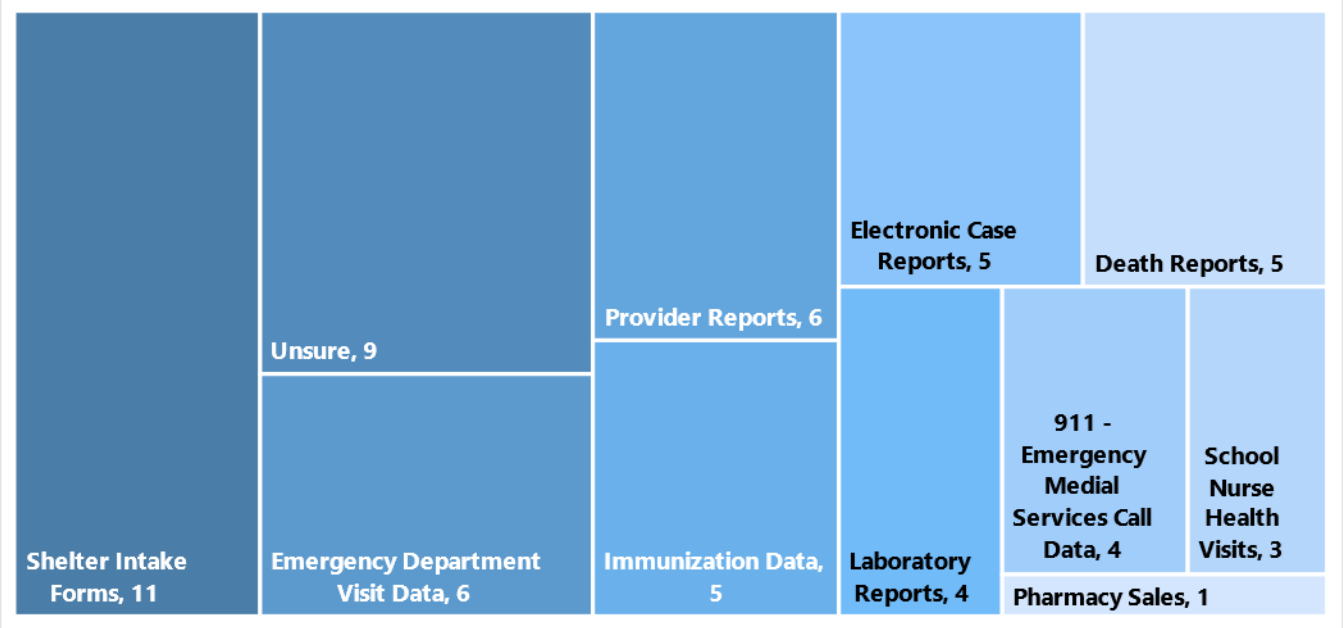
Figure 3: Individual-Level Disability Data Collection for Surveillance Purpose – Question 2A (n = 13)



Individual-Level Data Practices

The Jurisdictional Assessment asked participants whether they captured any information on disability in a structured way (e.g., disability is included as a discrete formatted variable(s) in the data collected with response options indicating presence or absence of disability, or if information on disability status is unknown) using any surveillance data sources and systems (Question 4). Of the 35 responding jurisdictions, 54% were aware of data that are captured in a structured way. Figure 4 summarizes the surveillance data sources and systems that collect disability data in a structured way.

Figure 4: Structured Disability Data in Surveillance Sources and Systems – Question 4 (n = 35; jurisdictions could select more than one option)



For case-based disease surveillance, a majority (60%) of jurisdictions' case investigation forms for interviewing patients who have reportable diseases or conditions *do not* include discrete structured variable(s) on disabilities; 23% of jurisdictions do for some diseases or conditions, 6% of jurisdictions were 'Unsure', and 11% did not respond. (Question 5). When asked for follow-up on why not all disease investigation forms collect these data, many jurisdictions cited that there is no requirement or standard that is in place to ensure disability data are routinely collected (Question 5A). The only jurisdiction that uses discrete structure variables on disabilities was Oregon, where Race, Ethnicity, Language, and Disability (READ) was recently passed into Oregon law, thus mandating that demographic information be collected by health care providers.

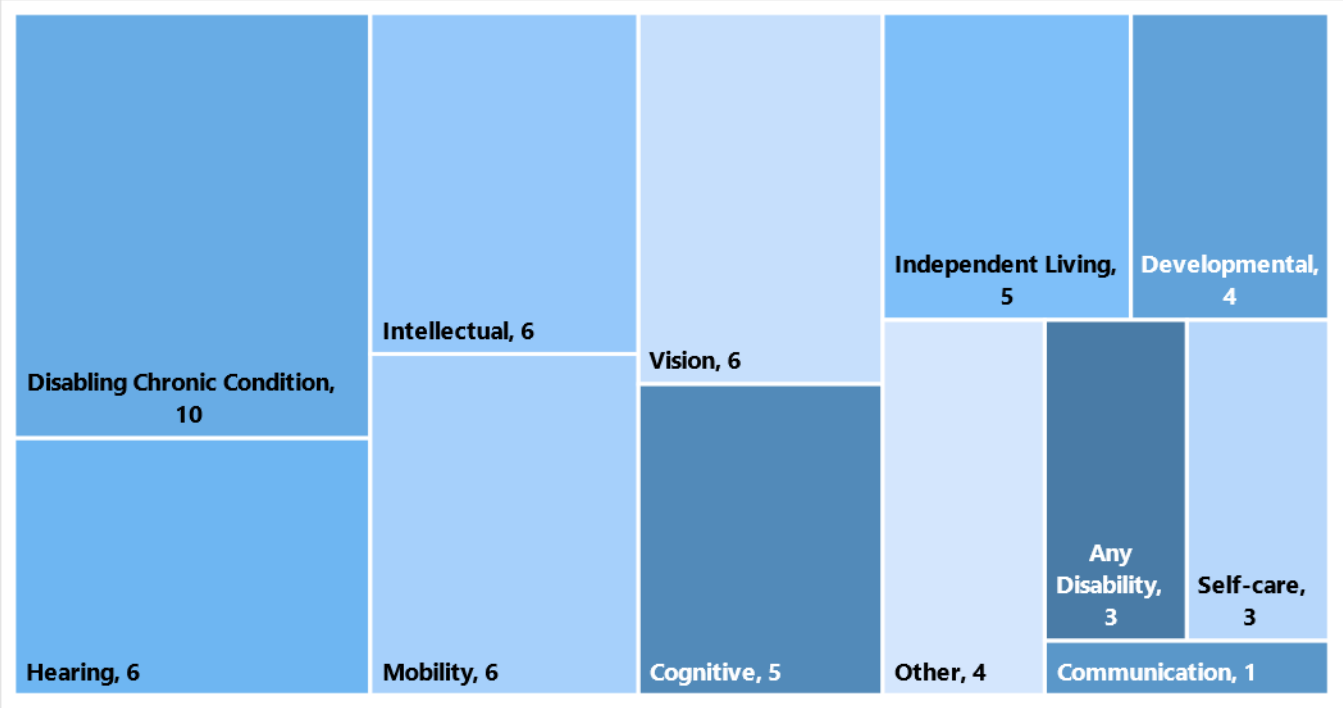
"We had not yet identified how these data might be used or developed standards for it."

"Some conditions are required to collect data on disabilities. At the state level we typically do not collect this information unless it's required. Local health jurisdictions collect these types of data."

"We have not been asked to provide information for disabled persons routinely in the past."

Slightly over half of jurisdictions captured data on specific disability types during individual case investigations during emergency responses (e.g., COVID-19 or Mpox, or heat-wave related mortality) (Question 64). Figure 5 summarizes the distribution of disability types captured during individual case investigations.

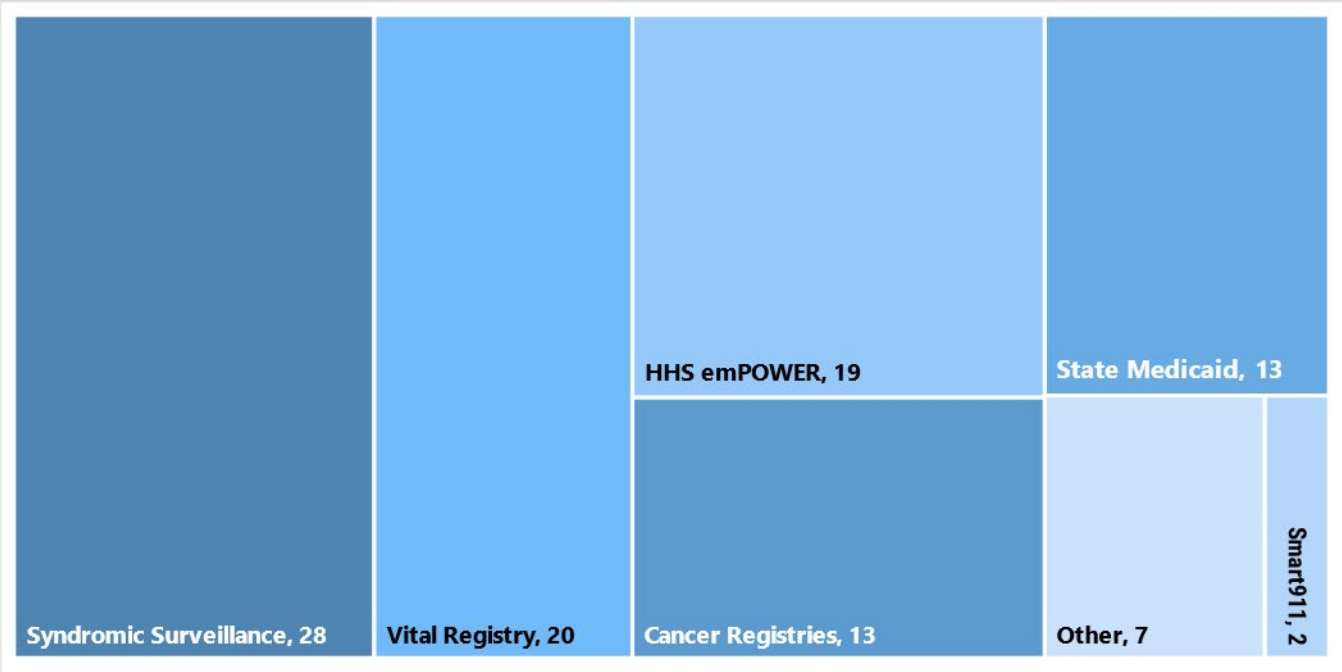
Figure 5: Disability Types Collected in Case Investigation Forms – Question 64 (n = 18; jurisdictions could select more than one option)



"The data we would collect would really be dependent on the disease/event. It is not standard data collection; it would be related to if a particular disabled person/group was at greater risk."

For emergency preparedness, response, and recovery, jurisdictions used a variety of individual-level data sources (Question 6). The overwhelming majority of jurisdictions (80%) use syndromic surveillance, followed by Vital Registry (57%) and HHS emPOWER (54%).

Figure 6: Individual-Level Data Sources for Emergency Preparedness, Response, and Recovery – Question 6 (n = 30; jurisdictions could select more than one option)



Responding jurisdictions also listed other specific individual-level data sources which included Emergency Medical Services, Medicaid waiver rosters, Federal Emergency Management Agency, Resilience Analysis and Planning Tool, Centers for Medicare & Medicaid Services, nursing home data, National Benefit Services, Nationwide Emergency Department Sample, state immunization systems (such as the Tennessee Immunization Information System), and longitudinal surveys.

Residential Facility-Level Data Practices

Over half of jurisdictions (57%) have access to information including facility name, address, and contract information on all residential facilities for people with disabilities (e.g., group homes, intermediate care facilities, supportive housing, etc.) in their jurisdiction (Question 7). Of those that do have access to this information, 40% (8 of 20 total responses) are able to match those data to individual-level data to assess burden by facility or detect outbreaks among residents during emergencies (Question 7A).

"During COVID-19, we cross-referenced case datasets with addresses of known DDD facilities in our jurisdiction, in order to provide additional resources and guidance."

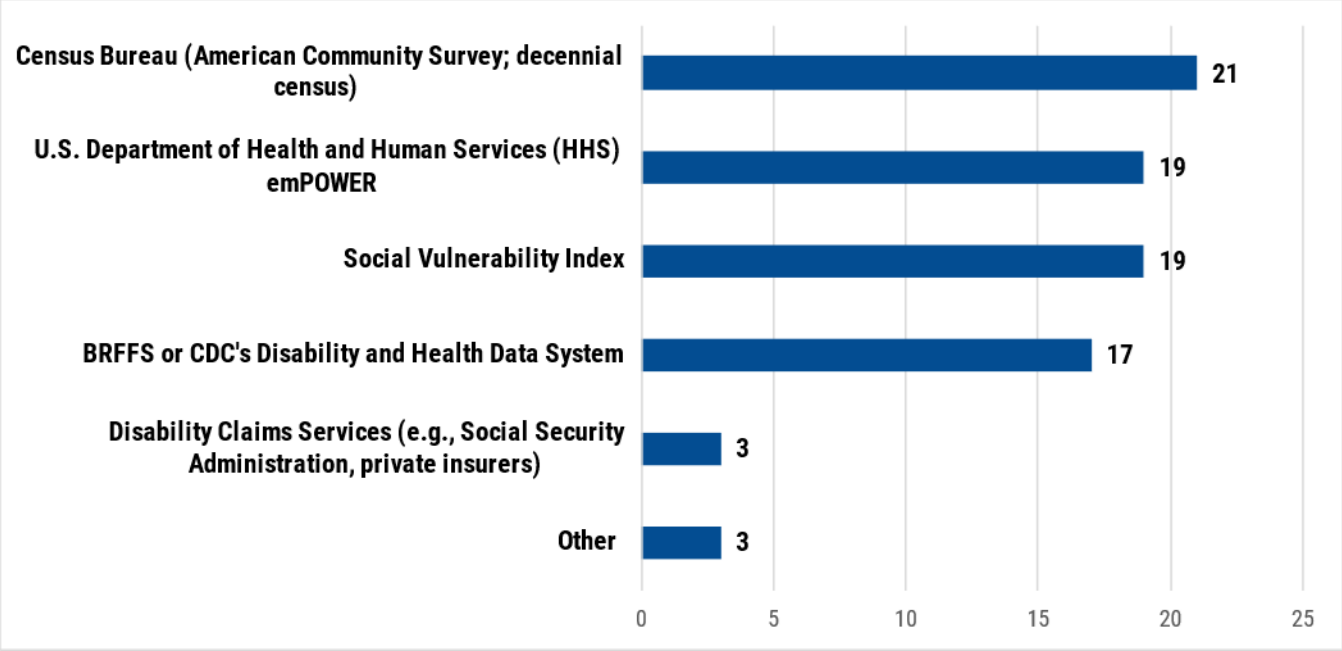
"I believe it is possible as we have used our IT dept to do geocoding (for example) and we have done matching against employment rosters, but it would again be dependent on the resources (personnel primarily) we would have available to us at the time."

"There's no way to currently link case-level information to spatial data because no data is currently geocoded. Further, spatial data on burden is also limited but could include census tract-based variables and other indexes."

Population-Level Data Practices

Most responding jurisdictions (89%) use some form of population data source for emergency preparedness, response, and recovery that includes disability status and/or of type (Question 8); the most common data sources being the Census Bureau, HHS emPOWER, Social Vulnerability Index, and BRFSS or CDC's Disability and Health Data System. Figure 7 summarizes the distribution of population-level data sources that jurisdictions currently use. A minority of responding jurisdictions use identifiers to match individual-level data to the population-level data sources (17%); the remaining respondents are not able to use identifiers (49%) or were unsure of the answer to this question (26%); an additional 9% did not respond to the question (Question 8B).

Figure 7: Population-Level Data Sources – Question 8 (n = 32; jurisdictions could select more than one option)



It is important to note that HHS asserts that all 50 states use emPOWER data for public health preparedness activities, however, the Jurisdictional Assessment results found that is not necessarily the case.

Public Health Emergency Preparedness, Response, and Recovery during Emergencies

The next section of the Jurisdictional Assessment aimed to understand jurisdictions' emergency preparedness, response, and recovery operations, focusing specifically on whether they include disability data in their rapid needs assessments and Situational Reports.

When asked if they conduct (or have plans to conduct) rapid needs assessments of individual households that include questions on disability as part of public health responses during emergencies, jurisdictions' responses were almost evenly distributed between yes (34%), no (26%), and unsure (29%); 11% of jurisdictions did not respond to this question. (Question 9). For jurisdictions that do not conduct or do not plan to conduct individual household assessments, many cited limited resources as the reason why they do not do household surveys (Question 9A).

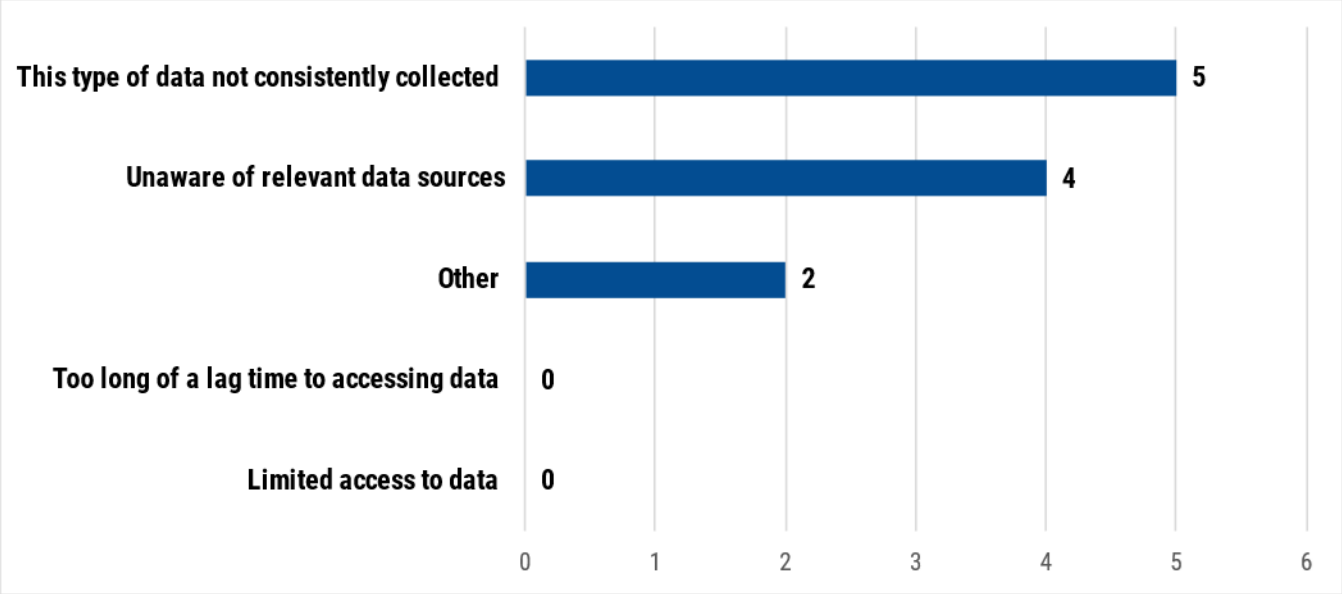
"Surveys are expensive and response rates for the few surveys we conducted in the past were extremely low."

"Resources for projects such as this are limited."

"We don't have staff capacity or expertise."

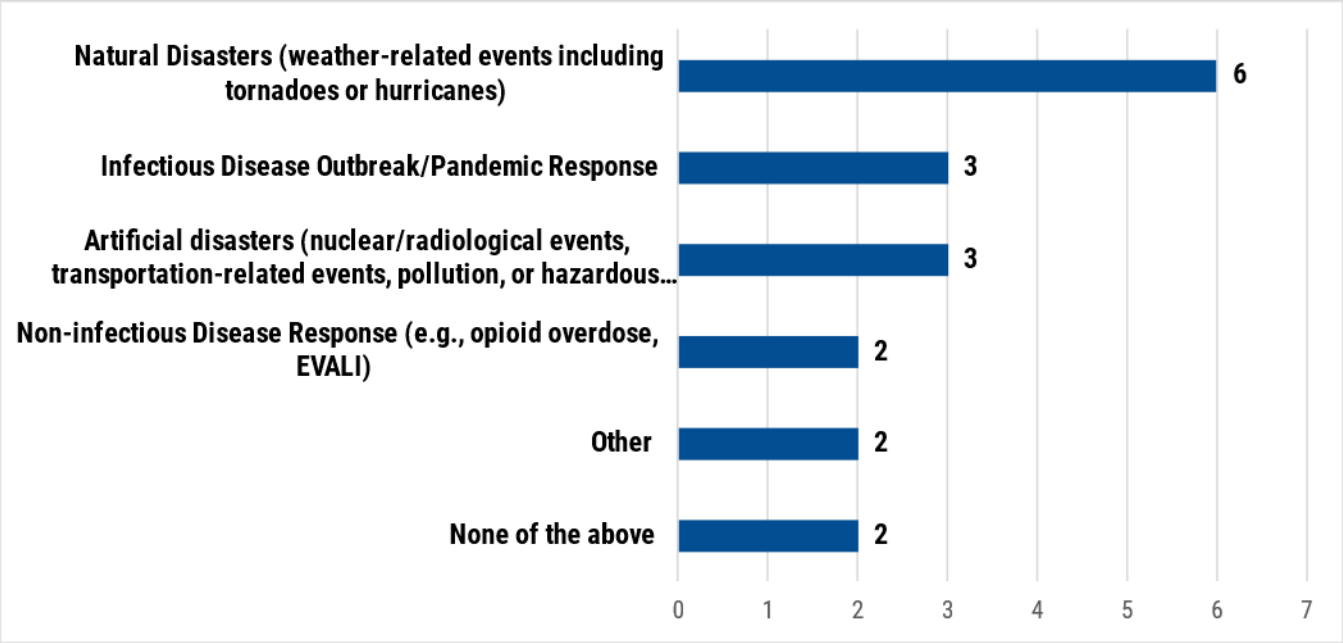
Most respondents (66%) chose not to answer if their jurisdiction included data on people with disabilities in Situational Reports during emergency response and only 19% reported that their Situational Reports include this information; 17% of jurisdictions responded 'No' or 'Unsure' (Question 9C). For jurisdictions where data on people with disabilities are not reported in their Situational Reports, the most common reasons cited was that these types of data are not consistently collected, or they were unaware of relevant data sources (Question 9D).

Figure 8: Reasons Disability Data Are Not Reported in Situational Reports – Question 9D (n = 7; jurisdictions could select more than one option)



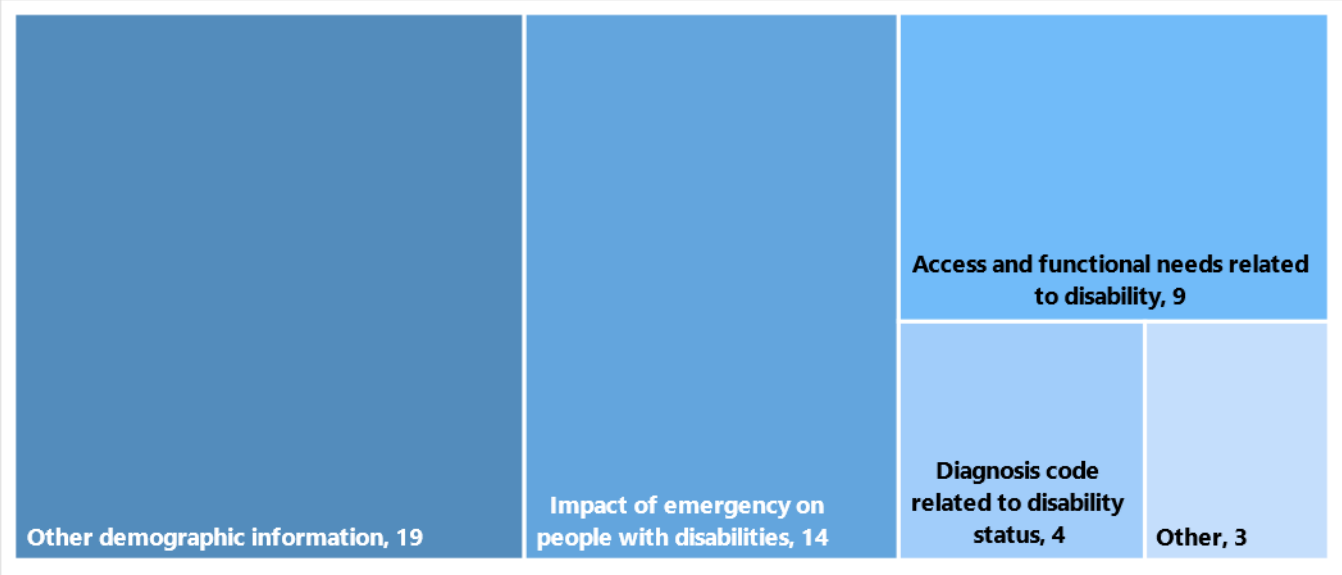
Although some jurisdictions include data on disabilities in their Situational Reports, this reporting is not done consistently for every type of emergency response. Of the 17% of responding jurisdictions that do include disability data in their Situational Reports, they most commonly do so during emergency response for natural disasters (Question 9E).

Figure 9: Types of Emergency Responses in Which Disability Data Are Included in Situational Reports – Questions 9E (n = 6; jurisdictions could select more than one option)



Additionally, the types of data elements related to people with disabilities that jurisdictions collect are not standardized. 54% of total jurisdictions collect demographic information but only 11% collect diagnosis codes related to disability status (Question 10).

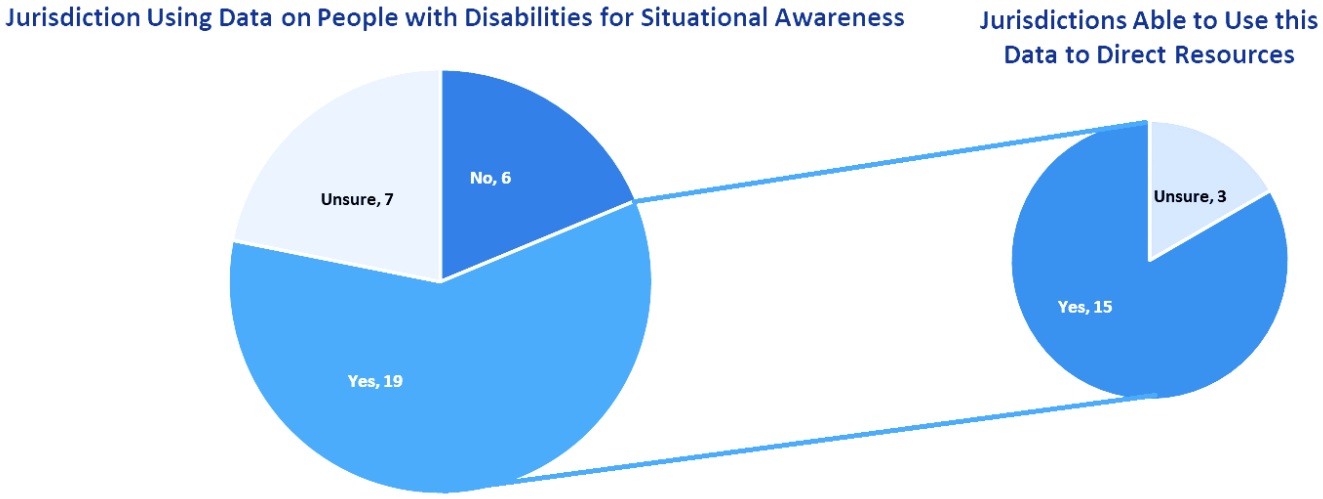
Figure 10: Data Elements Collected in Emergency Preparedness, Response, and Recovery – Question 10 (n = 25; jurisdictions could select more than one option)



> *"Collection of disability status will be completely response specific. This data is not part of a national standardized data collection and privacy concerns direct Public Health to collect minimal essential elements of information on patients to drive responses. We collect demographic data on all persons and do not single out those with a disability."*

Over half of responding jurisdictions (54%) use data on people with disabilities for situational awareness during emergency preparedness, response, and recovery operations (Question 11). Of those, the majority of jurisdictions (83%) use data collected on people with disabilities to direct resources to assist/ensure access to countermeasures and other types of emergency assistance (e.g., shelter, communications, transportation, recovery resources, etc.) (Question 11A). The remaining 17% of jurisdictions were unsure how the data were used. Figure 11 summarizes the distribution of jurisdictions using data on people with disabilities for situational awareness.

Figure 11: Using Data on People with Disabilities to Direct Resources – Questions 11 and 11A



"This was done during the COVID-19 response in regard to facilitating vaccines for homebound persons. But this is not routinely done."

"Limited capability or interest by PHEP to use the information for planning or response."

"We do not routinely collect disability data but if the emergency calls for it, we do have plans in place to reach out to agencies that would support the need."

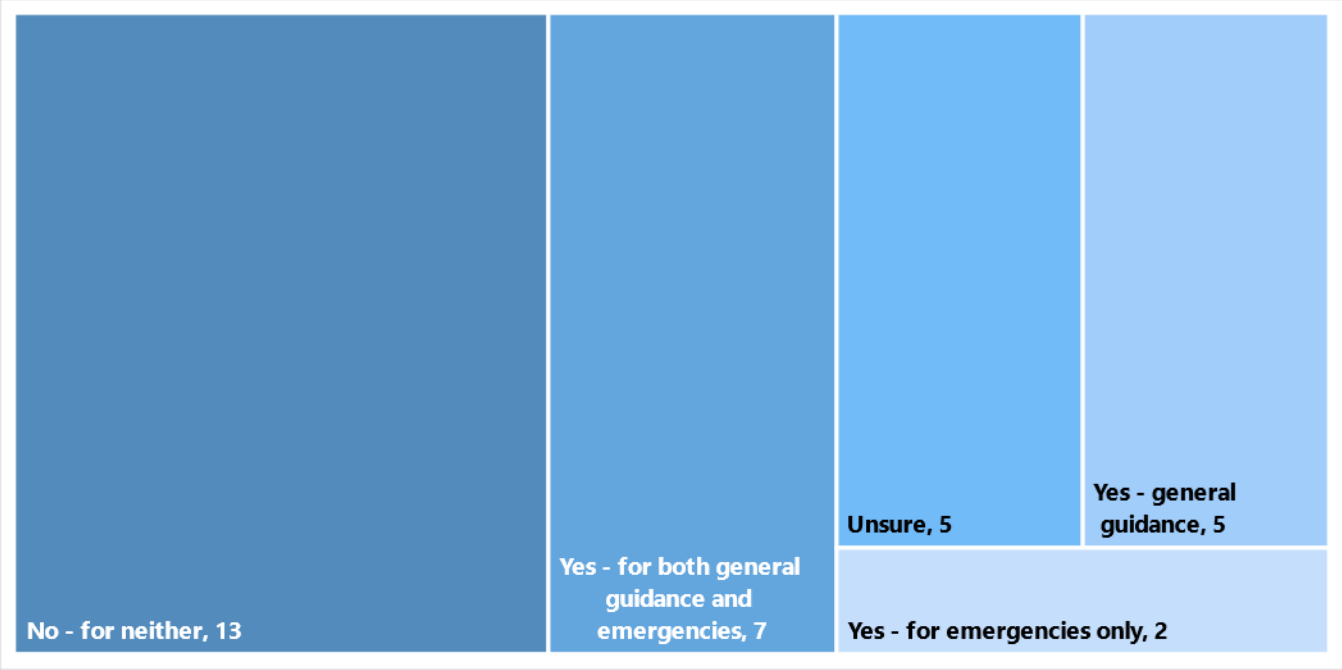
"Pushing information to organizations to further distribute information to their constituents is a standard force multiplier approach. In turn we ask feedback of the organizations regarding if the message about the service/resource is getting out to the intended communities and what are the gaps? We have a state workgroup (hazard mitigation vulnerable population subgroup) and are connected locally to various organizations i.e., BRIDGES. (Centers of Excellence for Blind, Deaf, and Hard of Hearing). Vulnerable Population Coordinators (VPCs) are funded contract positions to support preparedness and response work using COVID funds."

Jurisdictions were asked whether they work with state or local disability organizations (including disability-led organizations) or disability service organizations (e.g., home-based care or transportation services) that support people with disabilities during emergency responses. 34% of jurisdictions responded that they work with disability organizations, followed by 29% who were unsure, and 17% of jurisdictions who responded that they sometimes work with disability organizations (Question 12).

Educational Resources for Agency Staff

The Jurisdictional Assessment ended with questions to understand what existing educational resources (e.g., trainings, factsheets, toolkits, infographics, demos) are used or distributed by jurisdictions, as well as what additional educational resources they would like to see for public health staff on using data to support people with disabilities. Over half of jurisdictions responded either "no" or "unsure" for whether their jurisdictions use or distribute any educational resources for public health staff on using data to support people with disabilities (Question 13).

Figure 12: Jurisdictions Using or Distributing Educational Resources on Using Disability Data – Question 13 (n = 32)



When questioned on what kinds of educational resources jurisdictions would like, they expressed a desire for a variety of resources including trainings, toolkits, FAQs, factsheets, infographics, and guidance documents. A common theme across responses was the need for a national standard for questions to ask and an accountability structure.

> *"Materials specifically designed for surveillance and emergency response staff would be good. Standardized definition of disability is essential."*

> *"We would like a grant-funded mandate, national standard to train our staff on [collecting data to support people with disabilities] THAT JURISDICTIONS ARE HELD ACCOUNTABLE TO."*

Appendix B. Jurisdictional Assessment Form

Instructions and Background Information Sent with the Assessment

Purpose

The Council of State and Territorial Epidemiologists (CSTE) and the Centers for Disease Control and Prevention (CDC) are seeking to improve data collection and response efforts for people with disabilities during emergencies. CDC defines disability based on the World Health Organization's International Classification of Functioning Framework, *"A disability is any condition of the body or mind (impairment) that makes it more difficult for the person with the condition to do certain activities (activity limitation) and interact with the world around them (participation restrictions)."*

CSTE and Ross Strategic are conducting an assessment to understand how data for people with disabilities are collected as well has how they are used during emergency preparedness, response, and recovery activities by states and territories. Findings from this effort will inform the development of the following materials:

- A template form for jurisdictions to include with Situation Reports for reporting data on the impact of an emergency on people with disabilities.
- Resources for public health agencies on the importance of collecting and reporting data to support people with disabilities during emergencies.

This project was supported by the Centers for Disease Control and Prevention of the U.S. Department of Health and Human Services (HHS) as part of a financial assistance award totaling $250,000 with 100 percent funding by CDC/HHS. The contents are those of the author(s) and do not necessarily represent the official views of, nor an endorsement, by CDC/HHS, or the U.S. Government.

Objectives

The first phase of this process is to distribute an assessment to determine if/how state and territorial jurisdictions collect and report data (using situational reports to provide updates to agency and jurisdictional leadership) on people with disabilities during emergencies. The assessment is organized into the following sections:

1. Routine Disability Data Collection
2. Individual Level Data Practices
3. Residential Facility Level Data Practices
4. Population Level Data Practices
5. Emergency Preparedness, Response, and Recovery
6. Resources for Agency Staff

Process

Respondents do not need to complete the entire assessment in one attempt. The assessment can be saved in Qualtrics as respondents make progress with answering questions.

The assessment will be distributed to state and territorial epidemiologists, but each jurisdiction should determine which agency staff are best suited to complete the assessment. Staff involved with surveillance/epidemiology, infectious diseases, equity, disability and aging, informatics, populations with access and functional needs, and

emergency preparedness and response, are encouraged to work with the state and territorial epidemiologist to complete the assessment. We acknowledge that persons knowledgeable on these issues may vary by jurisdiction and encourage state/territorial epidemiologists to collaborate with other agency staff when completing the assessment.

Please contact Andrew Adams at CSTE and the Ross Strategic team with any questions related to completing the assessment.

Key Terms

The following terms are used in the assessment.

- **Disability:** A disability is any condition of the body or mind (impairment) that makes it more difficult for the person with the condition to do certain activities (activity limitation) and interact with the world around them (participation restrictions).[1]
- **Situational Report (or SitRep):** Situational report is the term used to describe the reporting format used to keep your agency and jurisdictional response leadership informed of changing circumstances during an emergency. It should be shared through an established forum, such as your agency's Incident Command System or jurisdiction's information sharing network or a secure web site.[2]
- **Situational Awareness:** Situational Awareness is the ability to identify, process, and comprehend the critical information about an incident. More simply, it is knowing what is going on around you. Situational Awareness requires continuous monitoring of relevant sources of information regarding the health and mental health impacts of actual incidents and developing hazards.[3]
- **Structured Data:** Structured data is standardized and stored in a predefined format, where unstructured data could be many varied types of data that are stored in their native formats (e.g., free text field).
    - Example of structured data format: What is your ethnicity?
        - Hispanic or Latino
        - Not Hispanic or Latino
- **Individual, Residential Facility, and Population-level Data:** See below for examples of data elements related to people with disabilities during emergencies.
- **The following disability types are included in the assessment:**
    - Intellectual (characterized by limitations in intellectual functioning and adaptive behavior originating before age 18) or Developmental (broad range of conditions due to an impairment in physical, learning, language, or behavior areas originating before age 22)
    - Cognitive (Difficulties such as concentrating, remembering or making decisions)
    - Hearing (serious difficulty hearing or deafness)
    - Mobility (serious difficulty walking or climbing stairs)
    - Vision (serious difficulty seeing or blindness)
    - Self-care (difficulty dressing or bathing)
    - Independent Living (difficulty doing errands alone)

- Communication (difficulty communicating, understanding others, or being understood)
- Disabling chronic condition
- Any disability – no distinction in the type of disability

Examples of Individual, Residential Facility, and Population-Level Data Elements

Term	Description	Examples of Data Sources
Individual-level	Individual-level data on disabilities collected as part of an existing surveillance system, or one set up at time of an emergency. Individual level data may or may not include personal identifying information.	Reportable disease surveillance data sources and systems, including provider and lab-based reporting as well as electronic case reports; Syndromic surveillance (emergency department visits, outpatient visits); Vital Registries (death certificates)
Residential Facility-level	List of residential facilities within the jurisdiction for persons with disabilities (e.g., group homes, supportive housing).	Centers for Medicare & Medicaid Services (CMS), Community level disability service organizations; Jurisdictional agencies that support/regulate residential facilities for persons with disabilities
Population-level	Population-level data on the number and/or percentage of population within the jurisdiction of persons with disabilities – overall or by disability type (ideally available state or territory wide, as well as at county level).	Jurisdiction-level surveys, HHS emPOWER, Census Bureau, Disability Claims Services, American Community Survey (ACS), Behavioral Risk Factor Surveillance System (BRFSS), Community Reception Center Simulation Program for Leveraging and Evaluating Resources (CRC SimPler)

Use of Data included in HHS Empower Program for Emergency Planning, Response, and Recovery

- **All datasets are/include:**
    - Updated monthly.
    - Medicare claims data for Medicare beneficiaries that are currently enrolled in the Centers for Medicare and Medicaid Service Medicare Fee-For-Service (Parts A/B) or Medicare Advantage (Part C).
    - https://empowerprogram.hhs.gov/Program-Fact-Sheet.pdf
- **HHS emPOWER Map, REST Service, and emPOWER AI:** https://empowerprogram.hhs.gov/about-empowermap.html
    - Access: Publicly available
    - In addition to Medicare claims data also includes real-time National Oceanic and Atmospheric Administration (NOAA) severe weather and natural hazards and GIS basemaps.
    - Use HHS emPOWER Map to help inform decision making regarding optimal shelter locations and resource allocation, evacuation assistance needs and power restoration prioritization following an incident, emergency or disaster.
    - More info on use: https://empowerprogram.hhs.gov/Map-Job-Aid.pdf
- **HHS emPOWER Emergency Planning De-identified Dataset:** https://empowerprogram.hhs.gov/de-identified-dataset.html
    - Access: Only available for state, territorial, and certain major metropolitan areas.

- Extra uses beyond publicly available HHS emPOWER - by type of electricity-dependent durable medical equipment (DME) and cardiac device, and certain health care services, can "identify planning factors; identify resources for emergency scenarios".
- More info on use: https://empowerprogram.hhs.gov/Optional-De-Identified-Dataset-Job-Aid.pdf

- **HHS emPOWER Emergency Response Outreach Individual Dataset:** https://empowerprogram.hhs.gov/outreach-individual-dataset.html
  - Access: Restricted use for authorized jurisdictions impacted by emergency.
  - Supports life-saving assistance and outreach.

Jurisdictional Assessment of Disability Data Collection during Emergencies Questions

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Start of Block: Default Question Block

Q00 Introduction

The Council of State and Territorial Epidemiologists (CSTE) and the Centers for Disease Control and Prevention (CDC) are seeking to improve data collection and response efforts for people with disabilities during emergencies. CDC defines disability based on the World Health Organization's International Classification of Functioning Framework, "A disability is any condition of the body or mind (impairment) that makes it more difficult for the person with the condition to do certain activities (activity limitation) and interact with the world around them (participation restrictions).

Respondents do not need to complete the entire assessment in one attempt. The assessment can be saved in Qualtrics as respondents make progress with answering questions.

Supplemental Information: Assessment of Jurisdictional Disability Data Collection Practices on Impacts of Emergencies on People with Disabilities

Assessment Deadline: Friday, September 1st, 2023

Q0 Please provide the following information:

- ○ Name (first and last) (1) _____
- ○ Job Title (2) _____
- ○ Email Address (3) _____

Q01 Please select your jurisdiction

▼ Alabama (1) ... Wyoming (51)

Page Break

Q00 Routine Disability Data Collection

Q1 Does your Jurisdiction use a set definition for "**disability**" for data collection activities as part of **disease surveillance** activities? (Please refer to the "Supplemental Information: Assessment of Jurisdictional Disability Data Collection Practices on Impacts of Emergencies on People with Disabilities" handout for more information)

- ○ Yes (1)
- ○ No (2)
- ○ Unsure (3)
- ○ Varies by program or disease (4)

Q1a If yes, please share the definition your jurisdiction uses to measure "disability" in your data collection activities; if no, unsure, or varies by program or disease, please feel free to share any other contextual information:

_____

_____

_____

_____

_____

Q2 Does your jurisdiction ***collect*** disability data at the following levels for surveillance purposes? (Select all that apply)

- [ ] Individual - Individual-level data on disabilities collected as part of an existing surveillance system, or one set up at time of an emergency. Individual level data may or may not include personal identifying information. (1)
- [ ] Residential Facility for people with disability - List of residential facilities within the jurisdiction for persons with disabilities (e.g., group homes, intermediate care facilities, supportive housing). (2)
- [ ] Population (e.g., jurisdictional surveys at the population or community level) - Population-level data on the number and/or percentage of population within the jurisdiction of persons with disabilities – overall or by disability type (ideally available state or territory wide, as well as at county level). (3)

Display This Question:

If Does your jurisdiction collect disability data at the following levels for surveillance purposes?... = Individual - Individual-level data on disabilities collected as part of an existing surveillance system, or one set up at time of an emergency. Individual level data may or may not include personal identifying information.

Q2a At the individual level, how often are disability data collected for surveillance purposes?

- ○ For all routine surveillance for reportable diseases and conditions (1)
- ○ For some reportable diseases and conditions, but not others (2)
- ○ During emergencies only (3)
- ○ All of the above (4)

Display This Question:

If At the individual level, how often are disability data collected for surveillance purposes? = For some reportable diseases and conditions, but not others

Or At the individual level, how often are disability data collected for surveillance purposes? = All of the above

Q2a1 If disability data are only collected for some reportable diseases and conditions, but not others, please elaborate:

_____

_____

_____

_____

_____

Q3 Does your jurisdiction ***have access*** to disability data collected by others at the following levels? (Select all that apply) (Please refer to the "Supplemental Information: Assessment of Jurisdictional Disability Data Collection Practices on Impacts of Emergencies on People with Disabilities" handout for more information)

- ☐ Individual (e.g., information on people with disabilities who reside in your jurisdiction) (1)
- ☐ Residential facility for people with disability (e.g., group homes, intermediate care facilities, supportive housing, etc.) (2)
- ☐ Population (e.g., aggregate data on the prevalence of disabilities in your jurisdiction) (3)

Page Break

Display This Question:

If Does your jurisdiction collect disability data at the following levels for surveillance purposes?... = Individual - Individual-level data on disabilities collected as part of an existing surveillance system, or one set up at time of an emergency. Individual level data may or may not include personal identifying information.

Or Does your jurisdiction have access to disability data collected by others at the following levels... = Individual (e.g., information on people with disabilities who reside in your jurisdiction)

Q00 Individual Level Data Practices

Individual level data on disabilities collected as a part of an existing surveillance system, or one set up at time of an emergency. Individual level data may or may not include personal identifying information.

Q4 Is any information on disability being captured in a structured way (e.g., disability is included as a discrete formatted variable(s) in the data collected with response options indicating presence or absence of disability, or if information on disability status is unknown) using the following surveillance data sources and systems? (Select all

that apply) (Please refer to the "Supplemental Information: Assessment of Jurisdictional Disability Data Collection Practices on Impacts of Emergencies on People with Disabilities" handout for more information)

- [ ] Provider Reports (1)
- [ ] Laboratory Reports (2)
- [ ] Electronic Case Reports (3)
- [ ] Emergency Department Visit Data (4)
- [ ] 911 - Emergency Medical Services Call Data (5)
- [ ] Pharmacy Sales (6)
- [ ] School Nurse Health Visits (7)
- [ ] Immunization Data (8)
- [ ] Death Reports (9)
- [ ] Shelter Intake Forms (10)
- [ ] None of the Above (11)
- [ ] Unsure (12)

Display This Question:

Is any information on disability being captured in a structured way (e.g., disability is included... = None of the Above

Or Is any information on disability being captured in a structured way (e.g., disability is included... = Unsure

Q4a Please note if your jurisdiction is able to capture this information in free text fields, if provided.

- ○ Yes (1)
- ○ No (2)
- ○ Unsure (3)

Q5 For **disease surveillance**, do case investigation form(s) that your jurisdiction currently uses for interviewing patients who have reportable diseases or conditions include discrete structured variables on disabilities? (Please refer to the "Supplemental Information: Assessment of Jurisdictional Disability Data Collection Practices on Impacts of Emergencies on People with Disabilities" handout for more information)

- ○ Yes (1)
- ○ Yes for some, but not all, diseases or conditions (2)
- ○ No (3)
- ○ Unsure (4)

Display This Question:

If For disease surveillance, do case investigation form(s) that your jurisdiction currently uses for... = Yes for some, but not all, diseases or conditions

Or For disease surveillance, do case investigation form(s) that your jurisdiction currently uses for... = No

Q5a If not all disease investigation forms collect data on disabilities, why not?

_____

_____

_____

_____

_____

Display This Question:

If For disease surveillance, do case investigation form(s) that your jurisdiction currently uses for... = Yes

Or For disease surveillance, do case investigation form(s) that your jurisdiction currently uses for... = Yes for some, but not all, diseases or conditions

Q5b If yes, what information on disabilities is included on case investigation forms?

_____

_____

_____

_____

_____

Q6 Which individual level data sources, systems, or platforms does your jurisdiction currently use for emergency preparedness, response, and recovery (data in general, not only disability-specific)? (Select all that apply)

- ☐ (Jurisdiction-level) Syndromic Surveillance (2)
- ☐ (Jurisdiction-level) Cancer Registries (3)
- ☐ (Jurisdiction-level) State Medicaid (32)
- ☐ (Jurisdiction-level) Vital Registry (34)
- ☐ (National-level Source) U.S. Department of Health and Human Services (HHS) emPOWER (Please refer to supplemental handout for more information) (35)
- ☐ (National-level Source) Smart911 (see https://smart911.com for more information) (36)
- ☐ Other (37)
- ☐ None of the Above (38)

Display This Question:

If Which individual level data sources, systems, or platforms does your jurisdiction currently use f... = Other

Q6a If other individual level data sources are used for emergency preparedness, response, and recovery, please list

_____

_____

_____

_____

_____

Q64 Please select whether you capture data on specific disability types during individual case investigations conducted as part of surveillance activities during emergency responses (e.g., COVID-19 or mpox, or heat-wave related mortality) (Select all that apply).

- ☐ Intellectual (characterized by limitations in intellectual functioning and adaptive behavior originating before age 18) (1)
- ☐ Developmental (broad range of conditions due to an impairment in physical, learning, language, or behavior areas originating before age 22) (2)
- ☐ Cognitive (difficulties such as concentrating, remembering, or making decisions) (3)
- ☐ Hearing (serious difficult hearing or deafness) (4)
- ☐ Mobility (serious difficulty walking or climbing stairs) (5)
- ☐ Vision (difficulty seeing or blindness) (6)
- ☐ Self-care (difficulty dressing or bathing) (7)
- ☐ Independent Living (difficulty doing errands alone) (8)
- ☐ Communication (difficulty communicating, understanding others, or being understood) (9)

- [ ] Disabling chronic condition (e.g., arthritis, hypertension, heart disease, depression, diabetes, respiratory disease, stroke, and cancer) (10)
- [ ] Any disability - no distinction in the type of disability (11)
- [ ] Other (12)
- [ ] None of the Above (14)

Display This Question:

If Please select whether you capture data on specific disability types during individual case invest... = Other

Q65 If other disability types are included in your data collection activities, please elaborate:

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Display This Question:

If Does your jurisdiction collect disability data at the following levels for surveillance purposes?... = Residential Facility for people with disability - List of residential facilities within the jurisdiction for persons with disabilities (e.g., group homes, intermediate care facilities, supportive housing).

Or Does your jurisdiction have access to disability data collected by others at the following levels... = Residential facility for people with disability (e.g., group homes, intermediate care facilities, supportive housing, etc.)

Q00 Residential Facility Level Data Practices

Q7 Does your jurisdiction ***have access*** to information (facility name, address, contract information) on all residential facilities for people with disabilities (e.g., group homes, intermediate care facilities, supportive housing, etc.) in your jurisdiction?

- ○ Yes (1)
- ○ No (2)
- ○ Unsure (3)

Display This Question:

If Does your jurisdiction have access to information (facility name, address, contract information)... = Yes

Q7a If yes, are these data able to be matched to individual case-level data via geocoding or a different method so that your jurisdiction can assess burden by facility, or detect outbreaks among residents during **emergencies**?

- ○ Yes (1)
- ○ No (2)
- ○ Unsure (3)

Display This Question:

If yes, are these data able to be matched to individual case-level data via geocoding or a differ... = Yes

Or If yes, are these data able to be matched to individual case-level data via geocoding or a differ... = No

Or If yes, are these data able to be matched to individual case-level data via geocoding or a differ... = Unsure

Q7a1 Please elaborate:

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Q00 Population Level Data Practices

Population-level data on the number and percentage of population within the jurisdiction of persons with disabilities – overall or by disability type (ideally available state or territory-wide, as well as at the county level).

Q8 Which population-based summary (or aggregate) data sources does your jurisdiction use for emergency preparedness, response, and recovery that include disability status and/or type of disability? (Select all that apply)

- ☐ U.S. Department of Health and Human Services (HHS) emPOWER (Please refer to supplemental handout for more information) (1)
- ☐ Census Bureau (American Community Survey; decennial census) (2)
- ☐ Disability Claims Services (e.g., Social Security Administration, private insurers) (3)
- ☐ Behavioral Risk Factor Surveillance System (BRFSS) or CDC's Disability and Health Data System (based on BRFSS) (4)
- ☐ Social Vulnerability Index (6)
- ☐ Other (e.g., qualitative data gathered via focus groups or other formats) (5)
- ☐ None of the Above (7)

Display This Question:

Which population-based summary (or aggregate) data sources does your jurisdiction use for emergent... = Other (e.g., qualitative data gathered via focus groups or other formats)

Q8a If other population-level summary data sources are used for emergency preparedness, response, and recovery that include data on disability status and/or type of disability, please list:

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Q8b For population-level data sources that your jurisdiction collects or has access to, are you able to use identifiers to match to individual level data?

- Yes (1)
- No (2)
- Unsure (3)

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Q00 Public Health Emergency Preparedness, Response, and Recovery during Emergencies

Q9 Does your jurisdiction conduct (or have plans to conduct) rapid needs assessments of individual households that include questions on disability as part of public health responses during **emergencies** (such as conducting a Community Assessment for Public Health Emergency Response (CASPER) - see https://cdc.gov/nceh/casper/default.htm for more information on CASPER)

- Yes (1)
- No (2)
- Unsure (3)

Display This Question:

If Does your jurisdiction conduct (or have plans to conduct) rapid needs assessments of individual h... = No

Q9A If your jurisdiction does not conduct rapid needs assessments of individual households as part of your public health response during **emergencies**, why not? Please elaborate

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Display This Question:

If Does your jurisdiction conduct (or have plans to conduct) rapid needs assessments of individual h... = Yes

Q9B If yes, does your jurisdiction capture whether a person in the household has a disability?

- ○ Yes (1)
- ○ No (2)
- ○ Unsure (3)

Display This Question:

If yes, does your jurisdiction capture whether a person in the household has a disability? = Yes

Q9b1 Please select which disability types are included in your ***data collection*** activities as part of surveys conducted as part of your public health response during **emergencies** (e.g. CASPER type surveys). (Select all that apply)

- ☐ Intellectual (characterized by limitations in intellectual functioning and adaptive behavior originating before age 18) (1)
- ☐ Developmental (broad range of conditions due to an impairment in physical, learning, language, or behavior areas originating before age 22) (2)
- ☐ Cognitive (Difficulties such as concentrating, remembering or making decisions) (3)
- ☐ Hearing (serious difficulty hearing or deafness) (4)
- ☐ Mobility (serious difficulty walking or climbing stairs) (5)

- [ ] Vision (serious difficulty walking or climbing stairs) (6)
- [ ] Self-care (difficulty dressing or bathing) (7)
- [ ] Independent Living (difficulty doing errands alone) (8)
- [ ] Communication (difficulty communicating, understanding others, or being understood) (9)
- [ ] Disabling chronic condition (e.g., arthritis, hypertension, heart disease, depression, diabetes, respiratory disease, stroke, and cancer) (10)
- [ ] Any disability - no distinction in the type of disability (11)
- [ ] Other (12)
- [ ] None of the Above (13)

Display This Question:

If Please select which disability types are included in your data collection activities as part of s... = Other

Q9b1a If other disability types are including in your ***data collection*** activities, please elaborate

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Display This Question:

If Does your jurisdiction conduct (or have plans to conduct) rapid needs assessments of individual h... = Yes

Q9c Are data on people with disabilities reported in your **Situational Reports** ((Please refer to the "Supplemental Information: Assessment of Jurisdictional Disability Data Collection Practices on Impacts of Emergencies on People with Disabilities" handout for more information) during emergency response in aggregate format to note impact of emergency on this population? (e.g., ICS 201, ICS 209, ICS 213, ICS 215A or similar forms)

- ○ Yes (1)
- ○ No (2)
- ○ Unsure (3)

Display This Question:

If Does your jurisdiction conduct (or have plans to conduct) rapid needs assessments of individual h... = No

Q9d If no, why not? (Select all that apply)

- ☐ This type of data not consistently collected (1)
- ☐ Limited access to data (2)
- ☐ Too long of a lag time to accessing data (3)
- ☐ Unaware of relevant data sources (4)
- ☐ Other (5)
- ☐ None of the Above (6)

Display This Question:

If no, why not? (Select all that apply) = Other

Q9d1 If other, please elaborate

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Display This Question:

If Are data on people with disabilities reported in your Situational Reports ((Please refer to the S... = Yes

Q9e Please select the type(s) of emergency response(s) where disability data are usually included in **situational reports.** (Select all that apply)

- ☐ Infectious Disease Outbreak/Pandemic Response (1)
- ☐ Non-infectious Disease Response (e.g., opioid overdose, EVALI) (6)
- ☐ Natural Disasters (weather-related events including tornadoes or hurricanes) (2)
- ☐ Artificial disasters (nuclear/radiological events, transportation-related events, pollution, or hazardous materials exposure(s) (3)
- ☐ None (4)
- ☐ Other (5)

Display This Question:

If Please select the type(s) of emergency response(s) where disability data are usually included in... = Other

Q9e1 If other, please explain:

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Display This Question:

If Please select the type(s) of emergency response(s) where disability data are usually included in... = None

Q9e2 Are the same data elements for disabilities collected across different types of emergency responses?

- ○ Yes (1)
- ○ No (2)
- ○ Unsure (3)

Display This Question:

If Are the same data elements for disabilities collected across different types of emergency respons... = No

Q9e2a If no, please explain:

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Q10 Please select data elements related to people with disabilities that you ***collect*** as a part of emergency preparedness, response, and recovery (Select all the apply)

- ☐ Other Demographic information (first name, last name, DOB, etc.) (1)
- ☐ Diagnosis code related to disability status or type (2)
- ☐ Access and functional needs related to disability (learning and applying knowledge, managing tasks and demands, mobility, managing self-care tasks, hearing and vision related disabilities, etc.) (3)

- [ ] Impact of emergency on people with disabilities (access to medical services, medications, home-based services, transportation services, etc.) (4)
- [ ] Other (5)
- [ ] None of the Above (6)

Display This Question:

If Please select data elements related to people with disabilities that you collect as a part of eme... = Other

Q10c If other, please explain:

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Q11 Does your jurisdiction use data on people with disabilities for situational awareness during emergency preparedness, response, and recovery operations? (situational awareness is defined as the ability to identify, process, and comprehend the critical information about an incident. More simply, it is knowing what is going on around you. Situational Awareness requires continuous monitoring of relevant sources of information regarding the health and mental health impacts of actual incidents and developing hazards)

- ○ Yes (1)
- ○ No (2)
- ○ Unsure (3)

Display This Question:

If Does your jurisdiction use data on people with disabilities for situational awareness during emer... = Yes

Q11a Is your jurisdiction able to use data collected on people with disabilities to direct resources to assist/ensure access to countermeasures and other types of emergency assistance (e.g., shelter, communications, transportation, recovery resources, etc.)?

- ○ Yes (1)
- ○ No (2)
- ○ Unsure (3)

Display This Question:

If Does your jurisdiction use data on people with disabilities for situational awareness during emer... = No

Q11b If your jurisdiction is not able to use the data collected on people with disabilities to direct resources to assist/ensure access to countermeasures, why not?

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Q12 Does your jurisdiction work with state or local disability organizations (including disability-led organizations) or disability service organizations (e.g., home-based care or transportation services) that support people with disabilities during emergency responses, to capture information on the impact of **emergencies** on the people they serve?

- ○ Yes (1)
- ○ Sometimes (4)
- ○ No (2)
- ○ Unsure (3)

Display This Question:

If Does your jurisdiction work with state or local disability organizations (including disability-le... = Yes

Or Does your jurisdiction work with state or local disability organizations (including disability-le... = Sometimes

Q12a Please elaborate on the information you gather from state or local disability organizations (including disability-led organizations) or disability service organizations (e.g., home-based care or transportation services) on the impact of **emergencies** on the people they serve (e.g., number of clients impacted by service disruption following emergencies; qualitative information regarding how the community has been impacted).

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Q00 Resources for Agency Staff

The purpose of these questions is to identify educational and training needs that jurisdictions would find helpful. Findings from this effort will help the development of resources for public health agencies on the importance of collecting and reporting data to support people with disabilities during **emergencies**.

Q13 Does your jurisdiction currently use or distribute any resources (e.g., trainings, factsheets, toolkits, infographics, demos) for public health staff on collecting data to support people with disabilities?

- ○ Yes - general guidance (1)
- ○ Yes - for emergencies only (2)
- ○ Yes - for both general guidance and emergencies (3)
- ○ No - for neither (4)
- ○ Unsure (5)

Display This Question:

If Does your jurisdiction currently use or distribute any resources (e.g., trainings, factsheets, to... = Yes - for emergencies only

Or Does your jurisdiction currently use or distribute any resources (e.g., trainings, factsheets, to... = Yes - general guidance

Or Does your jurisdiction currently use or distribute any resources (e.g., trainings, factsheets, to... = Yes - for both general guidance and emergencies

Q13a If yes, which resources regarding collecting data on people with disabilities during **emergencies** does your jurisdiction currently use and for what purpose do you use them?

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Display This Question:

If Does your jurisdiction currently use or distribute any resources (e.g., trainings, factsheets, to... = No - for neither

Q13b If no, which resources would you find helpful for agency staff during emergency planning, response, and recovery activities? This could include materials specifically designed for surveillance and emergency response staff.

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Q14 Does your jurisdiction have a **situational report** template?

- ○ Yes (1)
- ○ No (2)
- ○ Unsure (3)

Display This Question:

If Does your jurisdiction have a situational report template? = Yes

Q14a If you are willing to share a **situational report** template, please upload here

End of Block: Default Question Block