Collecting Data to Support People with Disabilities in Emergency Preparedness, Response, and Recovery

Capturing People with Disabilities in Public Health Data Systems

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] When public health agencies lack the necessary information to mobilize support and resources, people with disabilities may experience barriers that impact not only their health and safety during the emergency, but also the trajectory of their recovery afterward.[3]

This document is designed for public health agency staff to learn about various strategies that can improve the representation of people with disabilities in public health data systems for emergency preparedness, response, and recovery. These strategies specifically focus on ways that partnerships, data collection and use, and education and outreach can be leveraged by public health agencies to better represent people with disabilities. Information presented in this document is based on published materials and qualitative data collected in 2023 and 2024 with input from public health agency staff.

Additional Educational Resources

This document is part of a suite of resources to enhance public health agencies' use and reporting of disability data for inclusive emergency preparedness and response. **For additional materials, visit the CSTE Disaster Epidemiology Website**:

- *Disability Data: Situation Report Template* is a resource for public health departments to incorporate 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* provides population-level data sets that could be used to fill in some components of the SitRep template.

Case Story: Using HHS emPOWER Data During Wildfire Season in Oregon

Oregon Health Authority (OHA) staff has used HHS emPOWER data during wildfire season and winter storms in response to power shutoffs or outages. emPOWER data enabled OHA to identify households that may have people with disabilities who rely on electricity for medical equipment in the areas with power outages. In the case of wildfire power shutoffs, OHA used emPOWER data to direct emergency response services with conducting household visits to ensure people with disabilities were safe. During state-wide winter storms in 2024 that caused power outages in several counties, emPOWER data was used by counties to provide direct outreach and wellness checks to those impacted by power loss who were prescribed power-dependent medical devices.

Lessons learned: OHA staff noted that sometimes the address information in the emPOWER data set was out of date or missing. For example, during the winter storms, staff realized there were no contact phone numbers for any patients, and many addresses were listed as PO boxes, which did not support the ability to perform wellness checks. To address this challenge, OHA in collaboration with Oregon Department of Human Services, filled the missing demographics by cross-referencing Patient Unified Lookup System for Emergencies (PULSE). This approach to address limitations of emPOWER data could be applied to other types of emergencies that result in power outages.

[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

[3] National Council on Independent Living - Disability Equity During Disasters Toolkit

Collecting Data to Support People with Disabilities

Public health agencies can more effectively support people with disabilities before, during, and after emergencies by (1) building partnerships with disability-led and disability-serving organizations and people with disabilities to improve data collection and use; (2) integrating disability data elements into routine data collection activities; and (3) tailoring education and outreach to prioritize data on people with disabilities.

PARTNERING WITH DISABILITY-SERVING ORGANIZATIONS

Public health agencies can strengthen the collection and use of data on people with disabilities by building partnerships with local disability-serving and disability-led organizations such as community-based organizations (CBO) and Centers for Independent Living (CILs). Promising practices for partnering with disability organizations include:

- **Collaborate with disability-led and disability-serving organizations and people with disabilities:** Lean into working with disability organizations and people with disabilities to collect data on people with disabilities and inform public health interventions, especially in rural and other areas that have been underserved. CILs are operated by people with disabilities and can support public health agencies with engaging people with disabilities in information gathering and research. CILs can help develop accessible data collection methods.
- **Develop best practices for communication:** CBOs and CILs can help develop guidelines to use when collecting data from people with disabilities and disability advocates.
- **Leverage data from CBOs:** Work with CBOs and other disability partners to establish data sharing agreements with public health agencies. Analyze individual-level data from CBOs to understand the populations that they serve and how their needs can be better addressed by public health agencies during an emergency.
- **Provide technical assistance:** If your public health agency's data on people with disabilities are publicly available, then provide technical assistance to CBOs to support their use of the data.
- **Additional resources:**
  - Partnership Guide for Centers for Independent Living and State and Local Health Departments
  - List of SILCs and CILs | ACL Administration for Community Living
  - CDC Emergency Preparedness and Disability Inclusion Website

DISABILITY DATA COLLECTION AND USE

To improve the representation of people with disabilities in public health data systems, public health agencies can work towards integrating disability data collection into routine data collection activities across all public health program areas by leveraging different data sources, improving transparency during data collection processes, and designating staff to conduct these activities over time. Promising practices for disability data collection and use include:

- **Collecting and reporting data on people with disabilities:** Leverage CASPER data since this type of rapid needs assessment can include survey questions about limitations and disabilities of household members (see CDC Overview of CASPER). Report data on people with disabilities in Situational Reports (see Disability Data Situation Report Template for more information).
- **Review national survey data on disability:** There are several sources of publicly available data on people with disabilities that can be used to help inform emergency preparedness, response, and recovery. Many of these data sources are outlined in Population-level Publicly Available Disability Data Sources for Public Health Agencies.
- **Use case investigation forms to collect data on disability status:** Consider updating case investigation forms for disease monitoring to include specific questions about disability as a demographic variable.
- **Be transparent when collecting data on people with disabilities:**
  Help people with disabilities understand why you are collecting these data and address any concerns about data privacy and storage, so they understand how this information will be used to identify and support the health-related needs of people with disabilities before, during, and after emergencies. In these cases, staff who interview patients with reportable diseases or conditions should explain why they are also collecting information on disability status

(an upcoming training will be posted on CSTE Learn on Engaging with Sensitivity: Techniques for Interviewing Persons Experiencing Homelessness, Disability, and Substance Use Disorders).

The case investigation may not directly relate to disability status, but even if people with disabilities are not at increased risk, they are often disproportionately impacted; a justification or explanation helps to build trust between public health and healthcare workers and patients. See the REALD guidance from OHA for more information.

- **Consider different ways to determine disability status:**
  Two question sets that are commonly used to measure disability and focus on activity limitations are the American Community Survey (ACS-6) and the Washington Group Short Set (WG-SS). Both question sets are based on the World Health Organization's International Classification of Functioning (ICF) framework. These question sets can be included on surveys or questionnaires to ascertain disability status and type. Prevalence estimates will vary depending on question set used, but the population of people with disabilities they each identify have consistent demographic distributions.[4]

  The presence of one or more diagnostic codes related to disability can also be used to identify people with disabilities when demographic information is not available. Examples of code lists can be found at the Centers for Medicare and Medicaid Services (CMS) Chronic Conditions Warehouse, CDC's National Syndromic Surveillance Program on Setting a Clinical Definition for 'Disability', or in journal articles such as Severity of Coronavirus Disease 2019 Hospitalization Outcomes and Patient Disposition Differ by Disability Status and Disability Type. These definitions can be used when demographic data on people with disabilities are not available.

  Some people may not identify as a person with a disability, particularly if they have access to the appropriate assistive technology or supports. Some public health agencies use "functional capabilities" or "functional limitations" since medical definitions of disability do not fully capture the range of disability types.

- **Designate staff to conduct disability data collection:** Some public health agencies have dedicated staff that support data systems for people with disabilities and develop tailored emergency response plans based on these data. By having dedicated and long-term staff and by hiring staff with disabilities who focus on meeting the needs of people with disabilities, public health agencies can ensure that data on people with disabilities are effectively translated into action during emergencies.
- **Integrate training on collecting disability data into onboarding process:** Consider integrating training into the onboarding process for new case investigators and/or refresher trainings for staff (an upcoming training will be posted on CSTE Learn on Engaging with Sensitivity: Techniques for Interviewing Persons Experiencing Homelessness, Disability, and Substance Use Disorders). This training was developed with jurisdictions and reviewed by people with disabilities, and focuses on 1) effective, trauma-informed strategies for collecting complete and accurate data on disability status; and 2) purpose of collecting disability data for public health action to support communities.

EDUCATION AND OUTREACH

Education and outreach efforts can be designed to improve data on people with disabilities. Promising practices for education and outreach activities include:

- **Engage people with disabilities in developing resources:** Resources with data for people with disabilities should be informed by people with disabilities.
- **Stay in contact:** Provide educational information on data collection activities so that people with disabilities can inform how their data supports emergency preparedness, response, and recovery.

[4] Lauer EA, Henly M, Coleman R. Comparing estimates of disability prevalence using federal and international disability measures in national surveillance. Disability and Health Journal. 2019;12(2):195-202. doi:10.1016/j.dhjo.2018.08.008

- **Ensure materials are accessible:** Design educational and outreach materials to be accessible to people with disabilities. For example, a series of Federal Emergency Management Agency (FEMA) American Sign Language (ASL) videos on emergency preparedness available on YouTube share information about shelters and evacuation, water safety during a disaster, and other emergency preparedness topics with ASL interpretation and closed captioning in multiple languages for accessibility.

Appendix: Additional Project Information

People with disabilities experience significant inequities in health outcomes, healthcare access, and other social determinants of health compared to people without disabilities.[5] 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. To support public health jurisdictions, the Council of State and Territorial Epidemiologists (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. As part of that work, this educational resource was developed based on (1) information from existing resources developed by the CDC, public health agencies, and partners; (2) input from the 2023 CSTE Jurisdictional Assessment for Disability Data; (3) input from focus groups with public health agency staff, disability professionals, and people with disabilities; and (4) CSTE Disaster Epidemiology Subcommittee and Surveillance Practice & Implementation Subcommittee members. Refer to the full report for more information.

Disclaimer: *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 two financial assistance awards totaling $350,000 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.*

[5] Lee D, Kett PM, Mohammed SA, Frogner BK, Sabin J. Inequitable care delivery toward COVID-19 positive people of color and people with disabilities. PLOS Glob Public Health. 2023 Apr 19;3(4):e0001499. doi: 10.1371/journal.pgph.0001499. PMID: 37074996; PMCID: PMC10115306.