

Better Defining Disability Will Make Data More Inclusive and Usable

Over the past two decades, the frequency and intensity of natural disasters have increased—and will continue to do so. While disasters impact whole communities, [past incidents highlight](#) specific effects on people with disabilities, as it is more challenging for them to prepare for and recover from an incident. Understanding the prevalence of disability in a jurisdiction helps fully address the population's needs.

There is not a universally accepted way to collect data on people with disabilities. However, the need for disaggregated data by disability status is critical to helping [measure health disparities](#) and underlying factors contributing to inequities. Such data will support the development and continuous evaluation and improvement of public health programs and policies.

Key Considerations for Collecting Data on People with Disabilities

Disability data is essential for inclusive public health practice. Several factors are important to keep in mind when gathering data on people with disabilities.

- **Participation is critical** as exclusion from research can further marginalize already vulnerable groups and [limit access to advancements](#).
- **Accounting for historical trauma / negative impacts** helps people with disabilities who are at [increased risk of coercion](#), inclusion without consent, and other exploitation. Unwarranted disability assessments, particularly those implemented with [limited evidence of effectiveness](#), have been shown to have [negative mental health impacts](#) on participants with disabilities.
- **Different models of disability** provide a reference as programs, services, laws, and regulations are developed. Primary [models of disability](#) include the Medical Model, Functional Model, Social Model, and [Medical/Rehabilitative Model](#).

Current Measures and Definitions of Disability

Existing frameworks take a functional approach to defining disability, focusing on how inclusive policies, programs, and procedures are of individual needs.

- The [Developmental Disabilities Act](#) uses categories of functional limitations (e.g., three or more functional limitations in major life activities).
- The American Community Survey ([ACS](#)), Washington Group Short Set ([WGSS](#)), and International Classification of Functioning ([ICF](#)) are often used to measure disability in surveys.
- The Americans with Disabilities Act ([ADA](#)) provides a policy definition for state / local jurisdictions.

Disability Inclusion in National Syndromic Surveillance Program (NSSP)

NSSP includes electronic health record (EHR) data from 73% of the nation's emergency departments (EDs). However, it contains no systemic way to identify people with disabilities. Including disability data within a system as valuable as NSSP can help close gaps in monitoring the impacts of emergencies on people with disabilities. Syndromic surveillance data can guide decision-making during emergencies and policy formation at the local, state, and national levels.

There are limitations of using syndromic surveillance data. First, diagnostic codes may not map directly onto functional limitations. Second, codes do not provide information about residual functioning, loss of functioning, or disability severity. Additionally, reporting in EHRs may not be accurate due to [input or data errors](#). Codes can be related to a visit or encounter, even if it does not end up being true for a patient. Furthermore, diagnostic codes reflecting disability may [not be used in every encounter](#) and people with disabilities may be missed through using ED data as it only represents a snapshot in time.

Benefits of Expanding Disability Data Access and Use

Expanding the collection, access, and use of disability data for public health program development and emergency preparedness promotes health equity for people with disabilities. More specifically, this data can inform fiscal, programmatic, service policy, and public health planning decisions.

- When [Disaster Medical Assistance Teams](#) (DMATs) deployed to shelters in North Carolina, CDC's NSSP team asked health officials if they wanted to integrate these data. Within 24 hours, data from DMATs were available in NSSP, providing a snapshot of health in those shelters. Data were monitored along with ED visits to give a complete picture of the [storm's health impacts](#).
- In 2017, Hurricane Harvey made landfall in Texas, resulting in 88 deaths and \$125 billion in infrastructure damage. Public health officials used syndromic surveillance to understand increases in ED visits by those who evacuated to the Dallas–Fort Worth (DFW) area. Area hospitals saw roughly 4,400 more ED visits than normal; at least 600 were evacuees. Syndromic surveillance data demonstrated [extensive healthcare services](#) use outside the affected areas by highlighting the importance of surge capacity planning one to four hours outside the disaster area.

Ongoing Efforts

Through a cooperative agreement with CDC, ASTHO is working with subject matter experts to create a definition of disability for syndromic surveillance. ASTHO conducted [key informant interviews](#) with disability professionals to inform the development of this new diagnostic code-based definition, along with four scientific panels to assess the drafting and review of national and state-level pilot testing. An expansion of this kind benefits jurisdictions through increased data capacity for fiscal, programmatic, and service policy decision-making and supporting longitudinal tracking of prevalence and risk.

Conclusion

Efforts to expand data about people with disabilities can help build public health capacity to monitor the health and well-being of people with disabilities before, during, and after public health emergencies. However, efforts in data collection on disabilities require interoperability and standardization across all systems to be successful. Efforts to contextualize public health emergency data and gather supporting data on impacted populations allow health officials to better turn data into action in pursuit of health equity across public health emergencies.

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