

# Defining Disability for Syndromic Surveillance

Electronic health data is often used for syndromic surveillance, through systems like the [National Syndromic Surveillance Program \(NSSP\)](#), to provide public health professionals with timely information on the impact of public health emergencies. Information on disability status and type is not systematically collected during emergency department visits and, as such, it cannot be used during surveillance.

Identifying disability using a syndrome definition, or a set of criteria to identify healthcare visits using diagnostic codes [e.g., International Classification of Diseases (ICD)] and keywords representing patient reason for visit, could bolster ongoing surveillance and aid in identifying people with disabilities during emergencies. It could also improve national, state, and local capacity to respond to, detect, understand, and monitor health events among people living with disabilities during emergencies.

Through a cooperative agreement with CDC, ASTHO is helping develop and disseminate a disability definition within NSSP's Electronic Surveillance System for the Early Notification of Community-Based Epidemics (NSSP-ESSENCE). ASTHO conducted six key informant interviews (KIIs) with disability professionals to inform development of this new diagnostic code-based definition.

## Key Informant Interview Process and Participants

ASTHO's semi-structured key informant interview guide explores topics including syndromic surveillance knowledge, prior definition development, and perspectives on using syndromic surveillance to identify people with disabilities. Interviews were modified based on specific subject-matter knowledge. The key informants hold positions across academia, federal agencies, and independent contracting groups, and support a variety of CDC and federally funded projects and workgroups, including:

- [CDC-funded Disability and Health Program.](#)
- CDC-funded 10-State Medicaid Project.
- Federal Interagency Workgroup on Intellectual Disability and Developmental Disability (ID/DD) Data.

## Important Considerations and Lessons Learned

**Value-Add of Syndromic Surveillance.** Key informants indicated that using syndromic surveillance to identify people with disabilities during emergencies could significantly aid their work. They further indicated the benefits of using this data to inform fiscal, programmatic, service policy, and public health planning decisions. Using syndromic surveillance data could help close existing data gaps in disability data, particularly during emergencies.

**Analyzing Existing Definitions.** Informants shared perceived shortcomings of existing disability definitions and data sources (e.g., [American Community Survey](#), [International Classification of Functioning](#), [Washington Group Short Set](#)). They discussed variation in the types of questions used to define disability, which can result in misclassifying individuals or underestimating disability prevalence.

Interviewees discussed how different approaches to talking about disability—as a demographic group, functional need, or diagnosed medical condition—can influence where conversations about disability land in public health agencies. Whether the responsibility lies with healthy aging, chronic disease, or health equity impacts an agency’s ability to enact essential policy changes to support people with disabilities. When defining disability, informants stressed the importance of considering sensitivity, specificity, how definitions are developed over time, and whether that process included people with disabilities.

**Variation in Coding Practices: Regional Differences and Provider Bias.** Differences in coding hinders the accuracy of claims-based data sources, according to interviewees. Providers assess patients diagnostically, so they may not record symptoms inconsistent with the primary diagnosis.

Defining disability through claims data uses a provider’s interpretation of disability and excludes opportunity for self-reporting from the patient. Provider coding may vary based on the clinic, provider, and/or geographic location. Additionally, drift in defining conditions can occur, where certain conditions are diagnosed more frequently over time, not because of an increase in the prevalence of a condition but simply due to awareness and/or changes in diagnostic criteria.

**Difficulty Mapping Diagnostic Codes to Functional Definitions of Disability.** A potential roadblock to using diagnostic codes to identify people with disabilities is that they do not cleanly map to functional definitions of disability, like the [definition of disability](#) in the [Americans with Disabilities Act \(ADA\)](#). Often, diagnostic codes do not indicate possible residual loss of function following a medical diagnosis. Medical claims may not accurately document the severity of a disability or incorporate the influence of external factors that impact a disability, such as built environment, access to community support, and discrimination.

## Application of Findings and Next Steps

KII results not only provide actionable recommendations for developing a definition of disability for syndromic surveillance, but also offer valuable insights to guide dissemination strategy. Developing a diagnostic code-based disability definition for syndromic surveillance will provide health agencies with enhanced capability to disaggregate disability data and identify critical signals for public health response.

Over the next several months, ASTHO will:

- Engage a scientific panel of disability, syndromic surveillance, healthcare, and preparedness experts to expand on findings from the KIIs to further inform definition development.
- Support awareness on the value of syndromic surveillance and development of a disability definition through direct engagement with disability and preparedness stakeholders.

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