DISABILITY DEFINITIONS IMPLEMENTATION TOOLKIT

Enhancing Syndromic Surveillance for Emergency Response

ACKNOWLEDGEMENTS

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TABLE OF CONTENTS

INTRODUCTION

People with disabilities represent a significant portion of the U.S. population, over one in four adults, yet they remain underrepresented in public health data systems. Without comprehensive and timely information, their needs during public health emergencies can be overlooked, leading to greater risk and poorer outcomes. The Disability Definitions Implementation Toolkit was developed by the Council of State and Territorial Epidemiologists (CSTE) to help state, Tribal, local, and territorial (STLT) health departments implement and operationalize syndromic surveillance definitions that help identify people with disabilities in emergency department data. Building on work initiated by ASTHO, CDC, and Thought Bridge LLC, this toolkit provides practical guidance and lessons learned from jurisdictions that piloted these definitions.

Note: The term "people with disabilities" is a federally defined category. However, not everyone included within this definition identifies as having a disability. Some individuals strongly embrace cultural and linguistic identities instead. For example, many members of the Deaf community consider themselves part of a cultural–linguistic minority rather than identifying as disabled.

PURPOSE OF THE CSTE DISABILITY DEFINITIONS IMPLEMENTATION TOOLKIT

The primary purpose of this implementation toolkit is to enhance the use of a syndromic surveillance definition which can be used to disaggregate health outcomes by disability status during public health emergencies. The intended audience of this toolkit is public health professionals and disability community organization partners.

SCOPE OF THE TOOLKIT

This toolkit provides a brief background on disability, the development and use of the definition(s), rationale and motivation for definition development, and limitations and considerations for use of the definition(s). In addition, the toolkit provides results of analyses performed and lessons learned from three public health authorities (PHAs) which implemented the definition in their jurisdictions. Recommendations and best practices for incorporating the definition(s) during emergencies for taking public health action and for partnering with disability-led and disability-serving organizations as part of syndromic surveillance efforts are also described.

DISABILITY BACKGROUND

The Centers for Disease Control and Prevention (CDC) defines disability as "people with 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)" CDC, 2020. Disability can be related to conditions that are visible or nonvisible, stable or progressive, and physical, cognitive, sensory, or emotional. Figure 1 shows the prevalence of disability categories among US adults, age 19 and older, in 2022.

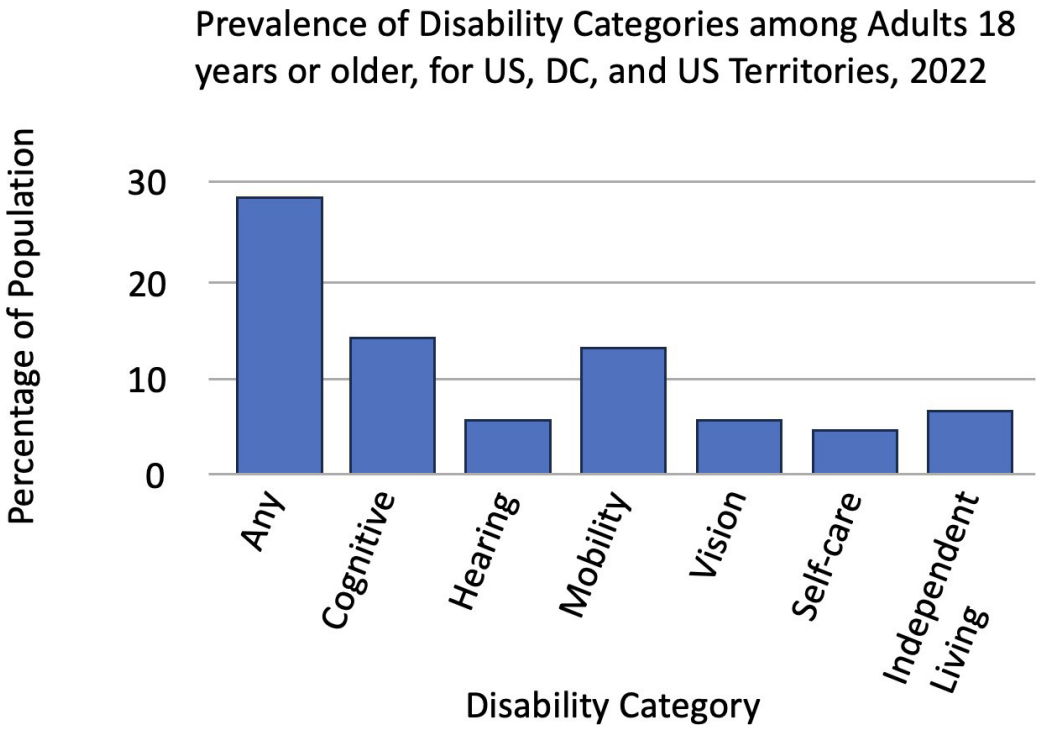


Figure 1. Prevalence of disability categories among adults 18 years or older in the US, 2022, Disability and Health Data System.

People with disabilities represent approximately 1 in 4 adults in the United States, yet they often face significant health disparities due to systemic barriers in access to care, health communication, and emergency response systems. During disasters and public health emergencies, these disparities can be amplified, placing people with disabilities at greater risk of adverse health outcomes and institutionalization.

INTEGRATING DISABILITY DATA INTO SYNDROMIC SURVEILLANCE

Integrating disability status into syndromic surveillance systems is essential for advancing health and ensuring that emergency preparedness, response, and recovery efforts are inclusive of disability-related considerations, barriers, and resources. Without intentional representation of people with disabilities in public health data systems, decisions risk overlooking access and functional needs—leading to interventions that may unintentionally perpetuate harm or exclusion.

For example, during the early stages of the COVID-19 pandemic, people with intellectual and developmental disabilities were not initially prioritized for personal protective equipment or vaccination, despite later being recognized as a population at elevated risk for severe outcomes. The absence of early data contributed to delayed protections and exacerbated existing health inequities. By contrast, one unanticipated benefit of additional COVID-19 funding was the ability to assign personnel specifically focused on disability and co-occurring emergencies. This investment led to positive outcomes for people with disabilities and others with access and functional needs.

Accurate and timely disability data allows public health agencies to:

- Identify and monitor disparities in emergency-related health outcomes and service utilization.
- Improve situational awareness and resource allocation by including planners with lived experience and subject matter expertise.
- Inform inclusive messaging, response strategies, and recovery planning that reflect the needs of all community members.
- Support compliance with federal requirements for nondiscrimination and accessibility in emergency response (e.g., the Americans with Disabilities Act).

Currently, the National Syndromic Surveillance Program's (NSSP) ESSENCE platform is widely used to monitor emerging threats and guide emergency response. However, it lacks a systematic method for identifying people with disabilities. Until disability status is consistently captured at the point of care, diagnostic codes with chief complaint key terms offer one potential—though limited—approach to begin addressing this gap. Unlike surveys that assess disability through functional limitations (such as difficulties in hearing, seeing, or walking), diagnostic code and chief complaint-based approaches focus on recorded health conditions. This narrow focus makes it difficult to directly translate codes and key terms into measures of functional and cultural disability and risks reinforcing the medical model of disability, which overlooks social and environmental dimensions.

Given these complexities, it is essential to involve people with disabilities in the development of any disability definitions or diagnostic code-based approaches. Their engagement ensures that methods are valid, grounded in lived experience, and more likely to be accepted and used in practice. Capturing disability data in this way enables public health agencies to design more equitable interventions and ensure that all community members—including those with disabilities—are protected before, during, and after public health emergencies.

DISABILITY CONSIDERATIONS: NOTES ON ETHICS AND LANGUAGE IN DISABILITY SURVEILLANCE

Finally, it is imperative to approach disability surveillance with language sensitivity. The use of respectful, person-first language—such as "people with disabilities"—is essential. Terms like "syndrome definition" or "definition of disability" can unintentionally frame disability in medicalized or stigmatizing ways and should be avoided. Public health communications must guard against harmful labeling, misclassification, or misuse of data that could reinforce stereotypes or result in discriminatory practices.
Engaging with disability communities and ensuring transparency in how data are used will support more ethical and inclusive public health surveillance practices.

DISABILITY DEFINITIONS DEVELOPMENT

The Association of State and Territorial Health Officials (ASTHO) was funded in 2021 by CDC to build public health capacity to monitor the health and well-being of people with disabilities before, during, and after public health emergencies. CDC, ASTHO, and Thought Bridge LLC convened a series of scientific panels, including people with disabilities, members of the NSSP CoP, and clinicians, to develop and test syndromic surveillance definitions to identify emergency department visits by people with disabilities. Simply stated, syndromic surveillance uses early health signals—like tracking symptoms reported in emergency rooms—to help public health officials spot outbreaks or health threats sooner. For an overview of syndromic surveillance including its purpose and uses, see *Introduction to Syndromic Surveillance Methodology*.

These new disability queries could be used to assess the health and well-being of people with disabilities during public health emergencies or to disaggregate health outcomes by disability status. Information about the development of the definitions and additional resources is available in the NSSP CoP Knowledge Repository. The disability query includes:

- An Overall Disability domain which is a combination of all sub-domains:
    1. Cognition and Central Nervous System Disorders
    2. Hearing

3. Intellectual and Developmental Disabilities (IDD)
4. Mental Health (using the existing NSSP definition)
5. Mobility
6. Self-care
7. Specific Developmental or Learning Disabilities
8. Vision

- Links for the Disability Definitions are provided in the Resources section of this Toolkit.
- An additional resource including lists of diagnostic codes for Chronic Conditions and Immune System Disorders is also available to determine how disability co-occurs with these conditions.

INTRODUCTION TO THE NATIONAL SYNDROMIC SURVEILLANCE PROGRAM (NSSP)

The National Syndromic Surveillance Program (NSSP) is a collaboration between the CDC, public health authorities, and national partners to strengthen the nation's syndromic surveillance capabilities. NSSP was developed to enhance early detection and situational awareness for public health threats while aiding in decision-making through integrated electronic data.

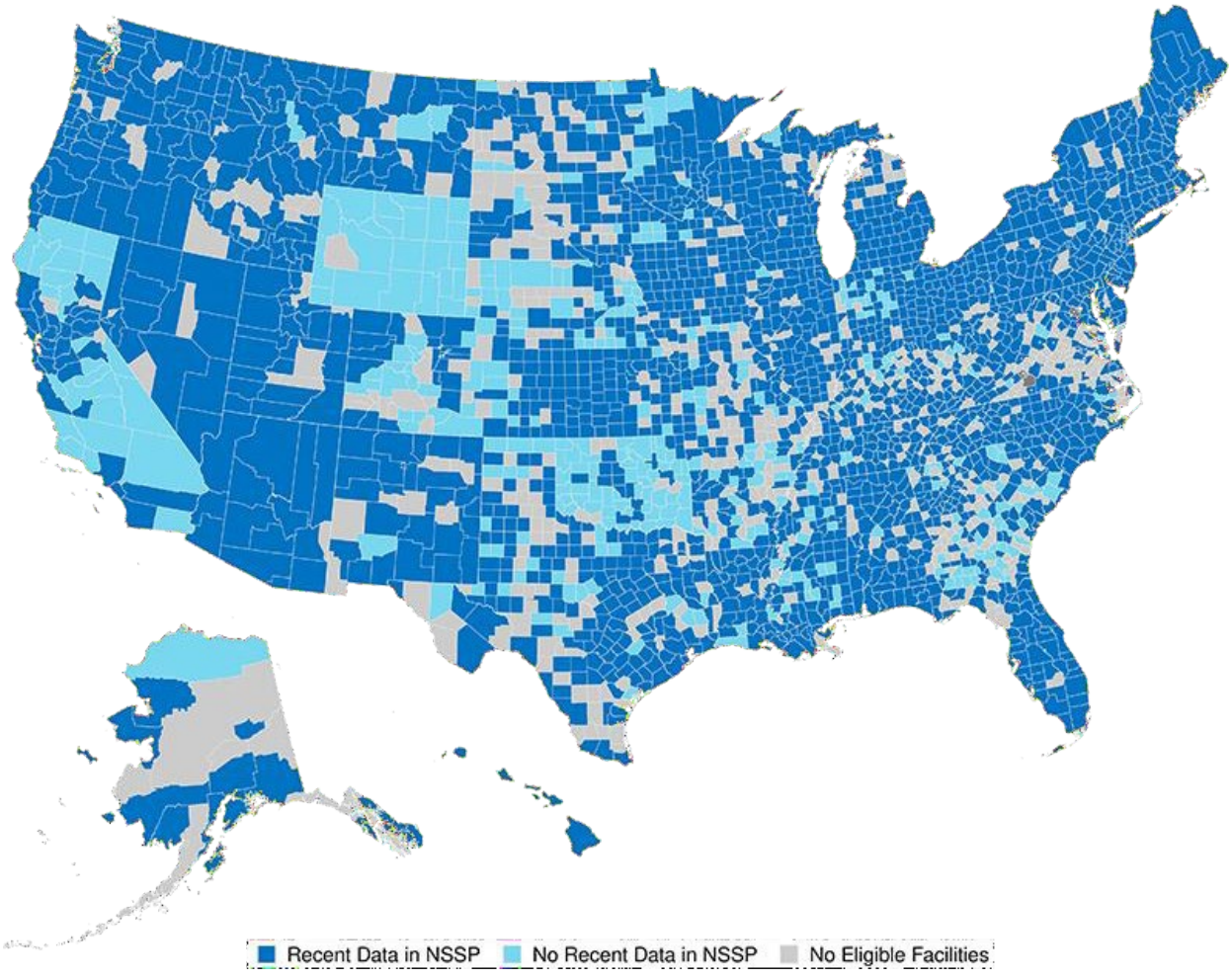
Syndromic surveillance uses near real-time data that are received within 24 hours of a patient's visit to a participating health care setting such as an emergency department, urgent care centers, hospitals, and other healthcare settings to detect and monitor health-related events before diagnoses are confirmed. This capability supports rapid public health response and resource allocation. NSSP provides a common platform, technical infrastructure, and analytic tools to participating jurisdictions, facilitating standardized data collection, interoperability, and collaborative analysis.

CURRENT USE AND NATIONAL SCOPE

Today, NSSP supports syndromic surveillance across most U.S. states and territories, covering approximately 83% of all emergency departments nationwide. Medical facilities send de-identified data to state, territorial, and local health departments or data aggregators such as Health Information Exchanges, often within 24 hours of the ED visit. Much of this data eventually flows to centralized data platforms. Public health practitioners access data via these centralized platforms hosted by CDC or states, where it is integrated, analyzed, and visualized in near real-time. These shared systems enhance the opportunities for public health professionals to detect emerging threats, monitor ongoing health events, and inform decision-making at local, state, territorial, and national levels.

Regional and local syndromic surveillance systems also collect and analyze near real-time data from emergency departments, urgent care centers, and other healthcare settings to detect unusual patterns of illness before diagnoses are confirmed. These systems may operate independently or in coordination with NSSP, providing public health officials with timely situational awareness. One example of a regional syndromic surveillance system is the National Capitol Region's Emergency Department Syndromic Surveillance System, which is a cooperative effort of Maryland, the District of Columbia, and Virginia, and has been in operation since September 11, 2001.

Non-federal Emergency Care Participation in the National Syndromic Surveillance Program: March 1, 2024 to June 1, 2025.



Key data elements in NSSP include patient chief complaints, discharge diagnoses, demographics, and visit timing—providing valuable insight into population-level health trends, including emerging syndromes and public health events. Before the introduction of these standardized disability definitions identifying subpopulations of people with

disabilities within these datasets was challenging. The availability of these definitions enables users to do more subpopulation analysis, allowing for valuable insights into the needs of these groups.

NSSP also integrates external data sources to provide complete, accurate, and timely information for decision-making capabilities. Other data sources available in NSSP include commercial laboratory data, mortality data, National Weather Service (NWS) data, air quality data via AirNow.gov, and National Notifiable Disease Surveillance System data.

ESSENCE: A CORE TOOL FOR SYNDROMIC SURVEILLANCE

A key component of NSSP is the Electronic Surveillance System for the Early Notification of Community-based Epidemics (ESSENCE). ESSENCE is a secure, web-based application that enables public health practitioners to:

- Monitor health trends in near real-time;
- Detect anomalies or spikes in syndromes;
- Conduct outbreak investigations and situational assessments; and
- Customize and share surveillance queries and dashboards across jurisdictions and with partners.

ESSENCE provides interactive data visualization tools including time-series graphs, spatial maps, and detailed tabular outputs. These features allow users to monitor syndromes (e.g., influenza-like illness, heat-related illness, substance use) across different geographies and timeframes.

QUERY DEVELOPMENT AND CUSTOMIZATION

Health departments use ESSENCE to create and customize syndromic surveillance queries tailored to specific surveillance objectives. Users select a predefined query for their use. Query development and customization typically involves:

1. **Defining a Syndrome or Condition of Interest:** This may include symptom keywords, diagnosis codes (e.g., ICD-10-CM), or visit characteristics. The Disability Definitions are available in the Resources section of this Toolkit.
2. **Selecting Relevant Data Fields:** Common fields include chief complaint, discharge diagnosis, triage notes, and facility information.
3. **Using Boolean Logic and Wildcards:** ESSENCE allows the use of AND, OR, and NOT logic, as well as partial word matching, to refine queries.

4. **Filtering by Time, Geography, or Facility Type:** Users can narrow queries by date range, region, or healthcare setting to examine trends in specific populations.
5. **Validating and Refining Queries:** Queries are tested iteratively to ensure sensitivity and specificity, often involving review of free-text entries and collaboration with epidemiologists or clinical experts.

The NSSP Community of Practice (CoP) enables sharing of resources, engaging with NSSP users and practitioners who use local syndromic surveillance systems. The NSSP CoP Knowledge Repository offers access to numerous surveillance resources, validated syndromic surveillance queries, and guidance documents. Membership in the NSSP CoP is free and open to anyone interested in syndromic surveillance. To join the NSSP CoP, complete this form.

SUMMARY

NSSP, through platforms like ESSENCE, provides a critical infrastructure for near real-time public health surveillance. By enhancing early detection, informing public health actions, and fostering cross-jurisdictional collaboration, NSSP plays a vital role in strengthening the nation's capacity to prepare for, respond to, and recover from public health emergencies. Integrating population-specific indicators—such as disability status—into ESSENCE queries can further improve health outcomes and ensure inclusive, data-driven responses.

BENEFITS OF UTILIZING THE NSSP DISABILITY DEFINITIONS

Despite limitations in the completeness and accuracy of disability-related data within syndromic surveillance systems, there are clear benefits for health departments in disaggregating health outcomes by disability status using available NSSP data. Even proxy indicators of disability can provide valuable, actionable insights into how people with disabilities are affected by public health emergencies, disasters, and emerging health threats.

Disaggregating data by disability status allows health departments to begin identifying disparities in emergency department utilization. This capability enhances situational awareness, supports equitable response planning, and enables more targeted public health messaging, resource distribution, and community engagement before, during, and after emergencies. Moreover, stratifying syndromic data can reveal important trends such as elevated rates of heat-related illness, injury, behavioral health crises, hospitalization,

and institutionalization within subpopulations experiencing disability. These insights can inform the design of interventions that are more inclusive and accessible.

Using syndromic surveillance data to examine health trends through a disability lens also strengthens partnerships across sectors, including emergency management, disability-serving and disability-led organizations, and healthcare systems. It encourages ongoing dialogue about data gaps and priorities, building momentum for system improvements that include standardized, self-reported disability data in the future.

While the data are imperfect, health departments that thoughtfully and transparently disaggregate outcomes by disability status position themselves to make more informed, ethical, and equitable public health decisions ultimately reducing preventable harm and advancing health for people with disabilities and strengthening a whole community approach in emergency management.

IMPORTANT CONSIDERATIONS WHEN USING THE DISABILITY DEFINITIONS

While the inclusion of disability-related definitions within syndromic surveillance systems represents an important step toward more equitable public health practice, there are critical limitations that must be acknowledged.

- Lack of self-reported data: Syndromic surveillance relies on information captured during emergency department and other healthcare setting visits, primarily through clinician-entered fields such as chief complaints and discharge diagnoses. This means disability status is not self-reported, and accuracy depends on what is documented at the point of care.
- Inconsistent use of diagnostic codes: Although ICD-10-CM Z-codes and other diagnostic codes could help identify disability-related factors, they are inconsistently applied and remain underutilized by medical practitioners.
- Use population-based or visit-based rates, not raw counts: When analyzing disability-related data, raw counts of patient records can be misleading. Counts may fluctuate for reasons unrelated to true changes in population health, such as:
    - More hospitals joining the reporting system (some with rehabilitation or specialty services, others without).
    - Natural variation in disability prevalence across communities, geographies, and service areas.
    - Shifts in how emergency department visits are documented as staff receive more training on disability identifiers and codes.
    - Changes in care settings (e.g., fewer people in institutional care, leading to more ED visits that previously would have been managed in-house).

- Proxy, not a full count: Any disability-related query should be interpreted as an indicator of potential disparities or patterns, not as a definitive count of people with disabilities in a community. Definitions are not to be used to identify disability conditions, rather they are to support subgroup analyses with people with disabilities.

HOW TO USE THE DATA RESPONSIBLY

- Treat findings as a starting point for identifying possible inequities in emergency department use.
- Recognize that syndromic surveillance data are updated and can be modified on a regular basis.
- Pair syndromic surveillance data with other sources (e.g., surveys, community engagement, or qualitative input from people with lived experience) to build a fuller picture.
- When sharing results, clearly communicate both the strengths and limitations of the data to avoid overgeneralization or misinterpretation.
- Emphasize that the goal is to highlight potential barriers and inform more inclusive planning, not to label or categorize individuals.

By acknowledging these limitations up front, public health professionals can better support the use of disability-related queries in syndromic surveillance as a valuable tool while striving for transparency, accuracy, and respect for the populations represented.

This surveillance approach is designed to fill a critical information gap, but it should not be viewed as a substitute for long-term improvements in public health data systems. Public health stakeholders are encouraged to advocate for modernization of electronic health records (EHRs) that include standardized, voluntary, and self-reported disability information. Incorporating such data would support a more accurate, respectful, and person-centered understanding of disability in public health contexts.

GENERAL LIMITATIONS OF SYNDROMIC SURVEILLANCE

Syndromic surveillance, more broadly, provides valuable early warning of potential public health threats. At the same time, it comes with important considerations:

- Non-specific signals: Because the data are based on symptoms rather than confirmed diagnoses, signals can be difficult to interpret without further investigation.

- Variable data quality: Information is only as reliable as what is recorded in emergency departments and urgent care settings, which can lead to inconsistencies or gaps.
- False alarms and missed events: Normal seasonal fluctuations may mimic unusual activity, while smaller or subtler outbreaks may go undetected.
- Incomplete coverage: Not all facilities participate, and in some geographies particularly rural or sparsely populated areas there may be no reporting facilities at all.
- Underrepresentation of populations: Certain groups may not be fully captured, limiting the representativeness of the system.
- Resource needs for validation: Even when signals are detected, additional staff time and expertise are required to confirm whether increases reflect true public health events or environmental/seasonal factors.
- Timeliness: Because syndromic surveillance data are subject to ongoing updates and revisions, it is important not to rely solely on information from the most recent 24–48 hours.

For these reasons, syndromic surveillance is best understood as an early detection tool that complements, but does not replace, laboratory testing and traditional case-based surveillance. When paired with modernized data systems that include disability status, it can become a more powerful resource for improving health outcomes and protecting all communities.

For additional information about definition specific limitations identified during the implementation and analysis phase are presented in the Example Workflow and Use Cases section of the toolkit.

BUILDING AND MAINTAINING RELATIONSHIPS WITH DISABILITY -SERVING AND DISABILITY-LED ORGANIZATIONS

Engaging with disability-serving and disability-led organizations is essential to ensuring that syndromic surveillance efforts reflect the lived experiences, needs, and rights of persons with disabilities. These partnerships strengthen public health response by bringing critical perspectives, building community trust, and ensuring that data interpretation and use are representative of the community.

Identifying key partners begins with mapping organizations that serve or are led by people with disabilities within your jurisdiction. This includes Centers for Independent Living,

Protection and Advocacy agencies, Developmental Disabilities Councils, Service Organizations, University Centers on Disability, and grassroots advocacy groups. Prioritize organizations that are led by individuals with disabilities ("nothing about us without us") to ensure authentic representation. Identifying points of contact within these organizations may involve outreach to executive directors, policy or advocacy staff, or community liaisons who are experienced in collaborating with public agencies. If such roles are not clearly defined, a direct inquiry can help clarify the appropriate contact.

Partnerships should be initiated early well before a public health emergency or disaster occurs. Engaging organizations during preparedness planning, rather than during response, builds the foundation for long-term collaboration. Early engagement allows for a shared understanding of surveillance goals, discussion of potential concerns about data use, and identification of opportunities for co-developing equitable strategies.

Trust and transparency are central to sustaining meaningful relationships. Health departments should be transparent about how data will be used, what the study limitations are, and how partner input will inform implementation. Partnerships should be mutually beneficial: disability organizations can provide critical insight, outreach support, and community credibility, while health departments can share findings, co-develop messaging, and ensure data are interpreted in ways that reflect community realities.

These relationships are not one-time transactions but ongoing collaborations. Regular communication, shared decision-making, and honoring disability expertise are essential to building an inclusive public health infrastructure that truly serves all members of the community.

COMMUNICATIONS BEST PRACTICES

Effective communication with disability-serving and disability-led organizations is essential for building trust, fostering collaboration, and ensuring that public health information is useful, accessible, and inclusive. Health departments should approach communication as an ongoing, bidirectional process that adapts to the evolving needs of communities before, during, and after public health emergencies.

Establishing when and what information to share is critical. Communication should begin during preparedness phases not just during active emergencies. Sharing surveillance findings, emergency planning updates, or relevant health alerts before a crisis allows disability organizations to anticipate needs, inform their networks, and provide feedback on messaging. During emergencies, concise, timely updates should focus on health

impacts, available resources, and actions that individuals with disabilities can take and that the community can take to help the whole community, including people with disabilities and access and functional needs. After an event, reporting findings, seeking feedback, and offering collaborative opportunities for evaluation and recovery planning help sustain relationships and improve future responses. People with disabilities and disability-serving organizations have played critical roles in shaping more inclusive emergency communications. Some examples include:

- Disability Rights Pennsylvania has highlighted the legal requirement for accessible alerts, pushing agencies to adapt notification systems so that people with disabilities receive timely, life-saving information.
- The National Association of County and City Health Officials (NACCHO) has documented partnerships between local health departments and disability organizations that improve the clarity and accessibility of outbreak alerts, evacuation orders, and other emergency messages.
- Similarly, the CDC, working with disability partners, developed its Access and Functional Needs Toolkit to guide jurisdictions in integrating inclusive practices into risk communication.

Together, these efforts demonstrate how advocacy and collaboration have strengthened emergency messaging, reducing the risk of disease and death among people with disabilities and those with access and functional needs.

Many disability organizations may be more familiar with emergency management or healthcare systems than with public health surveillance. Health departments should take time to explain public health's role in disaster response, including how surveillance data are used to detect trends, identify disparities, and support equitable interventions. Clarifying this role can demystify the process and foster greater collaboration and trust in how data are collected, interpreted, and applied.

All communications must meet accessibility standards to ensure equitable participation and understanding. This includes:

- Providing American Sign Language (ASL) interpretation and Communication Access Realtime Translation (CART) and other accommodations for meetings; and briefings as requested or needed, e.g., ASL and CART at meetings so they are a part of the meeting recordings and afford access to all for future review or reference;
- Sending materials in advance of meetings so organizations can identify accessibility barriers and review and prepare to participate in the meetings, e.g., a person who uses a voice-liberator or similar assistive technology can program their text-to-voice input and response to agenda items;

- Ensuring dashboards, data visualizations, and online platforms comply with Web Content Accessibility Guidelines (WCAG) and are compatible with screen readers and other assistive technologies; and
    - Ensuring materials include alternative text (alt text) for all graphics and visual content, including links to accessible data tables as accessible, alternative formats to graphs, maps and data illustrations;
    - Offering plain language summaries alongside technical documents.

Engaging with disability partners to review and test communications can identify barriers and improve accessibility. Clear, respectful, and inclusive communication not only supports effective collaboration, but it is also a foundational aspect of equitable public health practice. Communication strategies should reflect the intersectionality of needs, recognizing that disability status often overlaps with language requirements (e.g., Mexican Sign Language, Spanish CART) or other considerations, and therefore must incorporate multiple layers of accessibility.

DISABILITY DEFINITIONS USE CASES

APPLYING THE DISABILITY DEFINITIONS DURING EXTREME WEATHER EVENTS

Public health emergencies disproportionately affect people with disabilities, who may face greater barriers to accessing care, maintaining essential services, maintaining independence, or evacuating safely during these events. To better understand and respond to these inequities, three jurisdictions, Tacoma-Pierce County, Montana (University of Montana), and Kansas, piloted the implementation of the syndromic surveillance definitions designed to identify people with disabilities within select NSSP data for the purpose of contributing to this toolkit. The definitions used encompass a range of disability types, including mobility, cognitive, hearing, vision, self-care, and independent living disabilities.

Each jurisdiction applied the definitions in the context of extreme weather events, including heat waves, cold-weather incidents, severe storms, and wildfire smoke, to assess how well they performed in identifying people with disabilities affected by such hazards. Analyses included calculating the positive predictive value (PPV) of the definitions, and examining how disability-related visits varied before, during, and after these events. The jurisdictions engaged with local disability, emergency management, and public health partners to interpret the findings.

These use cases demonstrate how public health agencies can:

- Implement and adapt syndromic definitions to identify disability-related trends during emergencies,
- Validate and refine definitions through analytic methods, including machine learning and chart review, and
- Collaborate with disability led and disability serving partners to ensure that data interpretation and preparedness planning reflect lived experiences.

Together, these examples showcase the practical application of disability surveillance for improving inclusive preparedness, response, and recovery. They also highlight lessons learned around data quality, stakeholder engagement, and integration of findings into public health practice.
The following pages in the toolkit summarize the approaches, insights, and lessons from each jurisdiction's experience.

KANSAS

CONTEXT

The Kansas Department of Health and Environment (KDHE) explored all eight disability syndrome definitions to assess their performance and applicability across diverse extreme weather events. These events included severe heat waves, winter storms, tornadoes, a polar vortex (with temperatures reaching -40°F), and a wildfire in Yates Center that triggered a nursing home evacuation.

Given Kansas's varied climate and geographically dispersed population, the team aimed to evaluate the definitions both for acute response, and for broader applicability in emergency preparedness.

IMPLEMENTATION APPROACH

Kansas implemented all eight definitions within the National Syndromic Surveillance Program (NSSP) framework, conducting positive predictive value (PPV) assessments to validate accuracy and relevance. The Kansas team manually reviewed records within each category and discussed findings with local disability and emergency preparedness partners. The team also identified potential limitations caused by changes in electronic health record (EHR) data systems, notably the Cerner-to-Oracle transition at one of the

healthcare organizations, which reduced available chief complaint and diagnosis data, and disproportionately affected the behavioral and developmental disability definition.

FINDINGS AND INSIGHTS

- **Intellectual and Developmental Disabilities (IDD):** PPV ≈ 85%. Most cases reflected autism spectrum disorder, Cerebral palsy, or Down Syndrome. Some unrelated conditions (e.g., pectus excavatum) were also captured, suggesting a need to refine code inclusions.
- **Behavioral and Learning Disabilities:** PPV ≈ 80%. Some cases reflected speech disturbance codes, which represented acute events like stroke or UTIs in the elderly, rather than true speech or developmental conditions. The Kansas team recommended treating speech separately from behavioral disorders.
- **Cognitive and CNS Disabilities:** PPV ≈ 65%. Many visits involved acute head injuries or septic shock rather than chronic cognitive impairment. The team recommended narrowing to long-term or residual effects of neurological conditions.
- **Self-Care and Independent Living:** PPV ≈ 90%. This is likely an undercount due to limited provider use of relevant codes (e.g., "dependence on caregiver" or "use of medical devices").
- **Mobility Disability:** Lowest PPV (<20%) because visits for muscle pain or temporary injuries were being captured as disabilities. The team proposed separating acute mobility limitations (e.g., broken leg) from chronic functional limitations (e.g., wheelchair use).
- **Hearing Disability:** PPV ≈ 60%. This was challenging because there are no ICD codes for "deafness," and "hearing loss" and are often reflected in temporary infection-related symptoms.
- **Vision Disability:** A lower PPV (≈ 40%) due to transient vision loss, migraines, conjunctivitis, and foreign bodies.

COLLABORATION AND STAKEHOLDER ENGAGEMENT

The Kansas team worked with state disability partners, including the Kansas Association of Centers for Independent Living (KACIL), to interpret PPV results and discuss which conditions best reflected lived experiences. This collaboration also informed public health messaging, such as highlighting the connection between mobility limitations and pneumonia risk, emphasizing physical activity and respiratory health. The team also collaborated with preparedness colleagues to implement weather findings into their Jurisdictional Risk Assessment.

Participants noted that adverse weather conditions can significantly affect the health, mobility, and daily functioning of people with disabilities. They reported that poor weather—such as snow, ice, or heavy rain—can reduce mobility, make it difficult to leave the home, and exacerbate chronic pain, particularly for individuals with musculoskeletal or neurological conditions.

They also highlighted that thunderstorms and associated power outages pose risks for individuals who rely on electricity-dependent medical devices, potentially disrupting essential care. In addition, participants noted that extreme heat is a major concern, as many neurological disabilities are associated with heightened sensitivity to high temperatures, increasing vulnerability during heat events.

Overall, participants described the diverse ways in which weather and environmental conditions can affect people with disabilities and influence their ability to access care, maintain safety, and manage chronic conditions.

CHALLENGES AND LESSONS LEARNED

- **Data capture variability** across EHR systems impacts definition reliability.
- **ICD code inclusions** may be overly broad and warrant refinement for public health use.
- **Engagement with disability advocates** improves interpretation and messaging.
- **Hearing and vision** definitions require special attention to avoid conflating temporary impairments with chronic disabilities.

UNIVERSITY OF MONTANA

CONTEXT

The Montana team implemented two disability-related syndromic surveillance definitions—overall disability and mobility disability—to assess the impact of an extreme weather event, a derecho that struck parts of Missoula and Powell Counties in July 2024. The storm caused widespread power outages lasting nearly a week, creating significant challenges for residents who rely on assistive devices or home medical equipment.

IMPLEMENTATION APPROACH

Using data from the National Syndromic Surveillance Program (NSSP), the Montana Department of Public Health and Human Services partnered with University of Montana to

identify emergency department (ED) visits related to disability during, and after the storm (July 24–August 1, 2024). The dates of interest were compared with "blue sky" (baseline) data from the same week in 2023 to identify changes in patterns and outcomes.

The Montana team chose to focus on mobility and overall disability definitions due to higher case counts and the potential relevance to functional limitations during extreme weather. They conducted a positive predictive value (PPV) analysis for both definitions to assess accuracy and explored subcategories within the mobility definition such as:

- Neurological conditions
- Use of mobility devices
- Chronic pain and musculoskeletal conditions
- Mobility limitations related to chronic illness

This subcategorization approach, developed with input from local emergency preparedness teams, helped refine understanding of how mobility disabilities manifest during emergencies.

FINDINGS AND INSIGHTS

- The preliminary PPV for the mobility definition was approximately 65%, while the overall disability definition performed better, around 80%.
- A significant proportion of cases captured under mobility were acute pain conditions (e.g., back or knee pain) that did not represent chronic mobility limitations.
- Oxygen-dependent individuals affected by power outages were not captured by existing definitions, underscoring a gap in identifying people with functional or equipment-related access needs.
- The team found a 15% hospital admission rate among people with disabilities during the derecho period, up from 10% during baseline weeks, indicating potential vulnerability during power disruptions.
- These findings highlight the need to incorporate access and functional needs (AFN) indicators, such as reliance on electricity-dependent medical equipment, into future surveillance approaches.

COLLABORATION AND STAKEHOLDER ENGAGEMENT

The Montana team worked closely with emergency management partners and a state disability and health steering committee to interpret results and plan dissemination. The team plans to present findings at the Montana Disability and Inclusive Health Summit,

supported by Special Olympics and other organizations, and to develop educational materials to introduce NSSP definitions and data applications to emergency managers and disability advocates.

CHALLENGES AND LESSONS LEARNED

- **Data specificity:** Mobility-related terms often capture temporary conditions rather than established disabilities, reducing PPV.
- **Coding limitations:** Important functional needs (e.g., oxygen use) are not well coded in syndromic data, leading to undercounting.
- **Framing considerations:** Presenting the disability definitions as a method of data disaggregation, like stratifying by sex or geography, helped reduce misconceptions and improved stakeholder understanding.
- **Local interpretation is critical:** Montana emphasized maintaining standardized definitions for comparability but applying "localized PPV" interpretations to contextualize findings for their jurisdiction.

TACOMA-PIERCE COUNTY

CONTEXT

The Tacoma-Pierce County Health Department (TPCHD) implemented the disability syndrome definitions to evaluate health outcomes during five climate-related events: two heat waves, two cold-weather events, and one wildfire smoke episode. The project aimed to understand disability-related vulnerabilities during these climate hazards and strengthen partnerships between epidemiologists and disability advocates.

IMPLEMENTATION APPROACH

The team applied the definitions to syndromic surveillance data using three analytic windows for each event—pre-event, event, and post-event—ranging from 1 week to 1 month each. They also analyzed a "neutral" control period unrelated to emergencies or COVID-19 to establish baseline rates.

Instead of altering the definitions, TPCHD used dual categorization to increase PPV:

1. Clearly documented, chronic disabilities.
2. Clearly documented chronic disabilities plus acute or event-related disabling conditions likely to require additional support.

This approach produced consistently high positive predictive values (PPV) across all events, ensured the inclusion of individuals newly experiencing disability as a result of the emergency, and provided a more accurate reflection of healthcare burden during the incident.

FINDINGS AND INSIGHTS

- The positive predictive value (PPV) for the overall disability definition, considering only clearly documented chronic disabilities, was 77%. When including acute or event-related disabling conditions, the PPV was 95%.
- A machine-learning validation pilot showed that the definition performed reasonably well when evaluated using the more inclusive disability criteria. When the model was trained on the 'clearly documented chronic disability plus acute or event-related disabling conditions' dataset, it achieved a negative predictive value (NPV) of 77%.
- Although the NPV was relatively low, TPCHD determined that this level of performance was sufficient for advocacy efforts and for monitoring trends over time.
- Accounting for both short-term and long-term disabilities was essential for assessing the quality of the definitions and for supporting appropriate planning for disability-related needs during comprehensive emergency response.
- Hearing disability definitions skewed toward older populations (65+), prompting reflection on whether current coding captures the full disability spectrum.
- Community engagement with deaf and hard-of-hearing partners and interpreters helped identify potential biases and build awareness among local stakeholders.

COLLABORATION AND STAKEHOLDER ENGAGEMENT

TPCHD's success hinged on early and continuous collaboration among epidemiologists, clinicians, and community-based disability partners. The team:

- Developed a layperson-friendly presentation explaining syndromic surveillance, used to orient disability partners.
- Recommended including introductory videos with subtitles on topics such as "What is syndromic surveillance?" and "What does an epidemiologist do?" in future toolkits.
- Emphasized clear, mutual communication framing outreach as how public health can support disability communities, not just extract data.

- Paid community partners for their expertise, which strengthened trust and participation.

LESSONS LEARNED

- Education and transparency are essential for building trust around data use and disability inclusion.
- Clinical context (through clinician involvement) helps refine interpretation of PPV findings.
- Ethical compensation and acknowledgment of expertise encourage authentic engagement.
- Early investment in partner education yields more meaningful collaboration and better emergency preparedness outcomes.
- Future efforts should refine mobility and hearing definitions to distinguish temporary impairments from chronic disabilities.

RESOURCES

DISABILITY DEFINITIONS

The seven individual Disability Definitions can be found in the CSTE Syndromic Surveillance Knowledge Repository. An eight Disability definition, Overall Disability, which includes all seven individual definitions combined can be found here:

- Cognition and Central Nervous System: https://knowledgerepository.syndromicsurveillance.org/cognition-and-central-nervous-system-disability-v1
- Hearing: https://knowledgerepository.syndromicsurveillance.org/hearing-disability-v1
- Intellectual and Developmental: https://knowledgerepository.syndromicsurveillance.org/intellectual-and-developmental-disability-v1
- Mobility: https://knowledgerepository.syndromicsurveillance.org/mobility-disability-v1
- Self-Care and Independent Living: https://knowledgerepository.syndromicsurveillance.org/self-care-and-independent-living-disability-v1

- Specific Development, Behavioral, and Learning: https://knowledgerepository.syndromicsurveillance.org/specific-developmental-behavioral-and-learning-disability-v1
- Vision:https://knowledgerepository.syndromicsurveillance.org/vision-disability-v1

SYNDROMIC SURVEILLANCE

Syndromic Surveillance 101 – An Introductory Course in Syndromic Surveillance:

https://knowledgerepository.syndromicsurveillance.org/updated-syndromic-surveillance-101-introductory-course-syndromic-surveillance

COMMUNICATIONS RESOURCES

- CDC Resources for Facilitating Inclusion and Overcoming Barriers. The following resources may assist in creating and using inclusion strategies to improve the health, well-being, and participation of people with disabilities in all aspects of life.
- Section 508: U.S. Access Board Guidance. Official guidance on making electronic and information technology accessible in accordance with Section 508 of the Rehabilitation Act.
- Web Content Accessibility Guidelines (WCAG) – W3C. The international standard for digital accessibility, including criteria for screen reader compatibility, color contrast, navigation, and keyboard access.
- HHS Section 508 Compliance Checklists. A set of practical checklists for federal and public health agencies to ensure digital content meets accessibility requirements.
- National Center on Disability and Journalism: Disability Language Style Guide. Offers guidance on respectful, person-first, and identity-first language use, and terminology to avoid.
- American Foundation for the Blind (AFB): Digital Accessibility Resources. Best practices for designing digital content accessible to people who are blind or have low vision, including screen reader compatibility.
- Described and Captioned Media Program (DCMP): Captioning Key Guidelines. Standards for captioning educational media, videos, and public service announcements.
- ADA National Network: Effective Communication Guidance. Covers legal requirements and practical considerations under the Americans with Disabilities Act for communicating with people with disabilities.
- Sample Email/Letter for initiating a collaboration

SAMPLE OUTREACH EMAIL

Subject: Partnership Opportunity: Building Inclusive Surveillance with Disability Input

Dear [Name],

I hope this message finds you well. My name is [Your Name], and I am with the [Public Health Authority Name]. We are working to strengthen our public health surveillance systems, so they better reflect and respond to the needs of all communities, including people with disabilities.

We know from prior disasters that when disability-serving organizations are at the table, emergency planning and response are more effective, equitable, and lifesaving. That's why we are seeking to build partnerships with organizations like [Organization Name], whose leadership and expertise are essential to shaping strategies that work in practice—not just on paper.

We are interested in exploring how syndromic surveillance data (early health signals—like tracking symptoms reported in emergency rooms—that help public health officials spot outbreaks or health threats sooner) can be used to identify and address health disparities during disasters and public health emergencies. By working together, we can ensure this effort is transparent, ethical, and aligned with the priorities of the disability community.

Would you be open to a brief meeting in the coming weeks to discuss how we might collaborate? Your insight could directly influence how health departments design more inclusive systems that prevent harm and save lives.

Thank you for the vital work you do in our community. I look forward to the possibility of partnering with you.

Warm regards,

[Your Full Name] [Your
Title]
[Public Health Authority Name] [Email
Address]
[Phone Number]