



Defining Disability for Syndromic Surveillance: Data to Action

ASTHO Connect Webinar

April 29, 2024

Disclosure

This project is supported by cooperative agreement OT18-1802 from the U.S. Centers for Disease Control and Prevention (CDC). The contents of this document are the responsibility of ASTHO and do not necessarily represent the views of CDC.

WELCOME!

As you get settled, please enter the following information into the chat:



NAME



TITLE/ROLE



ORGANIZATION

Speaker Introductions



Adrianna Evans, MPH
ASTHO



Margaret Nilz, MPH
ASTHO



Erika Austhof, PhD
Aengle Consulting



Kelley Chester, DrPH
Thought Bridge

Agenda

- Overview of the Defining Disability Project
- Overview of the National Syndromic Surveillance Program (NSSP)
- Scientific panel results
- Overview of definitions for each disability type
- State pilot test results
- Call to action

Defining Disability Project Overview

Adrianna Evans

Project Goal

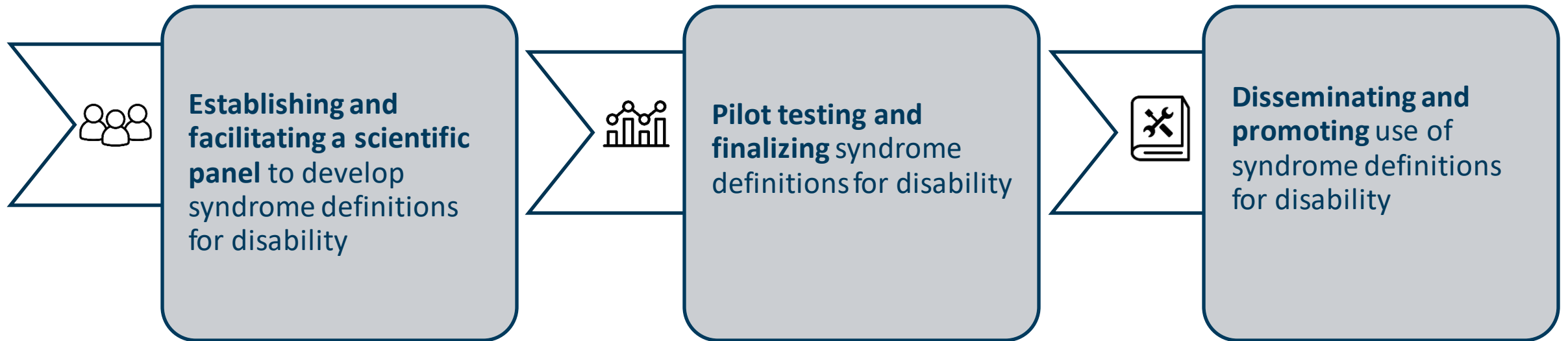
The goal of this project is to build public health capacity to monitor the health and well-being of people with disabilities before, during, and after public health emergencies.



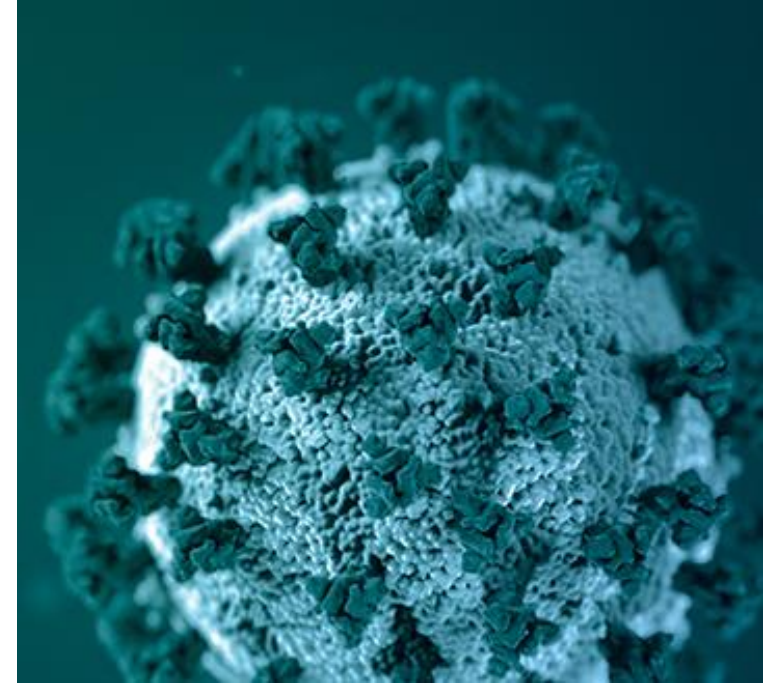


We are achieving our goal by developing, testing, and disseminating syndromic surveillance definitions to identify people with disabilities.

Key Activities



Syndrome definitions to identify people with disabilities will improve emergency and ongoing surveillance efforts.



National, state, and local jurisdictions will be able to quickly and efficiently identify people with disabilities to inform appropriate intervention strategies.

Impact of Public Health Emergencies on People with Disabilities

Without timely identification and response, people with disabilities may be inadvertently excluded from public health preparedness and response which could exacerbate existing health disparities.

Overview of the National Syndromic Surveillance Program

Kelley Chester

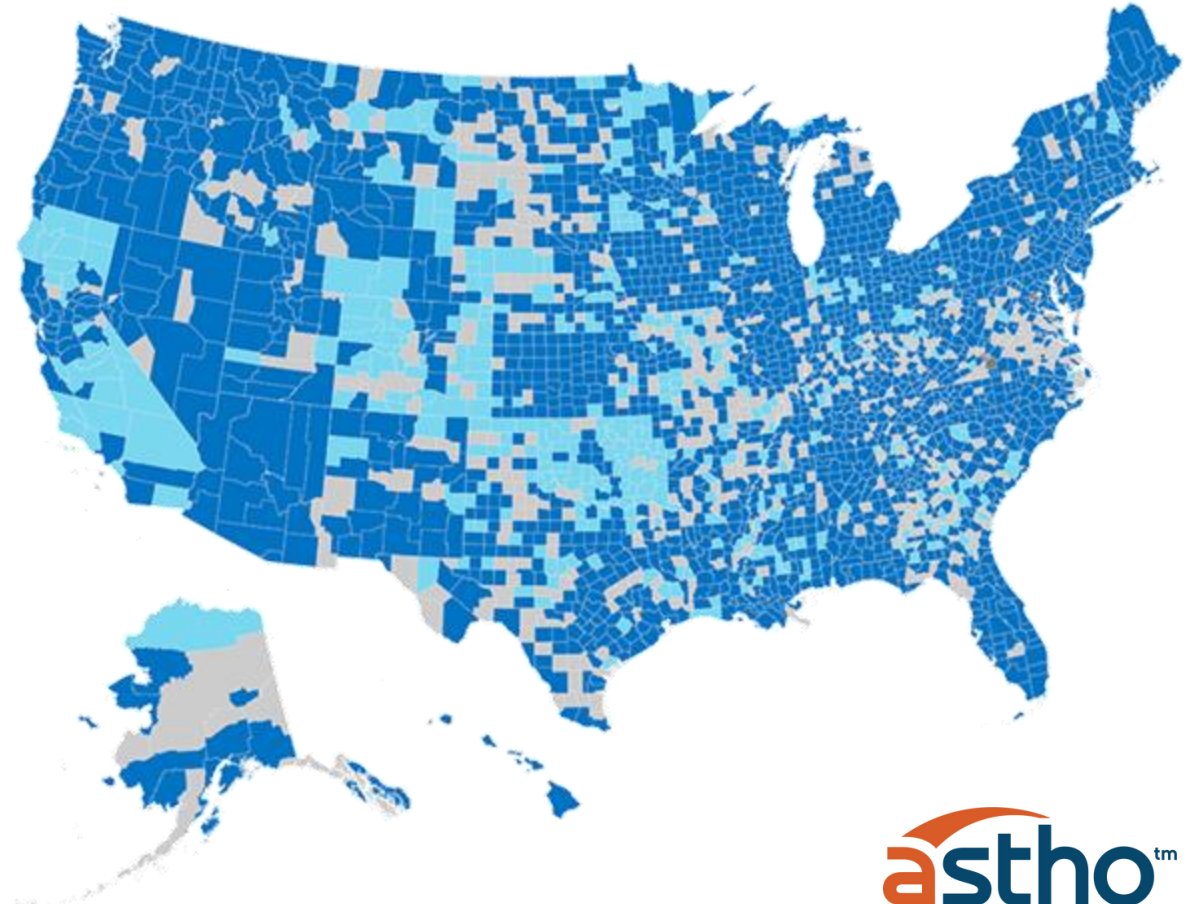
National Syndromic Surveillance Program (NSSP) By the Numbers

- ~77% of U.S. EDs report
- 50 states + D.C. and Guam participate
- 75% of data received within 24 hours of the visit
- 6 million messages received daily
- >2,000 registered users of the system
- Estimated 73.5% of U.S. population represented*

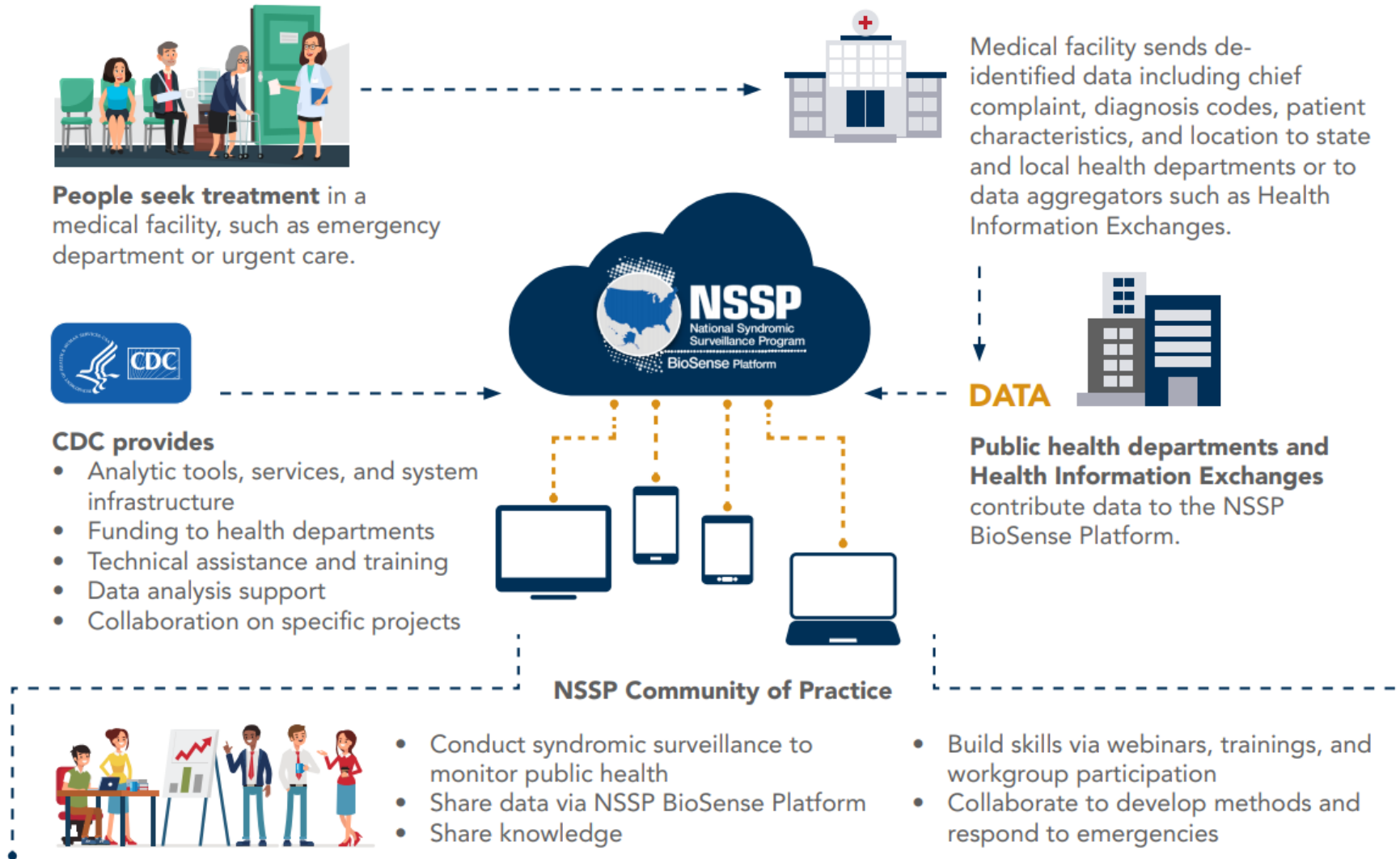
*Estimate based on proportion of Health Service Area populations served by NSSP Participating Facilities

NSSP Facility Participation by US County

Non-federal Emergency Care Participation in the National Syndromic Surveillance Program:
August 1, 2023, to November 1, 2023.



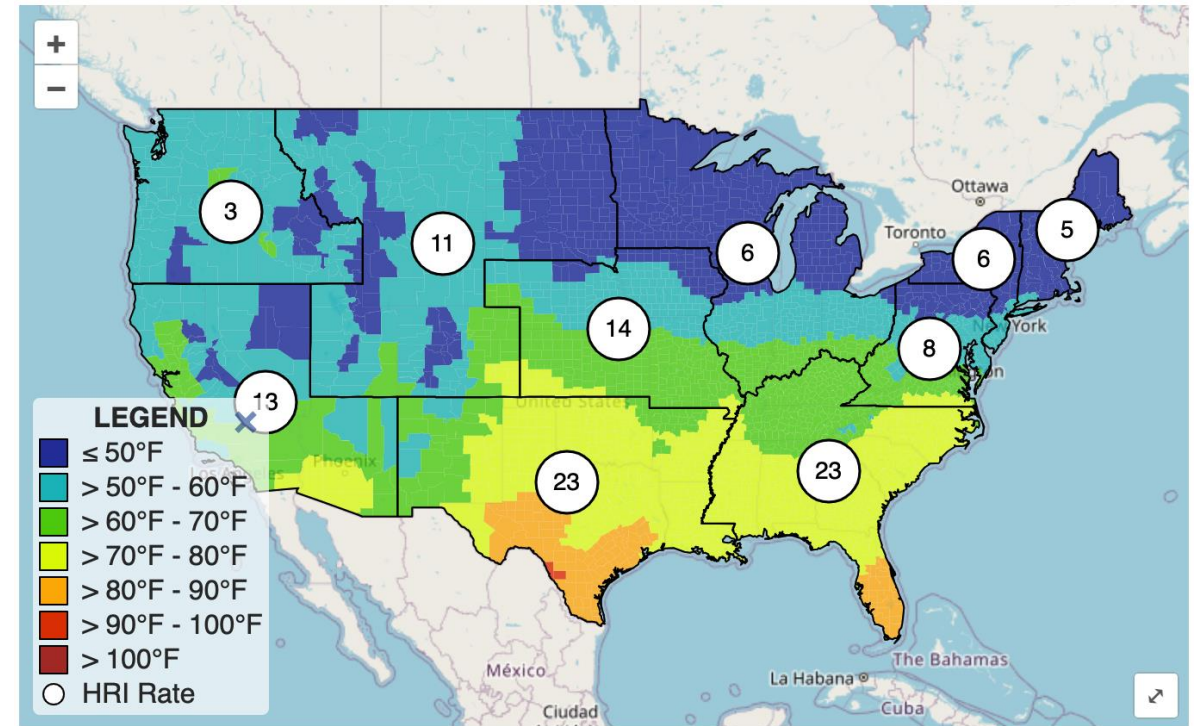
How NSSP Conducts Syndromic Surveillance



How NSSP Data is Used

The Heat-Related Illness and Temperature map shows the rate of emergency department (ED) visits associated with heat-related illness (HRI) per 100,000 ED visits by HHS region for the selected week using data available through the National Syndromic Surveillance Program (NSSP)

CDC Heat & Health Tracker



<https://ephtracking.cdc.gov/Applications/heatTracker/>

Results from the Scientific Panels

Margaret Nilz

Scientific Panel

The purpose of the scientific panel was to:

- Decide on disability definition for mapping diagnostic codes (e.g., WG-SS, ACS-6)
- Identify existing algorithms for identifying disability with diagnosis codes
- Map ICD codes to chosen disability definition
- Provide input on syndrome definition
- Review pilot test results
- Finalization of the definition



Scientific Panel

Panel 1

- Determined use of statutory definitions of disability as the baseline
- Focus on domains of functional disability types (e.g., hearing, vision, mobility, etc.) rather than specific definitions

Panel 2

- Established Intellectual and Developmental Disabilities remaining one domain
- Included existing mental health definition in disability definition reference materials

Panel 3

- Renamed Learning Domain as 'Specific Developmental and Learning Disabilities' domain
- Relocated ADHD, Conduct Disorders, and Hyperkinetic Syndromes to Specific Developmental or Learning Disabilities

Scientific Panel

Chronic Conditions Work Group

- Formatted Chronic Conditions as a supplemental product to allow additional flexibility
- Determined Chronic condition domain will not be tested through state and local pilot testing process

Panel 4

- Refined chief complaint and keywords for each domain
- Discussed communication and dissemination barriers and strategies

Disability Definitions Overview

Erika Austhof

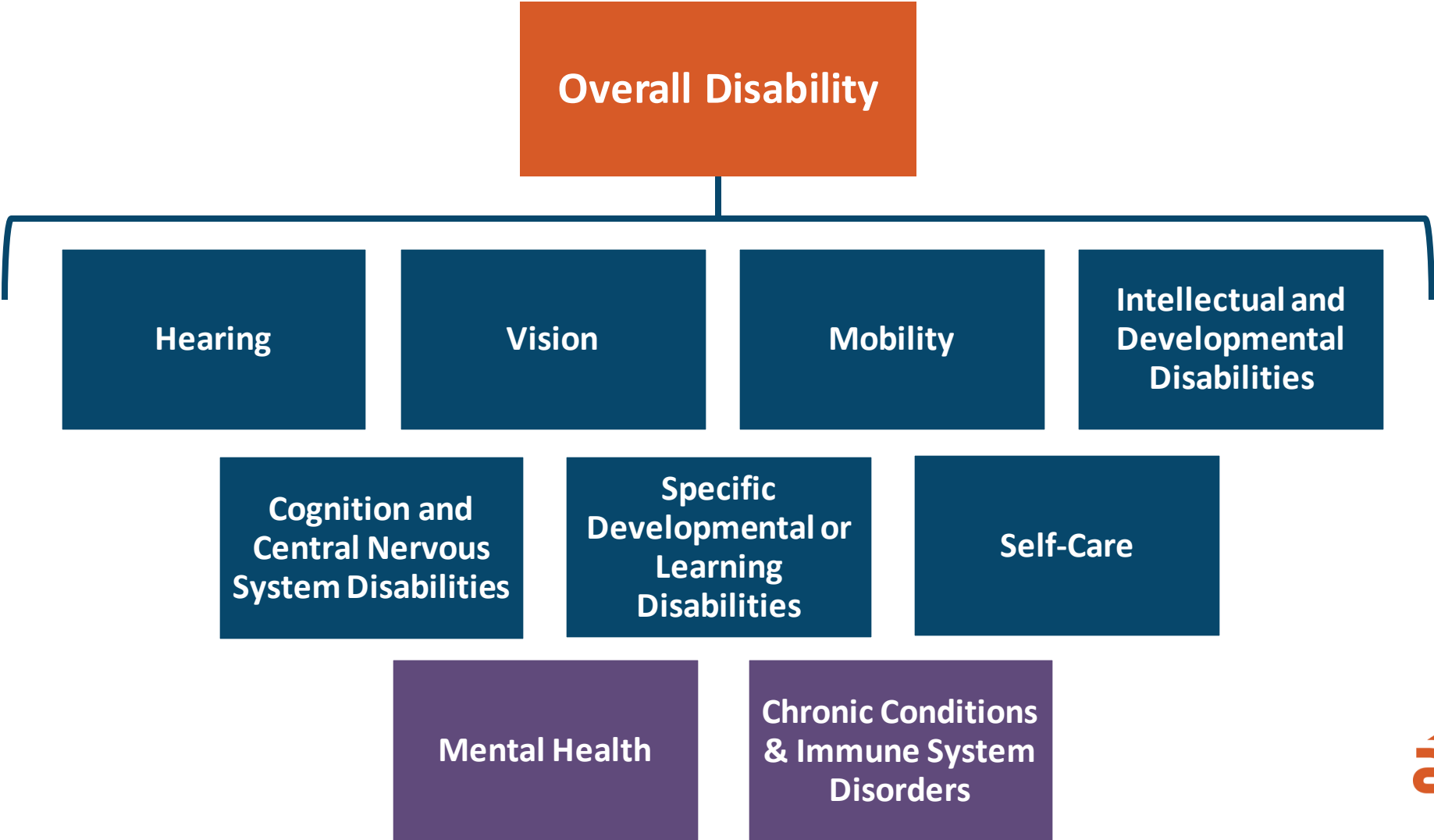
Definition Development Methods

- Key Informant Interviews to guide development
- Iterative search strategy to identify codes (ICD 9/10, SNOMED)
 - Chronic Conditions Warehouse
 - ADA Regulations and documentation
 - Research publications
 - Reports and documents from disability advocacy groups
 - CDC documents and guidance
- Four scientific panels
- National pilot testing
- State/local pilot testing

Exclusions

- Excluded medical conditions which are generally expected to resolve:
 - In under 6 months
 - With treatment
 - With surgery
 - Or, are generally self-limiting, acute conditions
- Few conditions occur in multiple domains
 - Sorted into best fitting domain
 - Overlap amongst domains is allowed

Final Definition



Hearing Domain Example

- Includes diagnosis codes for
 - Hearing loss
 - Hearing impairment
 - Deafness
 - Refsum’s disease
 - Cochlear implant status
 - Acoustic neuroma
 - Auditory processing disorder
- Exclude acute diagnosis codes for
 - Impacted earwax
 - Ear infection
 - “denies hearing loss”

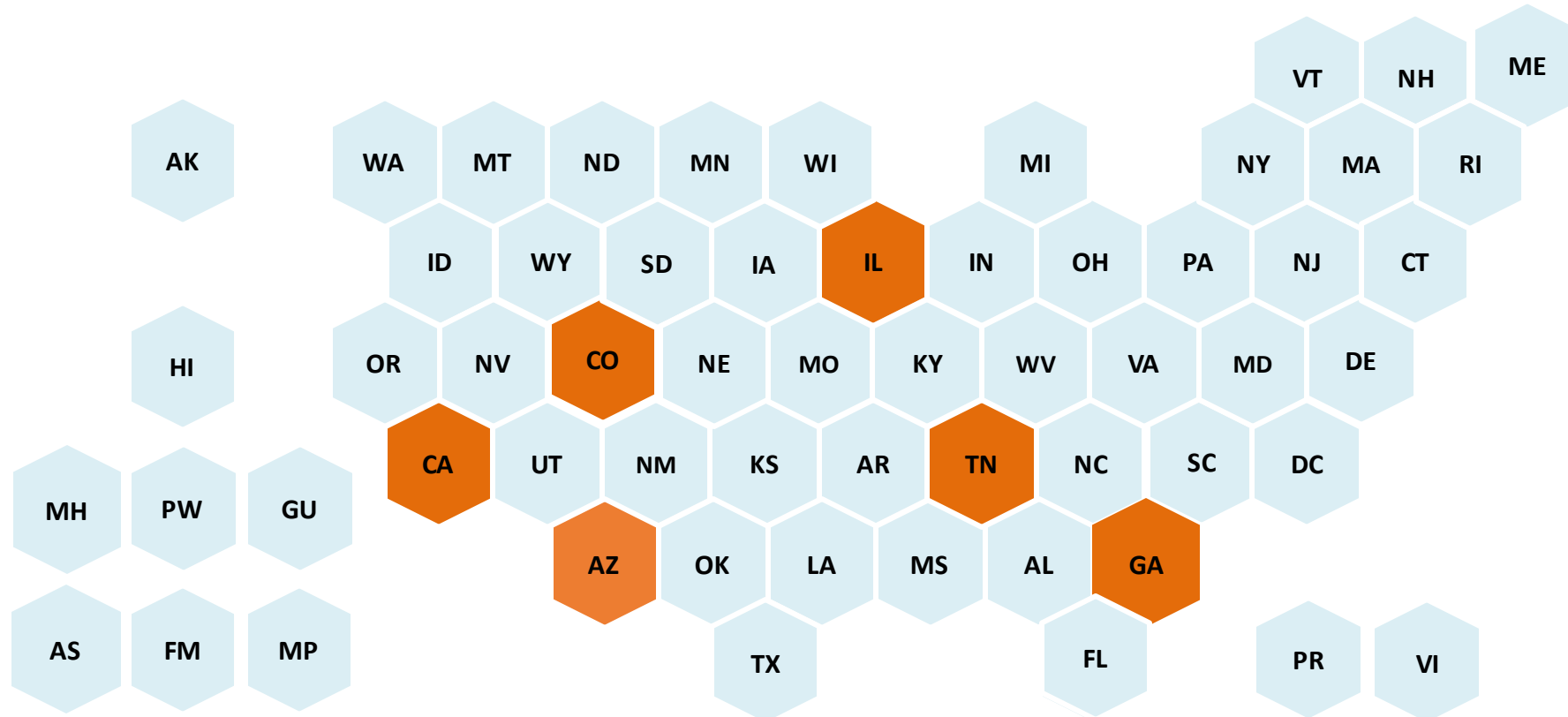


Hearing

Summary of Jurisdiction Pilot Testing

Erika Austhof

Participating Jurisdictions



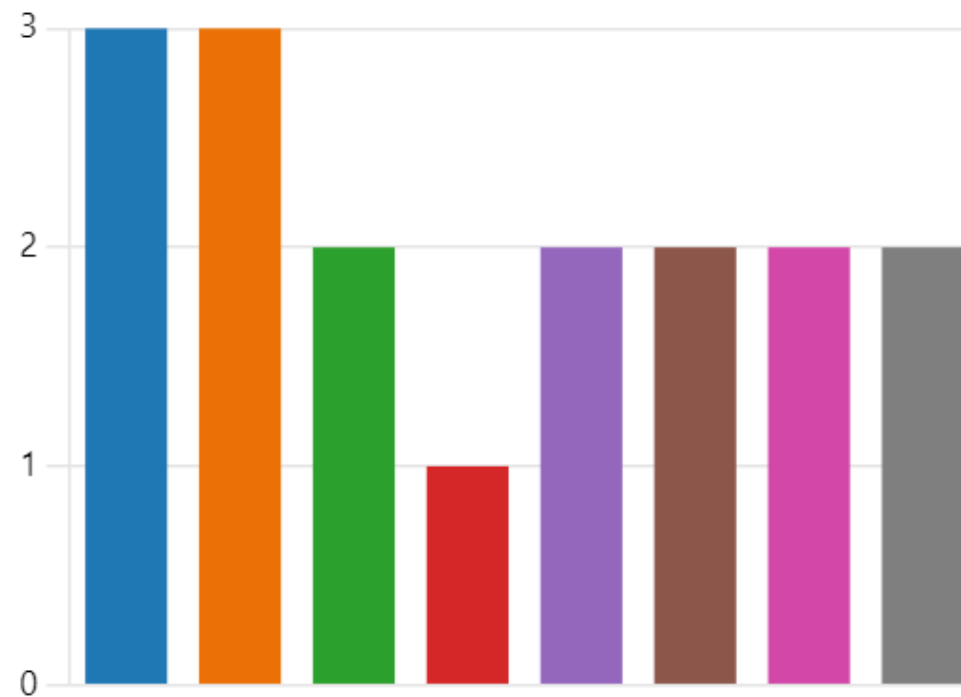
- State Pilot Tester
- Not participating

Results

For which domain are you reporting results?

[More Details](#)

● Hearing	3
● Vision	3
● Mobility	2
● Intellectual and Development Di...	1
● Cognition and Central Nervous ...	2
● Specific Developmental or Learn...	2
● Self Care	2
● Disability Overall	2



Results Overview

Positive Predictive Value(PPV)

- PPV indicates the likelihood the definition can successfully identify if people have the target condition
- Wide range of jurisdiction PPV values based on domain
- Low PPVs indicated that some draft definitions were too broad

Overall Impression

- Overall, the definitions captured the intended cases
- Clear false positives including misspellings, variations, and negations

Recommendations

- Recommendations from state jurisdictions including:
 - Enhancements
 - Recommended removals/exclusions
 - Recommended Negations
 - Key word revisions

National Testing Results

Disability Domain	National Level Testing PPV
Hearing	96.5%
Vision	97.6%
Mobility	91.7%
IDD	95.2%
CNS/Cognition	98.4%
Self-Care and Independent Living	95.5%

Call to Action

Adrianna Evans

Call to Action



Improve coordination amongst all stakeholders including public health agencies, NSSP, healthcare providers, disability experts, and people with disabilities.

Increase disability documentation in health records across all areas of the healthcare system.

Recognize how diagnostic codes support public health capacity to monitor the health and well-being of people with disabilities

Questions?



**Defining Disability for
Syndromic Surveillance: Data To Action
Technical Assistance**

Tuesday April 30 4-5 pm EST

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