

The National Center for a System of Services for CYSHCN

Title V Virtual Cafes

Calculating CYSHCN Prevalence: A Deep Dive

Friday April 5, 2024 12-1pm CT/1-2pm ET

The National Center for a System of Services for CYSHCN is supported by the Health Resources and Services Administration (HRSA) of the U.S. Department of Health and Human Services (HHS) as part of an award totaling \$1,500,000 with no funding from nongovernmental sources. The information or content are those of the author(s) and do not necessarily represent the official views of, nor an endorsement, by HRSA, HHS or the U.S. Government.

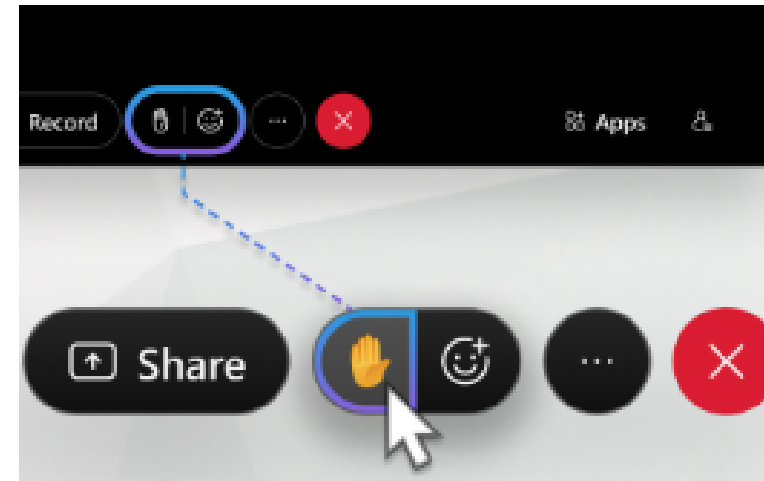
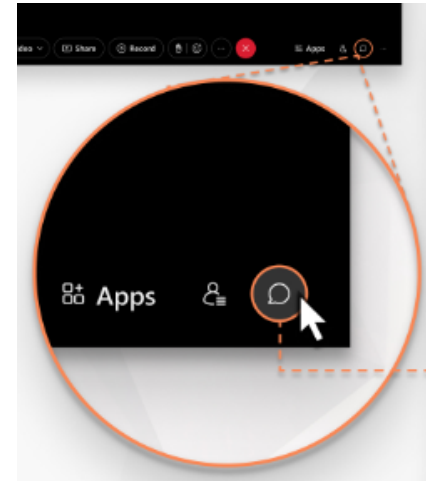
American Academy of Pediatrics

DEDICATED TO THE HEALTH OF ALL CHILDREN®



HOUSEKEEPING

- **The didactic presentation will be recorded; peer discussion will not be recorded**
- All participants have been muted
- Utilize chat box to share comments, questions, or relevant resources
- Utilize hand raising feature during discussion portion
- Rename yourself to include your name and state/jurisdiction
- Direct chat AAP staff with technical issues



SESSION AGENDA

1. Brief overview of Blueprint National Center
2. Proposed changes to the CYSHCN prevalence calculation in the NSCH
 - Outline proposed updates to CYSHCN prevalence calculations
 - Benefits, challenges and implications for Title V CYSHCN programs
3. Discussion/Peer Sharing
4. Closing/Evaluation Poll



THE BLUEPRINT NATIONAL CENTER



Goal: To advance and strengthen the system of services for CYSHCN and their families/caregivers at the community, state, and national levels by leading the field to promote health care and other supports that are integrated, family-centered, evidence-informed, and culturally responsive.

What We Do



One-on-one
technical assistance



Tools



Training



Strategies



Connections to
peers and experts





Blueprint Center Café: Calculating CYSHCN Prevalence—A Deep Dive

Jeff Brosco, MD, PhD
Director, Division of Services
for CYSHCN
Maternal and Child Health
Bureau

Shirley Payne, PhD
Director, Division of State and
Community Health
Maternal and Child Health
Bureau

Reem Ghandour, DrPH, MPA
Director, National Survey of
Children's Health
Office of Epidemiology and Research
Maternal and Child Health Bureau

Vision: Healthy Communities, Healthy People



OBJECTIVES

- Describe the population of children captured and not captured using the Children with Special Health Care Needs Screener (CSHCN Screener) as implemented in HRSA's National Survey of Children's Health (NSCH)
- Discuss the proposed timeline for rolling out changes
- Discuss strengths and limitations of the proposed approach with peers
- Keep the conversation going!

Impetus: Renewed interest in “At-Risk” CYSHCN

- The Pennsylvania Title V program, with support from Dr. Christy Bethell, explored options to quantify the proportion of children **at risk** for special health care needs using only *stem* items from the CSHCN Screener, i.e., endorsement of follow-up questions related to medical cause or duration *not required*.
- Bethell and colleagues suggested a more complex approach: Integrated Child Risk Index (ICRI) which includes medical health risk (MHR), social health risk (SHR) and relational health risk (RHR) domains.¹
- Prior work has documented the potential for both over- and under-identification of CYSHCN among specific sub-groups of children, e.g., those of Hispanic ethnicity, and those with diagnosed conditions or known functional limitations but without related impacts.²

1. Bethell C, Blackwell CK, Gombojav N, Davis MB, Bruner C, Garner AS. Toward Measurement for a Whole Child Health Policy: Validity and National and State Prevalence of the Integrated Child Risk Index. *Acad Pediatr*. 2022 Aug;22(6):952-964.

2. Bethell CD, Blumberg SJ, Stein RE, Strickland B, Robertson J, Newacheck PW. Taking stock of the CSHCN screener: a review of common questions and current reflections. *Acad Pediatr*. 2015 Mar-Apr;15(2):165-76.



Methods: Data Source & Variables

- Data were pooled across the 2016-2021 National Survey of Children's Health.
- Describe the proportion of children identified SHCN among two subgroups of children:
 - 1+ current health conditions (of 22 conditions)
 - 1+ functional difficulties (of 6 difficulties)
- Health and social impacts were selected based on their salience to both extant and evolving models of a well-functioning system of services, including:
 - Child-level: 2+ past-year ED visits; unmet healthcare needs; frequent and significant activity limitations; flourishing
 - Family-level: out-of-pocket costs >\$1000; employment impacts; frustration obtaining services
 - Systems-level: Adequate Insurance and Medical Home access.

CYSHCN Screener Impacts:

- 1) Need and use of prescription medication;
- 2) Above-routine use of medical, mental health, or educational services;
- 3) Presence of functional limitations;
- 4) Need and use of specialized therapies; and
- 5) Need and use of treatment or counseling for an emotional, behavioral, or developmental condition.

Each “stem” question is followed by two questions to confirm the presence of a related condition and an expected duration of 12 months or longer.



Methods (cont.): Conditions & Difficulties

Conditions:

Physical

- 1) Cerebral Palsy
- 2) Arthritis
- 3) Asthma
- 4) Frequent Headache
- 5) Allergies

Genetic

- 6) Seizure
- 7) Diabetes
- 8) Down Syndrome
- 9) Genetic, Other
- 10) Cystic Fibrosis
- 11) Heart conditions
- 12) Blood disorders

Behavioral

- 13) Behavioral/conduct problems
- 14) ADHD

Emotional

- 15) Depression
- 16) Anxiety problems

Developmental

- 17) Intellectual disability
- 18) Autism
- 19) Developmental delay
- 20) Learning disability
- 21) Tourette
- 22) Speech problems

Difficulties:

All Children

- 1) Eating or swallowing difficulties
- 2) Breathing or other respiratory problems
- 3) Deafness
- 4) Chronic pain
- 5) Blindness
- 6) Digestive difficulties

Children aged 0-5 years

- 7) Difficulty with coordination
- 8) Difficulty using hands

Children aged 12-17 years

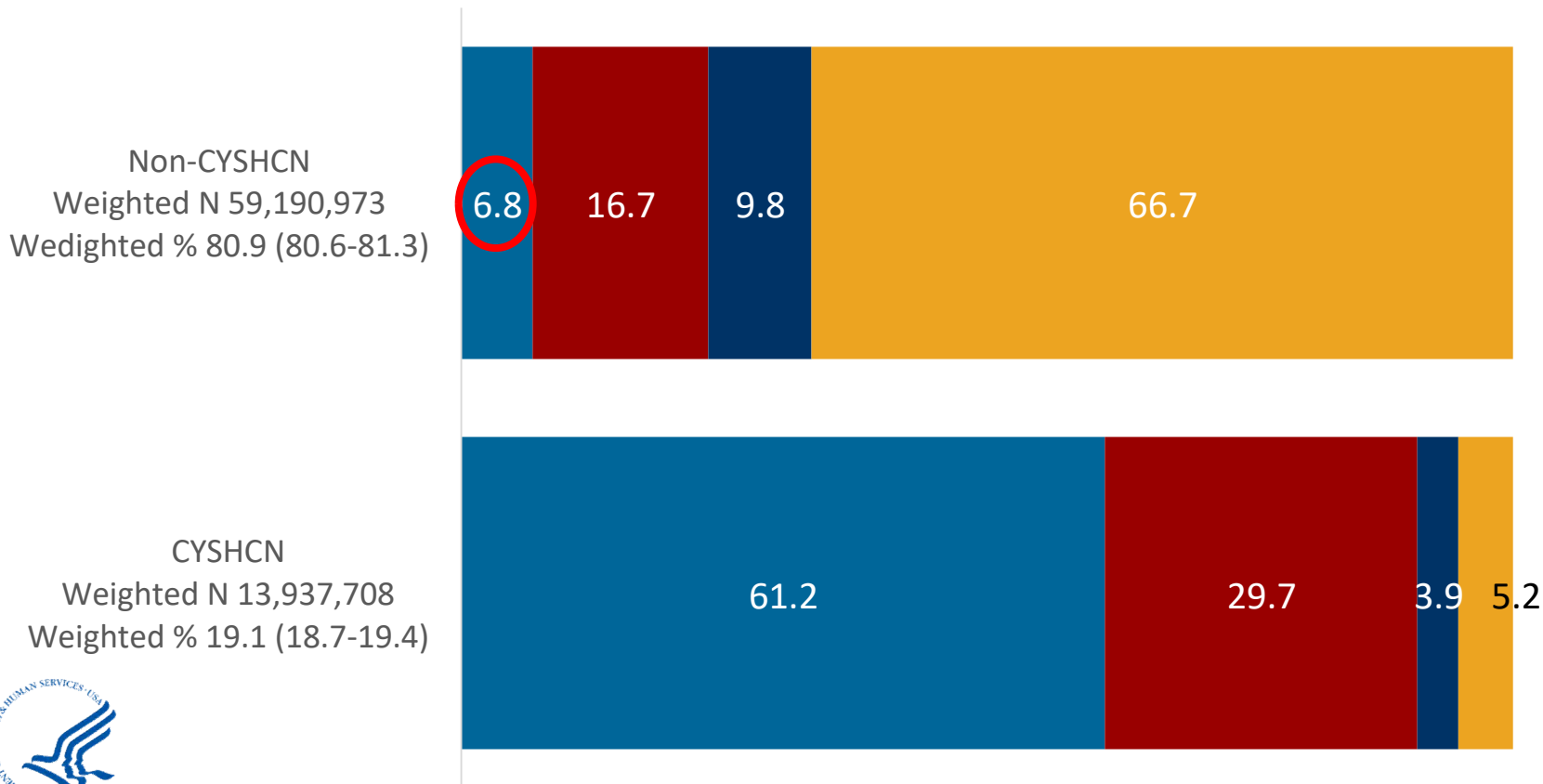
- 9) Difficulty dressing or bathing
- 10) Difficulty doing errands alone
- 11) Serious difficulty concentrating, remembering or making decisions
- 12) Difficulty walking or climbing



Results: As expected...mostly

Sample Characteristics, by SHCN Status, Conditions and Difficulties

■ Conditions and difficulties ■ Conditions only ■ Difficulties only ■ No conditions or difficulties

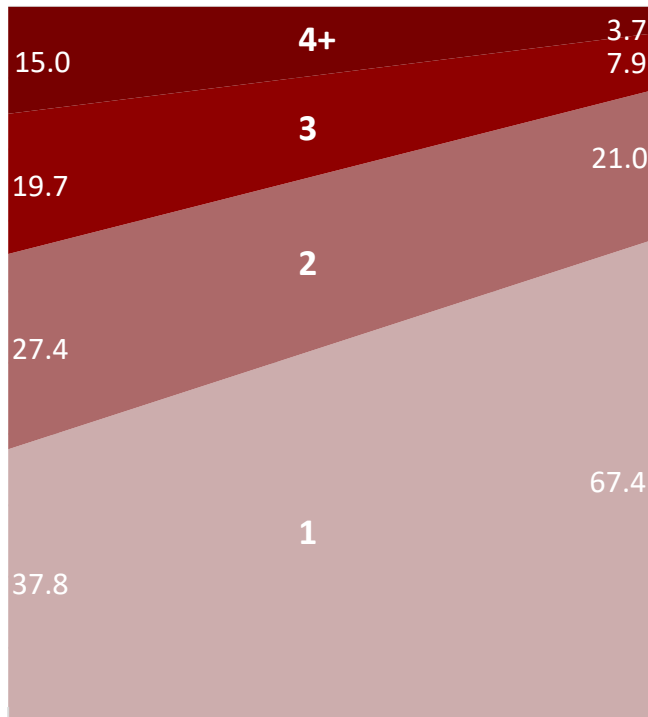


- Overall prevalence of SHCN in 2016-2021 was 19.1%, representing 14M children.
- Nearly 2/3 (61.2%) of CYSHCN have both conditions and difficulties.
- 5.2% of CYSHCN have neither conditions nor difficulties.
- 6.8% of children with conditions and difficulties did not meet the criteria for special health care needs based on the CSHCN Screener, representing 4M children.



Results: Who are children with ≥ 1 Condition and ≥ 1 Difficulty?

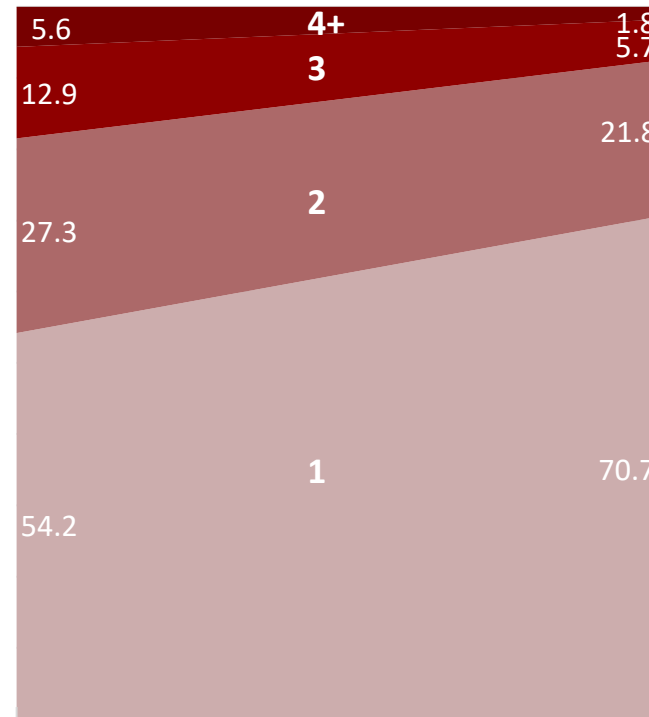
Number of Conditions



CYSHCN

non-CYSHCN

Number of Difficulties



CYSHCN

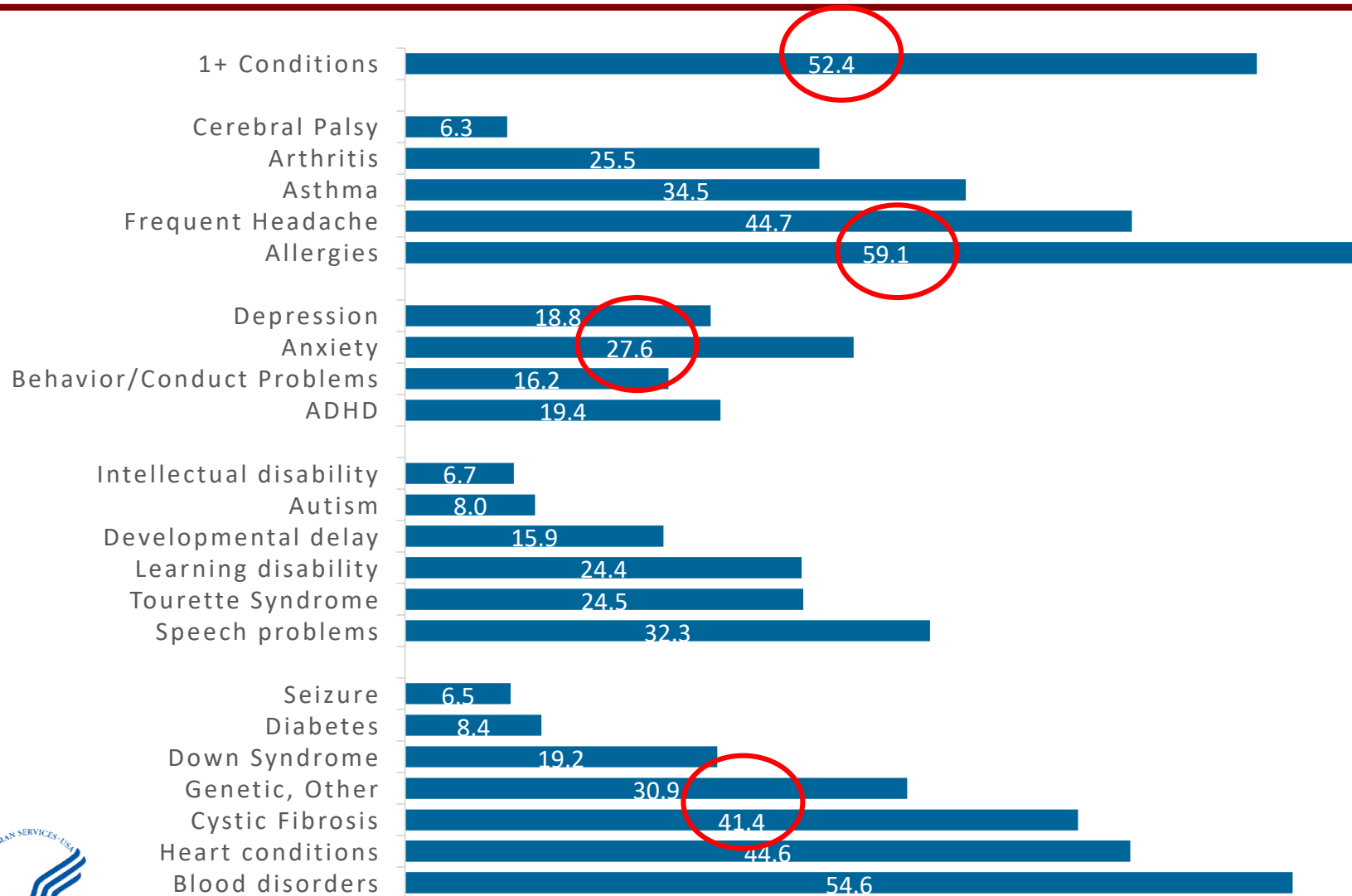
non-CYSHCN

Among those with conditions and difficulties:

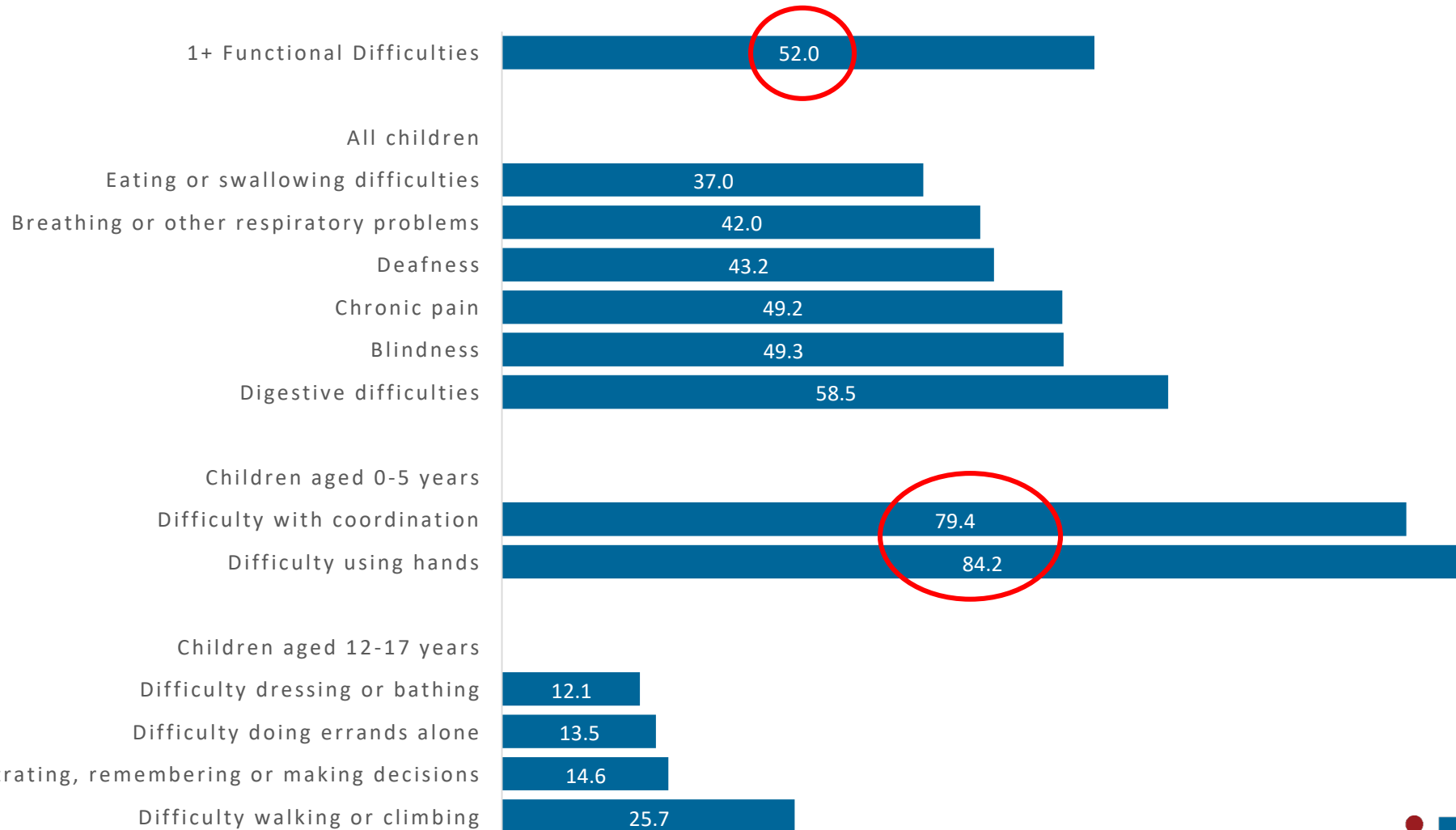
- CYSHCN are more likely to have multiple conditions/difficulties
- Yet, 1 in 3 non-CYSHCN have multiple conditions/difficulties
 - Some even have 4+



Results: Conditions among Non-CYSHCN



Results: Difficulties among Non-CYSHCN



Results: Demographic Characteristics

Stratified the population by:

- 1) SHCN status (CYSHCN/non-CYSHCN), and
- 2) Presence of ≥ 1 condition AND ≥ 1 difficulty.

Children with ≥ 1 condition AND ≥ 1 difficulty who were:

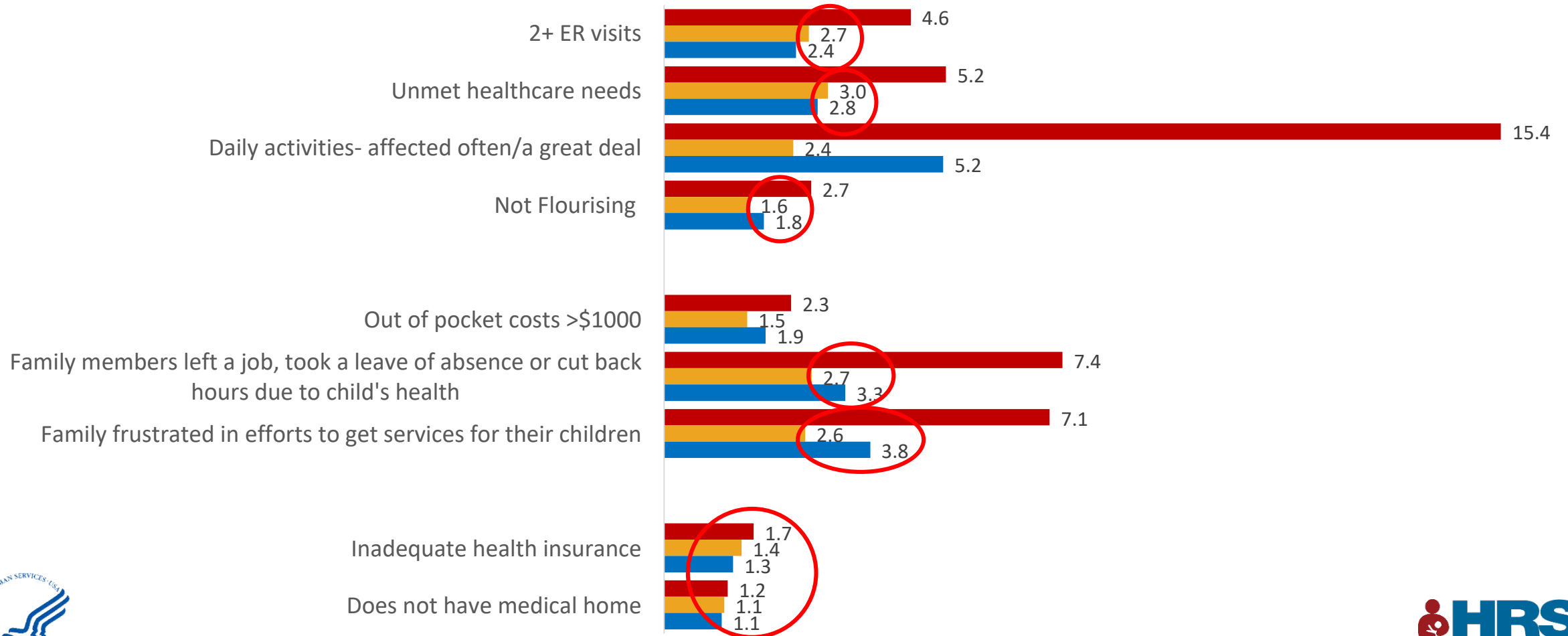
- Younger (0-5 years);
- Female;
- Hispanic or non-Hispanic Multiple/Other Race;
- Uninsured or privately insured;
- Living in a household with low educational attainment.

Were more likely not to be identified as having a special health care need.

- Despite clear utility to the field, the CSHCN Screener demonstrates some important limitations.

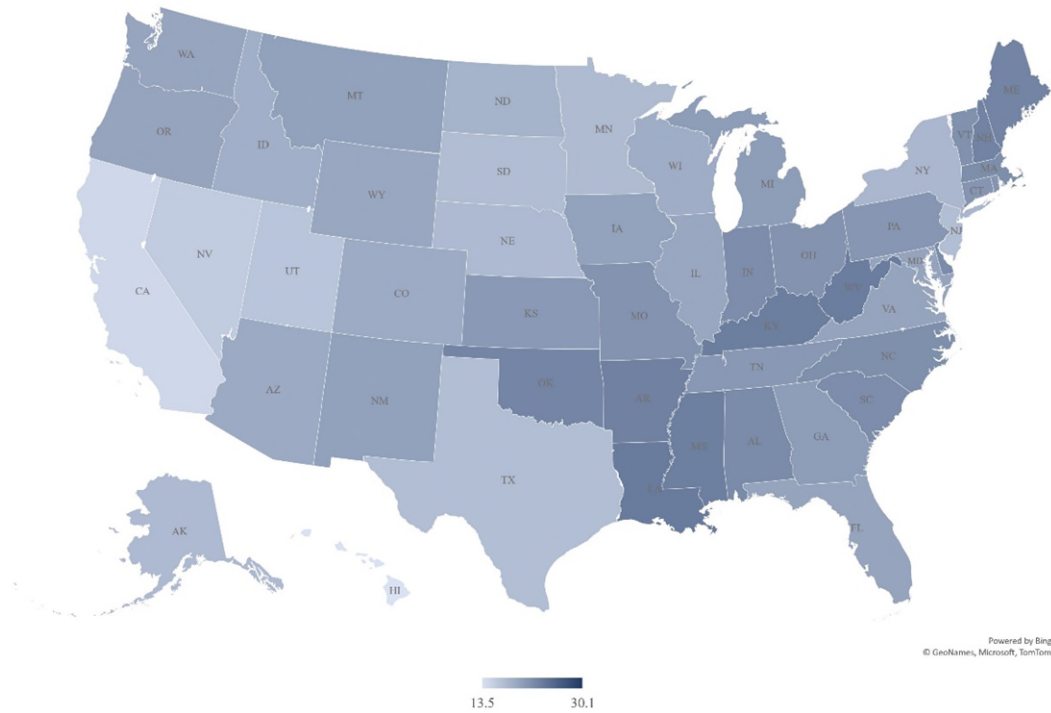
Results: Impacts after Adjustment

■ Conditions and difficulties, CYSHCN ■ Conditions and difficulties, Non-CYSHCN ■ Conditions only, difficulties only, no conditions or difficulties, CYSHCN

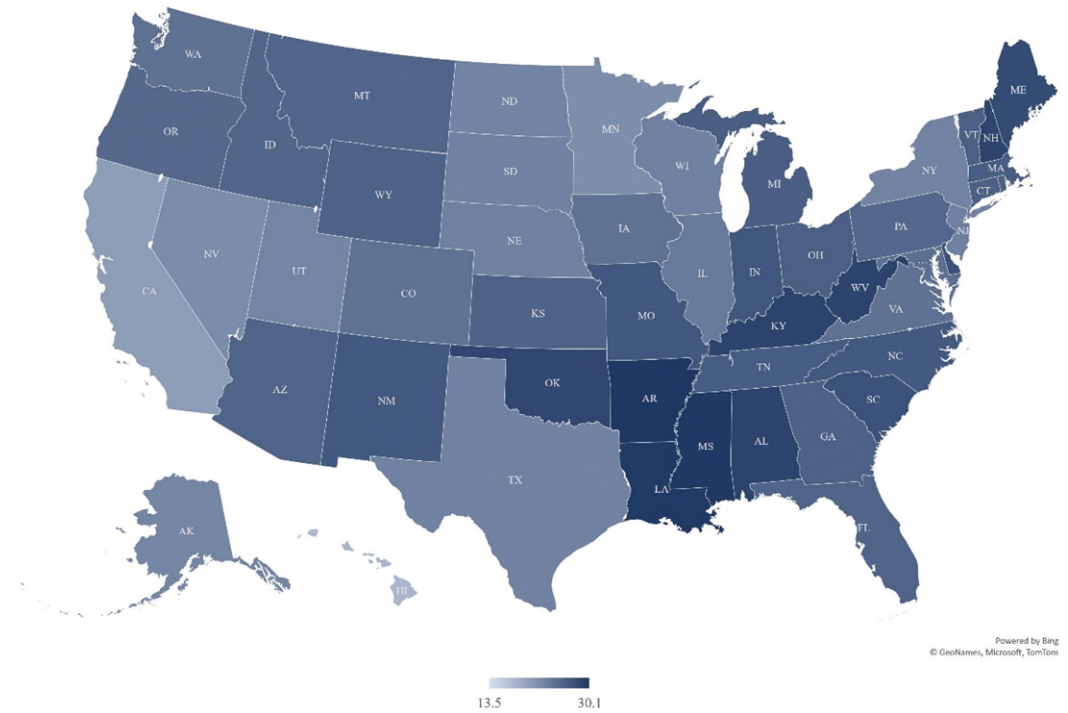


Results: State Prevalence

Prevalence of CYSHCN --
Current Calculation



Prevalence of CYSCHN --
Expanded Calculation



What does this all mean?

MCHB Proposes...

To **expand** the calculation of CYSCHN in the National Survey of Child Health (NSCH) by including children whose caregivers report both a condition and a limitation

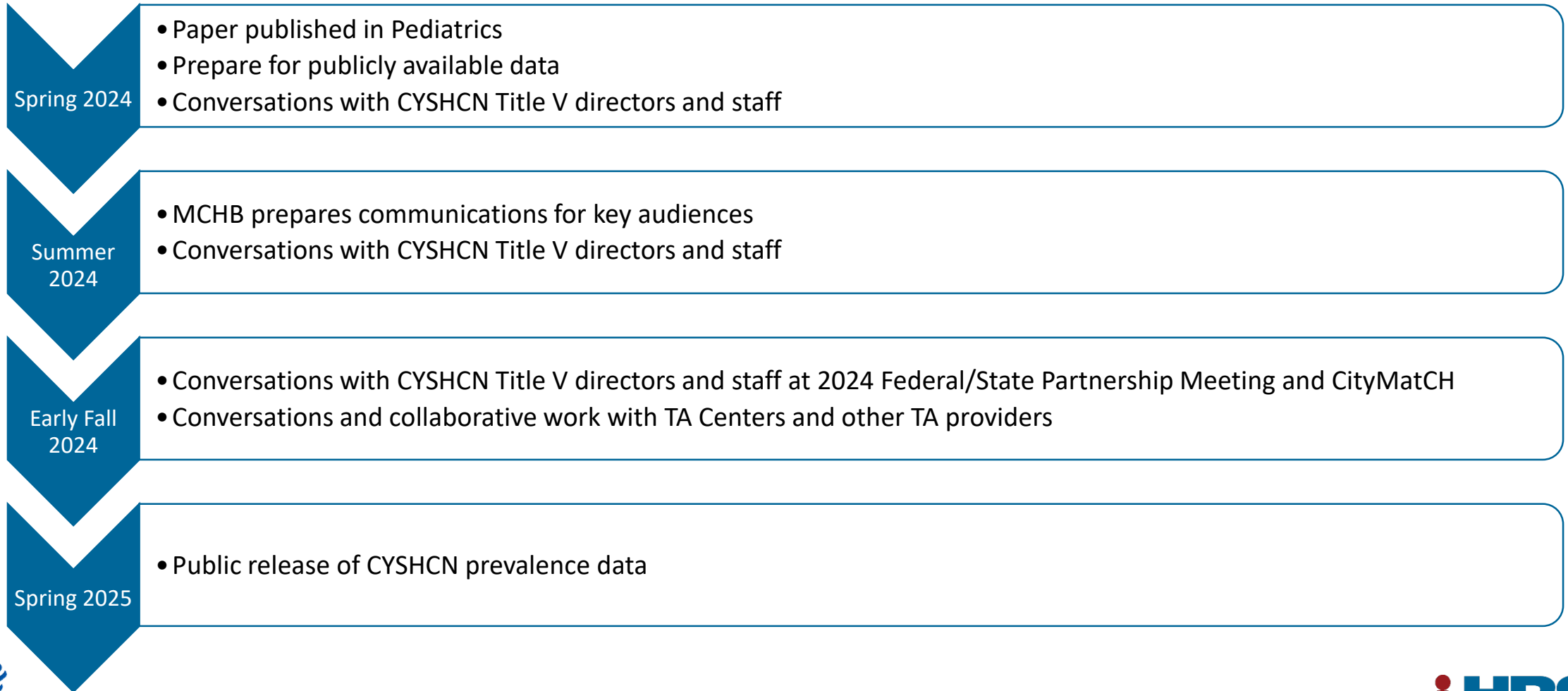
- Currently CYSCHN: screen positive on CSHCN Screener
- Increase CYSCHN from 19% to 25% of all children

Conclusions:

- Analyses using the latest NSCH data confirm discordance between children being identified as SHCN using the CSHCN Screener and children with reported conditions and functional difficulties.
- Some populations of children appear to be less likely to be identified as having a SHCN through the CSHCN Screener despite having ≥ 1 reported condition and ≥ 1 reported functional difficulty.
- Non-CYSHCN with conditions+difficulties were just as likely as CYSHCN without conditions+difficulties to experience: 2+ ER visits in the past year, unmet healthcare needs, to not be flourishing, to experience employment impacts, frustration getting services, and inadequate insurance.
- Extending the calculation of CYSHCN to include those with conditions and functional difficulties regardless of parental/caregiver response to the CSHCN Screener would increase the overall prevalence of SHCN by 29%, from 19.1% to 24.6%. State prevalence estimates would increase between 4.1-7.1 percentage points with southern (FL, LA, AL, MS, AR) and western states (AZ, NM NV, ID) having the largest increases.



Proposed Timeline



Discussion

- How do these changes impact your ongoing activities and work?
- What are the benefits of these proposed changes?
- What are the potential challenges of changes to NSCH?
- What are the implications on the subpopulations you work with, such as children with medical complexity?
- What resources do you need to communicate this change to your partners? What partners would need this information?



THANK YOU!



CONTACT US!

- Blueprint4CYSHCN@aap.org
- [National Center for a System of Services for CYSHCN Web site](#)
- Subscribe to the [National Center for a system of services for CYSHCN listserv](#) to get access to valuable resources, event notifications, and so much more!



VIRTUAL CAFÉ EVALUATION SURVEY

