# CYSHCN Director Gathering

## Title V MCH Federal-State Partnership Meeting
## Division of Services for CYSHCN

***November 5, 2023***

Welcome!

*Please feel free to grab a snack.*

ACTIVITY: You will see three large white Newsprints around the room. Throughout the afternoon, please use the stickies and respond to the questions on the Newsprint.

Vision: Healthy Communities, Healthy People

# Welcome!


## Shirley Payne
### Director
### Division of State and Community Health


# Overview of agenda, objectives, and setting expectations

# Introductions and Icebreaker

# Measuring what Matters *for CYSHCN and their families*

# CHILDREN AND YOUTH WITH SPECIAL HEALTH CARE NEEDS

## WHO ARE CYSHCN?

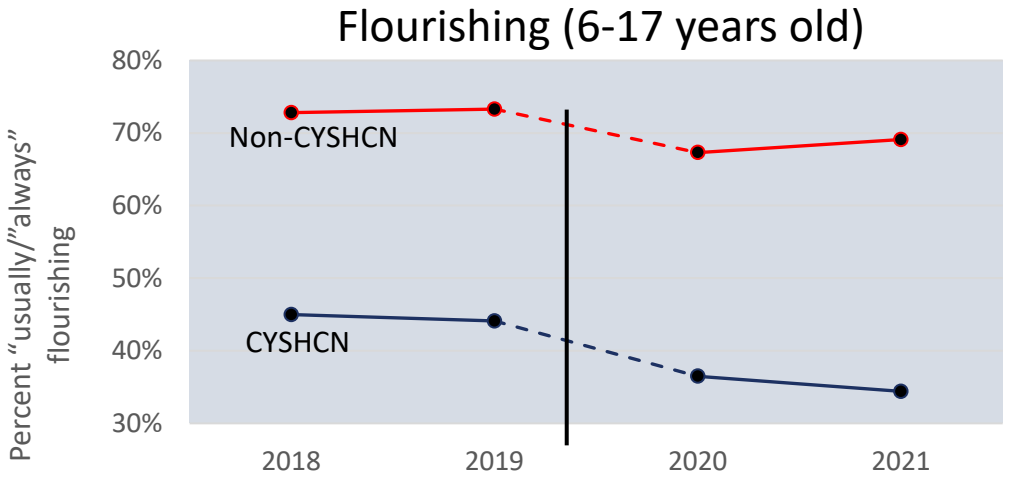
Children or youth ***who have or are at increased risk for*** chronic physical, developmental, behavioral, or emotional conditions and who also require health and related services of a type or amount beyond that required for children generally.

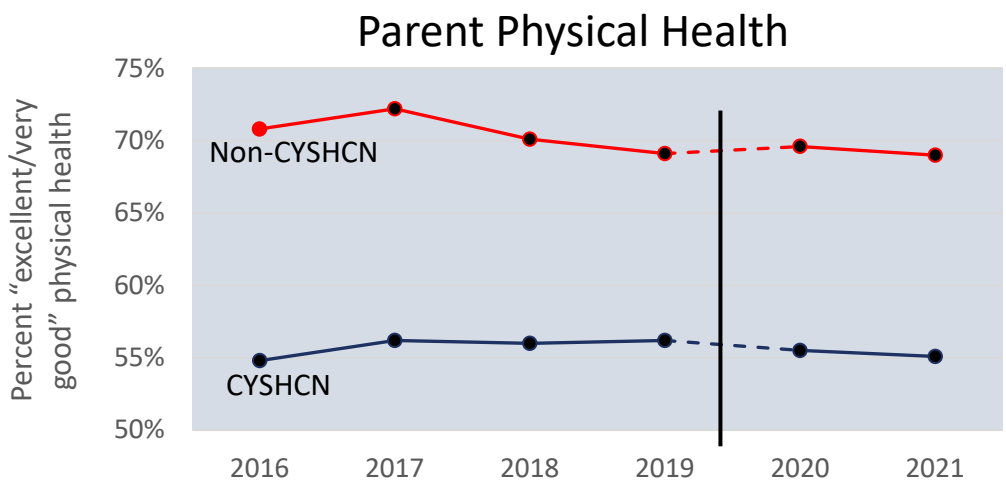
# ASIDE: Changing the word “special” to . . .

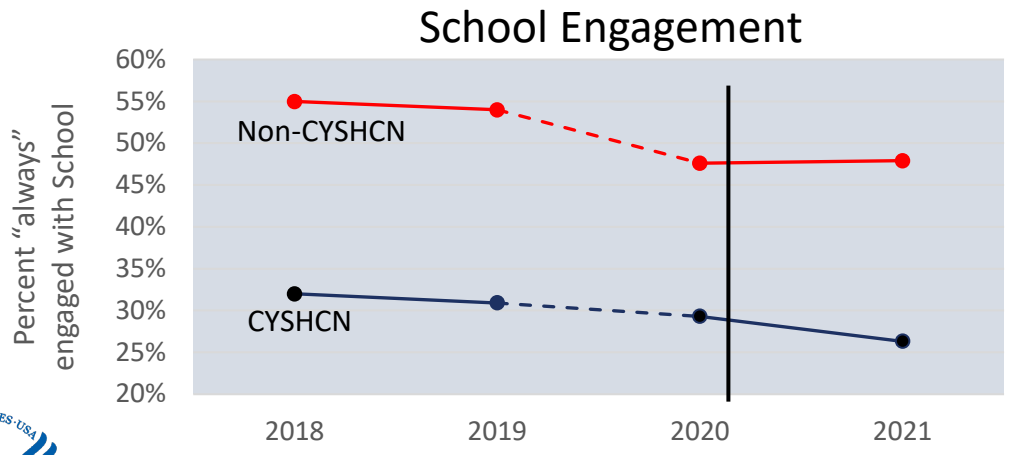
- When we say “CYSCHN,” that means . . .
  - Children and Youth with Special Health Care Needs
  - Children and Youth with Specific Health Care Needs
  - Children and Youth with Social Health Community Needs

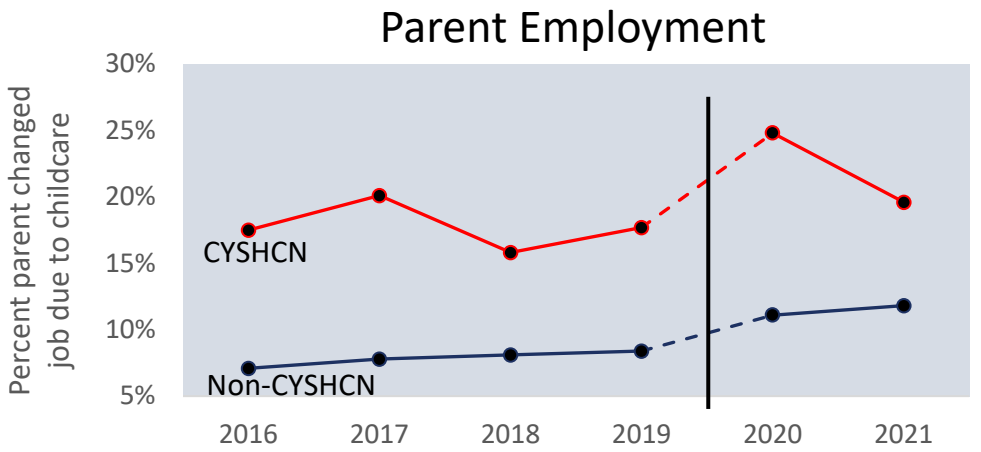
- What do you think is best?

# CYSHCN & Family Quality of Life & Well-Being (MCHB data)



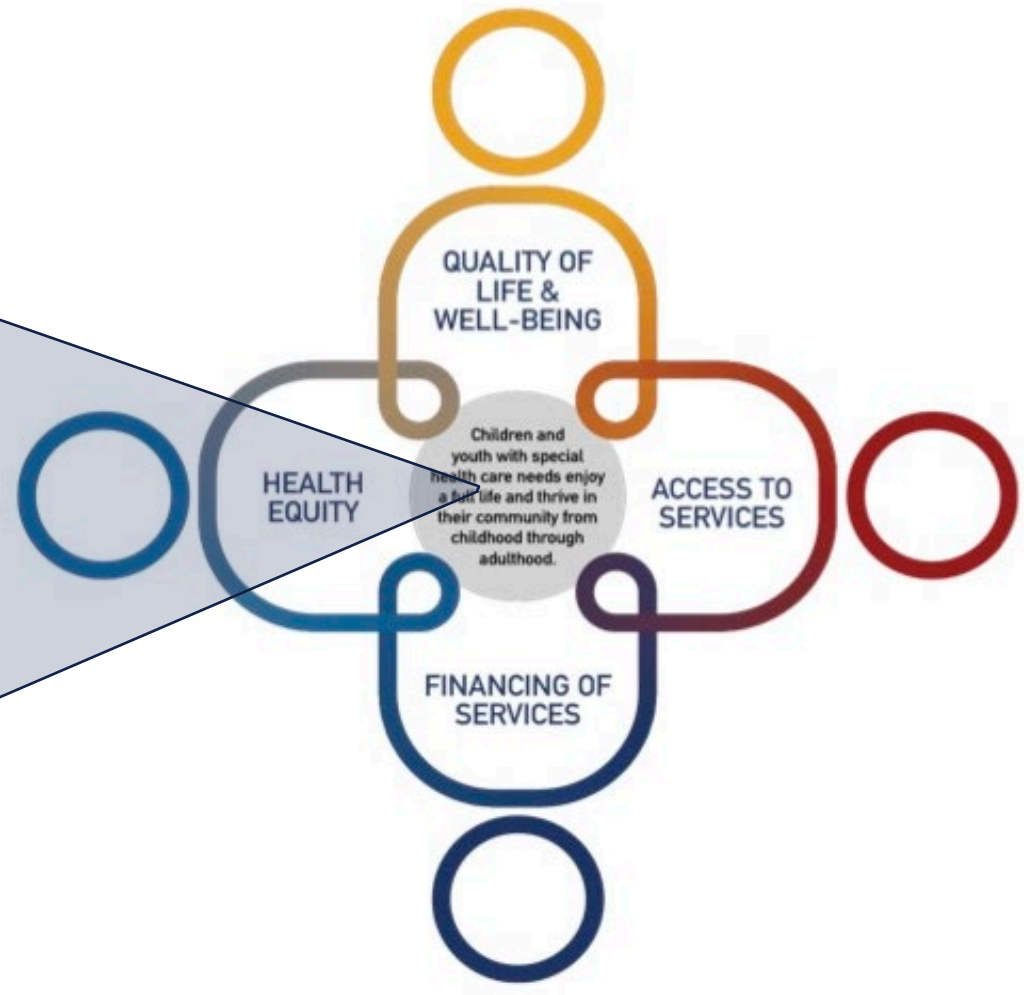



# BLUEPRINT FOR CHANGE FOR CYSHCN

Every family is able to get what their child needs so that they can play, go to school, and become a healthy adult.



# WHAT DO WE DO? "MEASURE WHAT MATTERS"

## Quality of Life

- Universal measures
  - Child thriving
  - Kindergarten readiness
  - Healthy weight
  - Successful transition to adulthood
  - Caregiver well-being
- At least one condition-specific measure

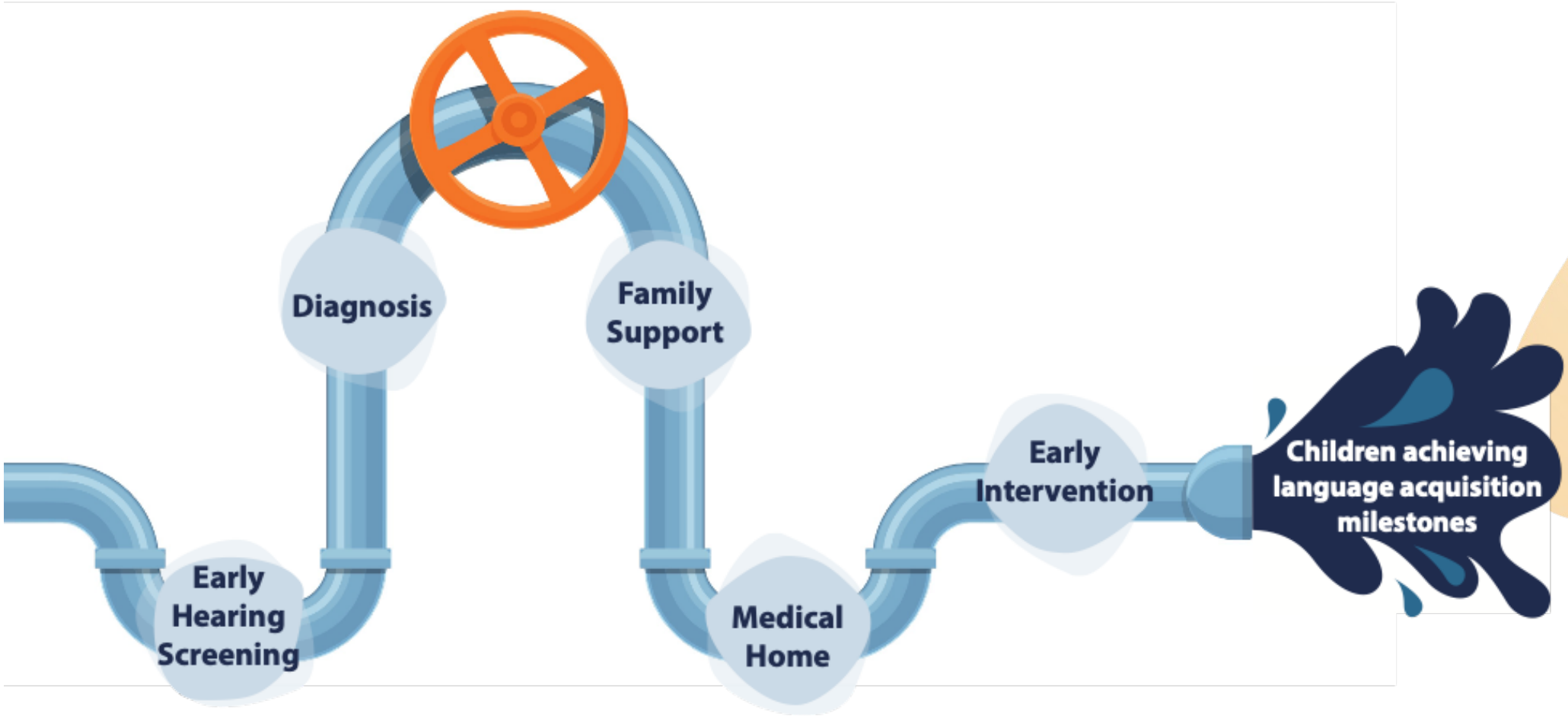
## Population

- Systems-level approach
  - What % of all children, youth, caregivers are achieving the universal measures?
- Equity
  - Do the demographics of numerator match those of the denominator?
  - Disaggregate the data based on historically underserved groups

## Accountable

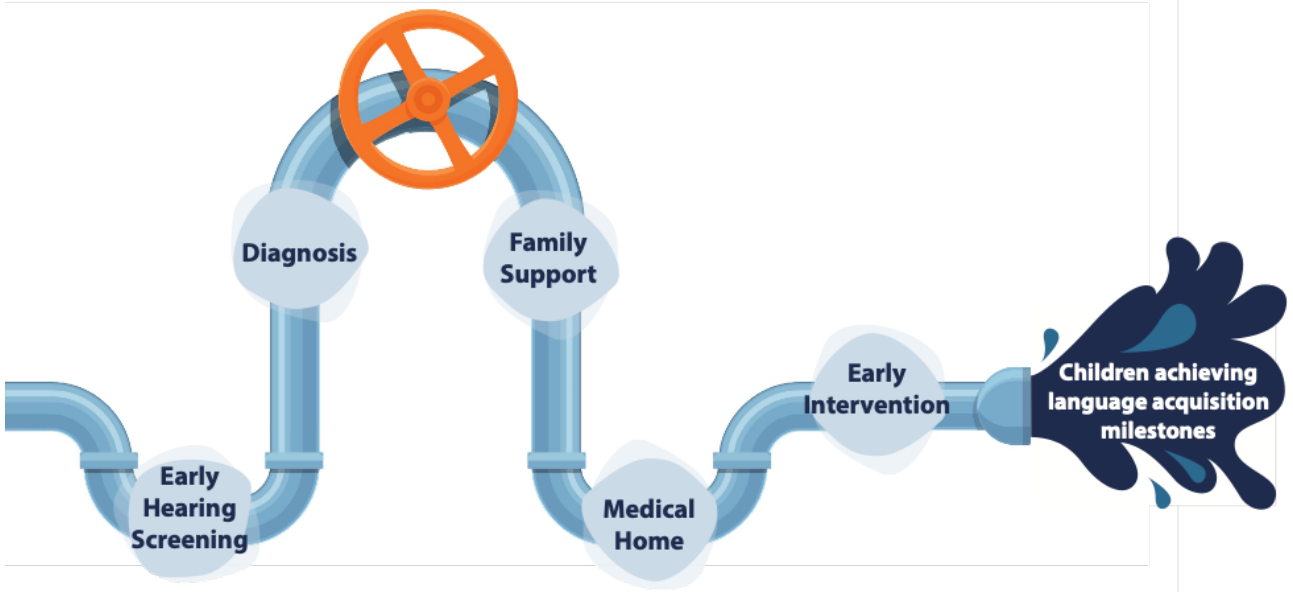
- Organizations plan, track, explain (some SDOH/HRSN not in their control)
- Some organizations (e.g., health insurers) rewarded for improvements in % of people achieving measures?

# EXAMPLE: NEWBORN HEARING SCREENING

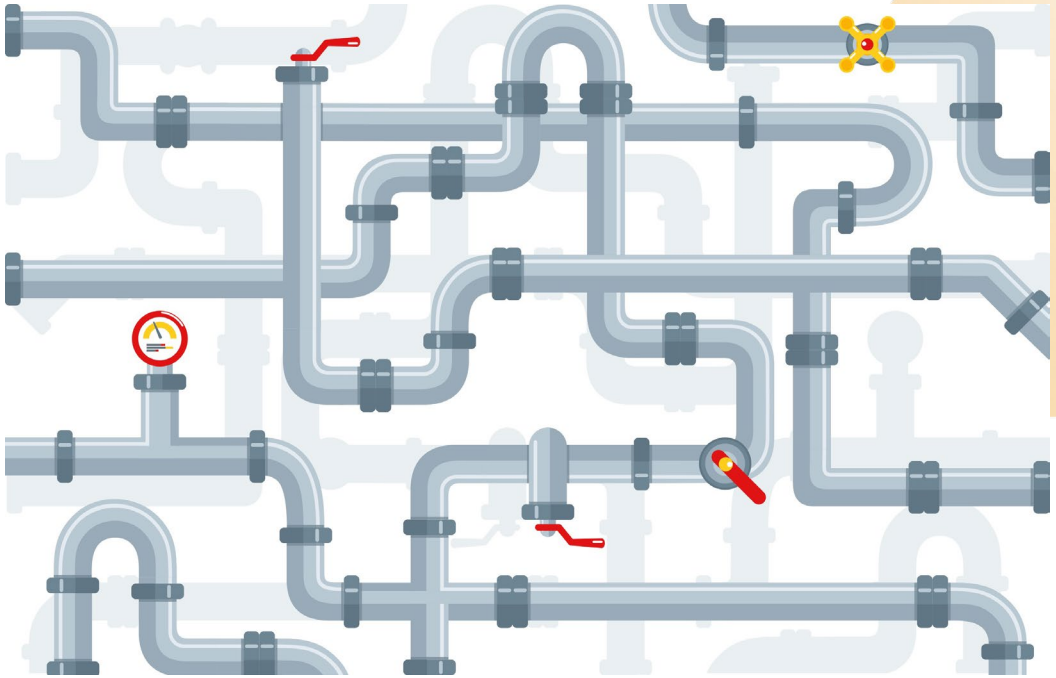


# CHALLENGES

## What Pipeline Could Look Like




## Reality



# FAMILY JOURNEY (through the “pipeline”)

- **Supporting families**
  - Help set goals for a child
  - Make path more predictable
  - Clear obstacles
  - Provide a map and guideposts
  - Teach navigation skills
  - Support them on the journey

# BLUEPRINT IN PRACTICE: FUNDING

- **Family** Engagement and Leadership in Systems of Care (FELSC)—Family Voices
  - Shared definitions/metrics for family engagement
  - Diverse families in systems of care
- CYSHCN **Research** Network (CYSHCNet)—University of Colorado
  - QoL measures for CYSHCN and for caregivers
  - Critical elements of complex care health homes
  - Epidemiology of subpopulations of CYSHCN
- National Center for a **System of Services** for CYSHCN (Blueprint Center)—AAP
  - Partners include Catalyst Center, Family Voices, and Got Transition
  - Implement the Blueprint across state Title V programs and other key partners
- Enhancing Systems of Care for **CMC**—Academy Health
  - Addressing the elevated social needs and risks of CMC
  - Measuring patient/family experience of care
  - Sustainable models of complex care health homes

# CYSHCN EPIDEMIOLOGY

MCHB proposes . . .

1. 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 CYSHCN from 19% to 25% of all children
2. Report data by both CYSHCN and specific **subpopulations**, such as CMC or developmental-behavioral conditions

# National Survey of Children's Health: An Overview

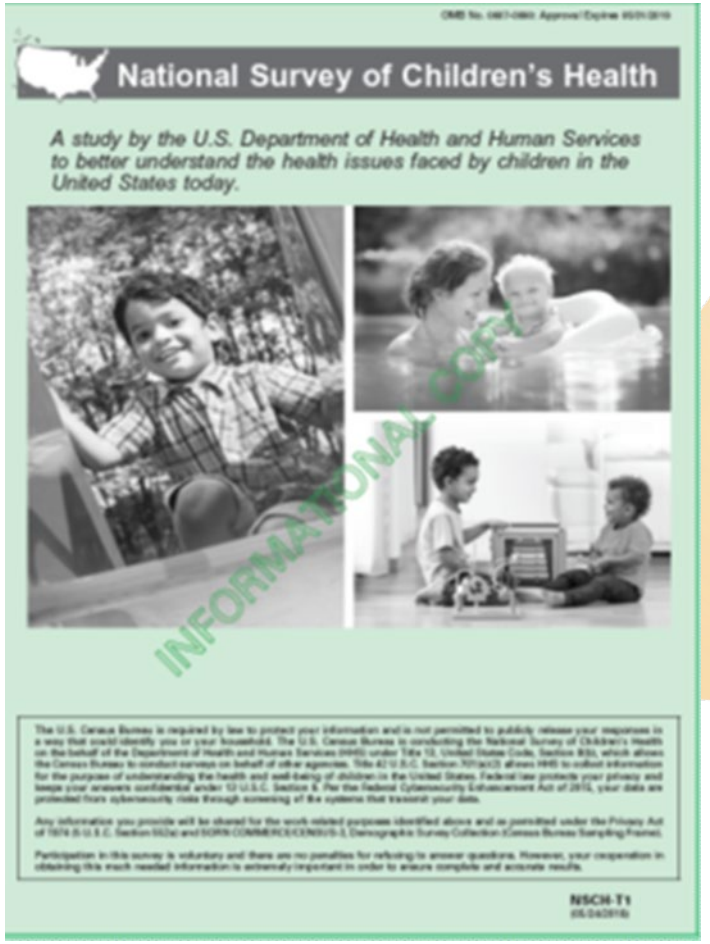
- Sponsored by the **Health Resources and Services Administration's Maternal and Child Health Bureau**; conducted by the U.S. Census Bureau.
  Co-sponsorship by CDC and USDA.

- **Annual**, cross-sectional, address-based survey that collects information via the web and paper/pencil questionnaires.

- Designed to collect information on the health and well-being of **children ages 0-17**, and related health care, family, and community-level factors that can influence health.

- Provides both **national** and **state-level** estimates for all non-institutionalized children ages 0-17 years in the U.S.

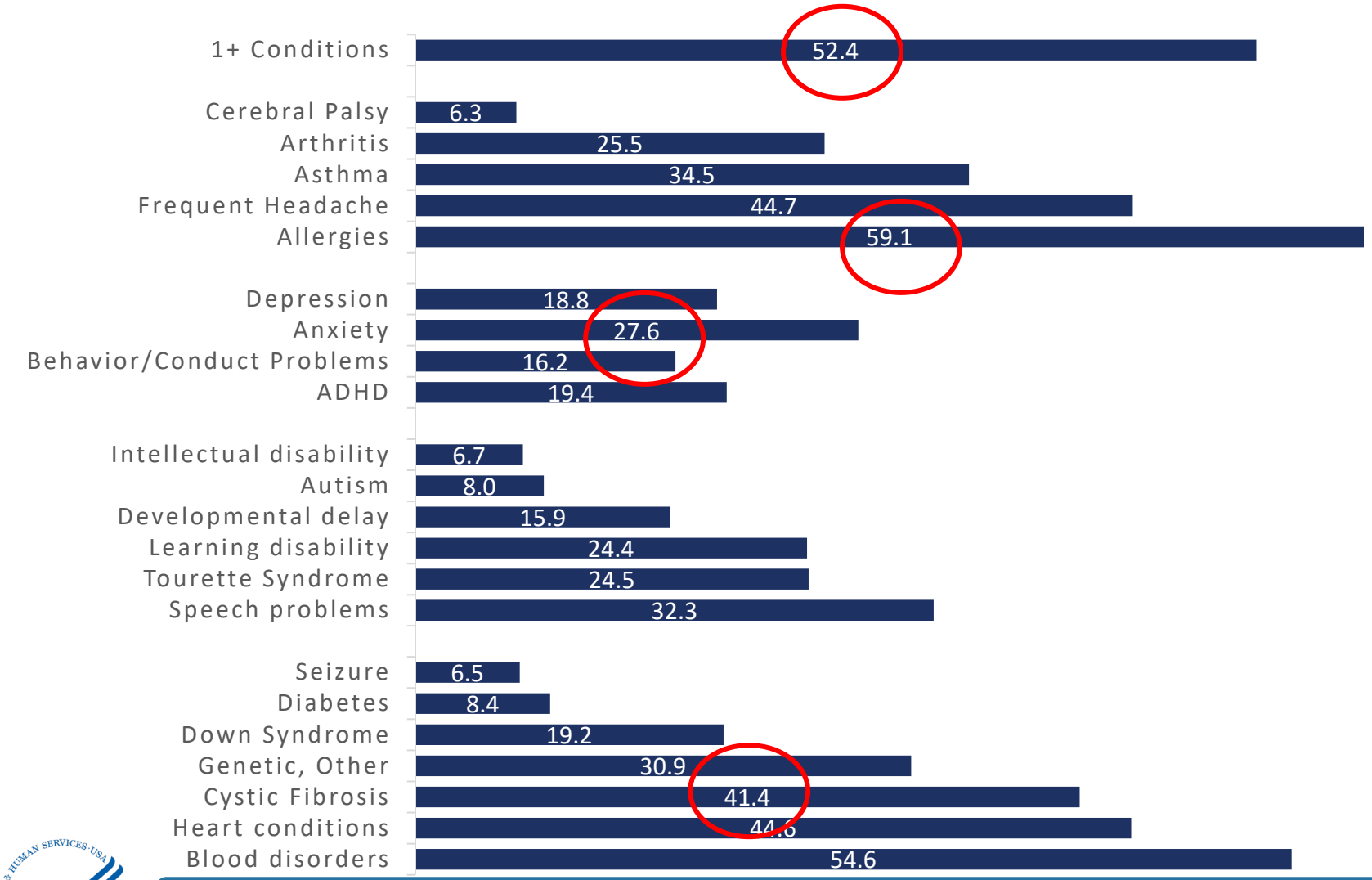
- Data are released annually on **Child Health Day**



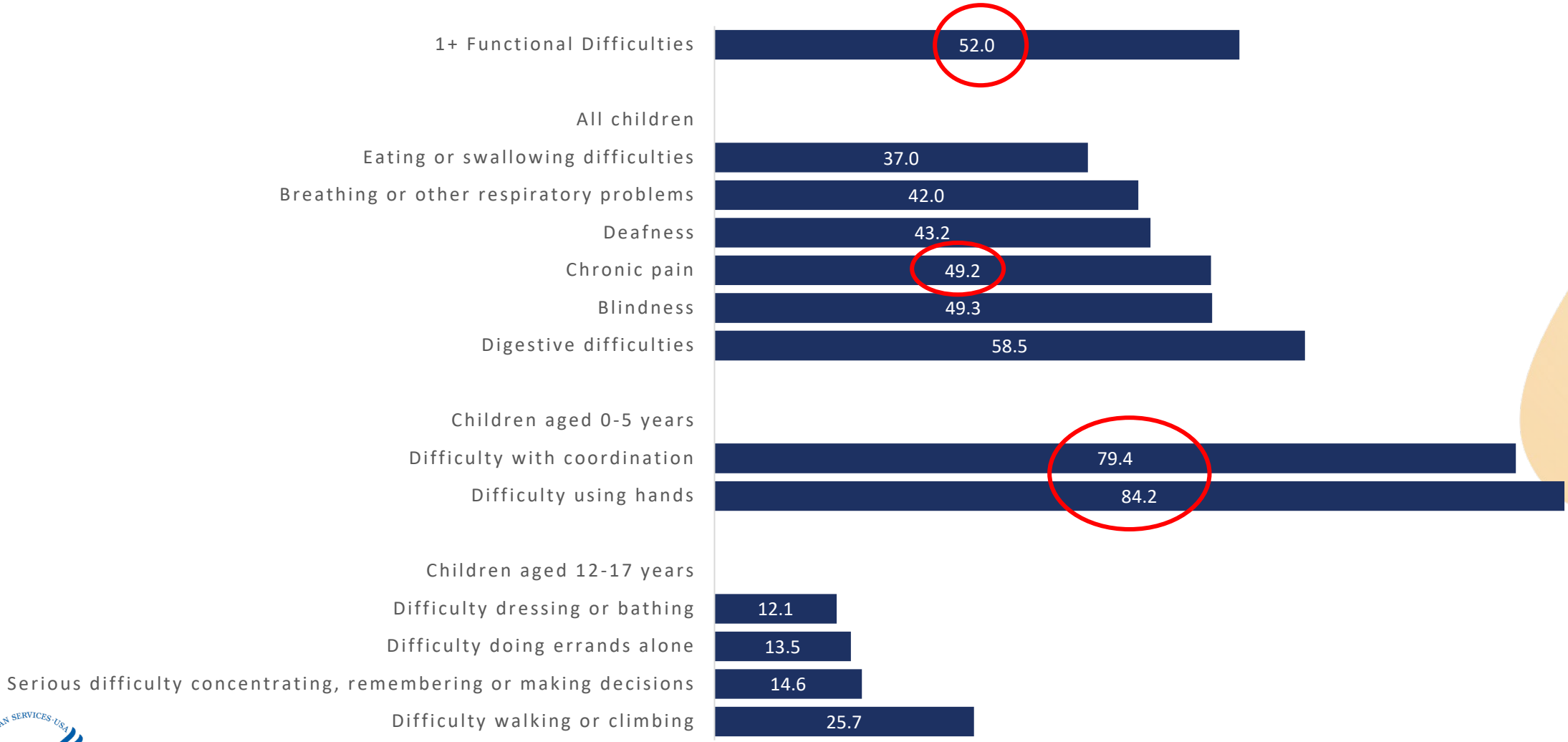
# CSHCN Screener

1. Does your child currently need or use medicine prescribed by a doctor (other than vitamins?)
2. Does your child need or use more medical care, mental health or education services than is usual for most children of the same age?
3. Is your child limited or prevented in any way in his or her ability to do the things most children of the same age can do?
4. Does your child need or get special therapy, such as physical, occupational or speech therapy?
5. Does your child have any kind of emotional, developmental or behavioral problem for which he or she needs to gets treatment or counseling?
    - Is this because of ANY medical, behavioral or other health condition?
    - Is this a condition that has lasted/is expected to last for > 12 months?

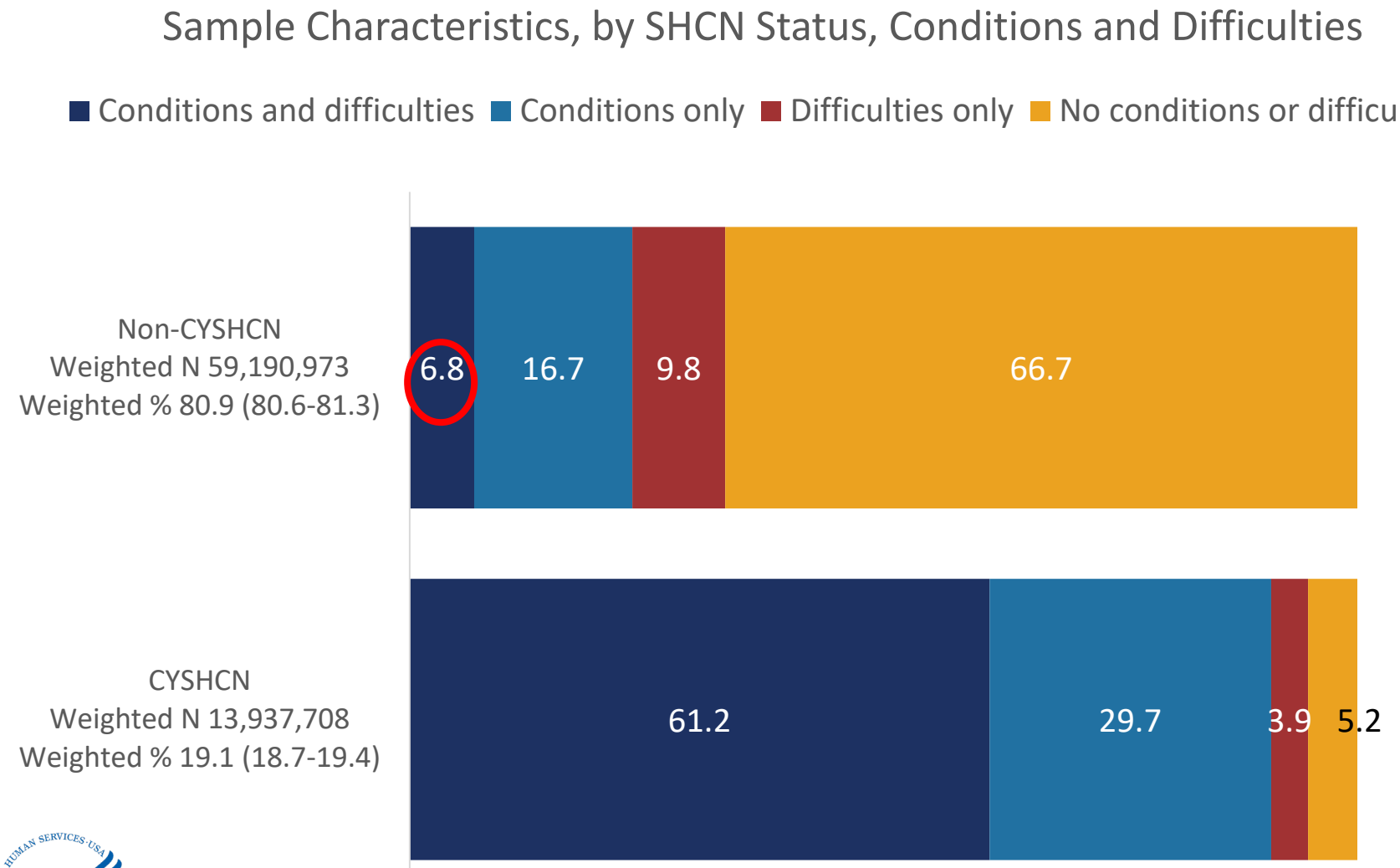
# Results: Conditions among Non-CYSHCN



# Results: Difficulties among Non-CYSHCN

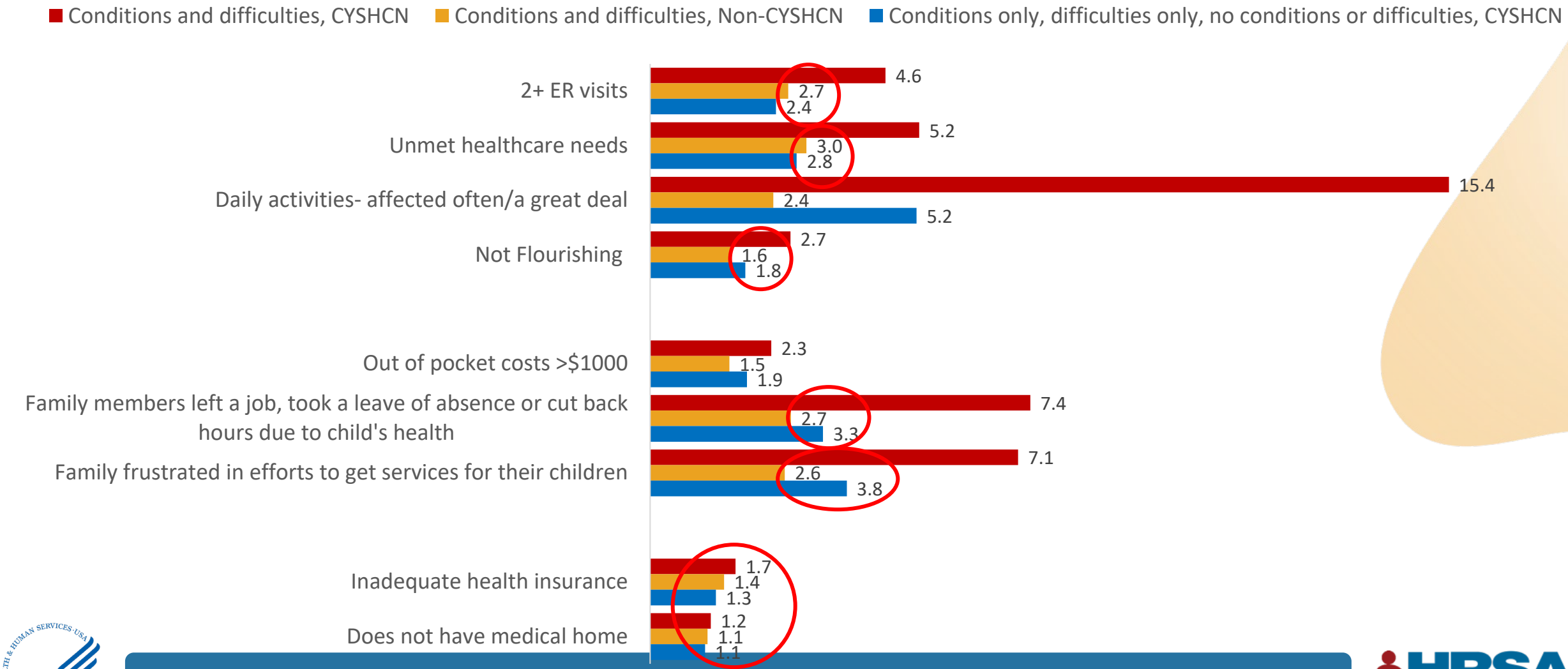


# Children with Dx and Difficulties in “non-CYSHCN”




- 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: Impacts after Adjustment




Learn more at https://mchb.hrsa.gov

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# 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:

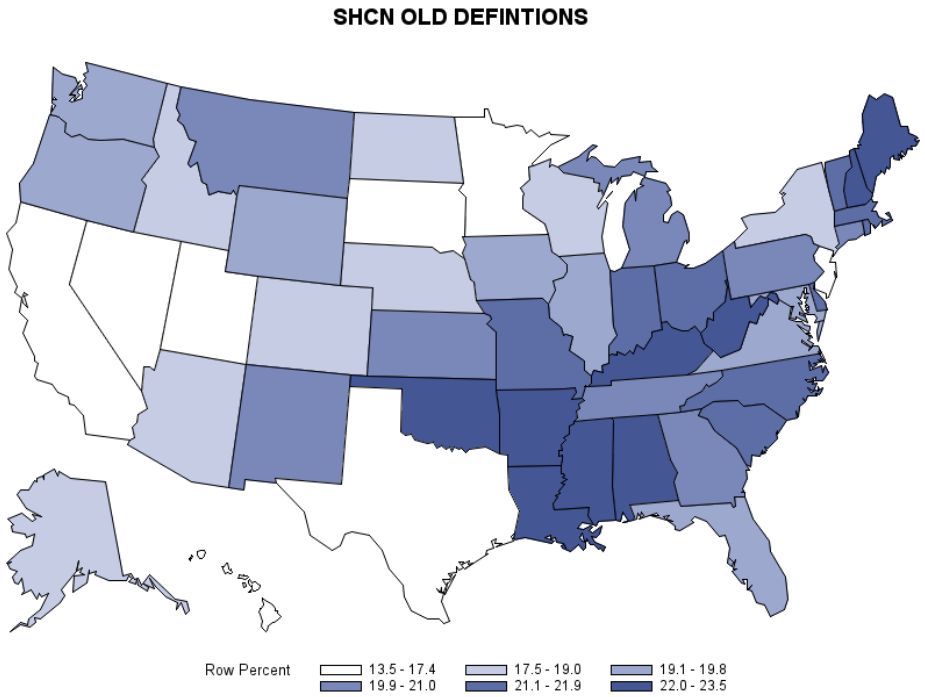
- Younger (0-5 years);
- Female;
- **Hispanic** or non-Hispanic Multiple/Other Race;
- **Uninsured** or privately insured;
- Living in a household with **low educational attainment**.

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

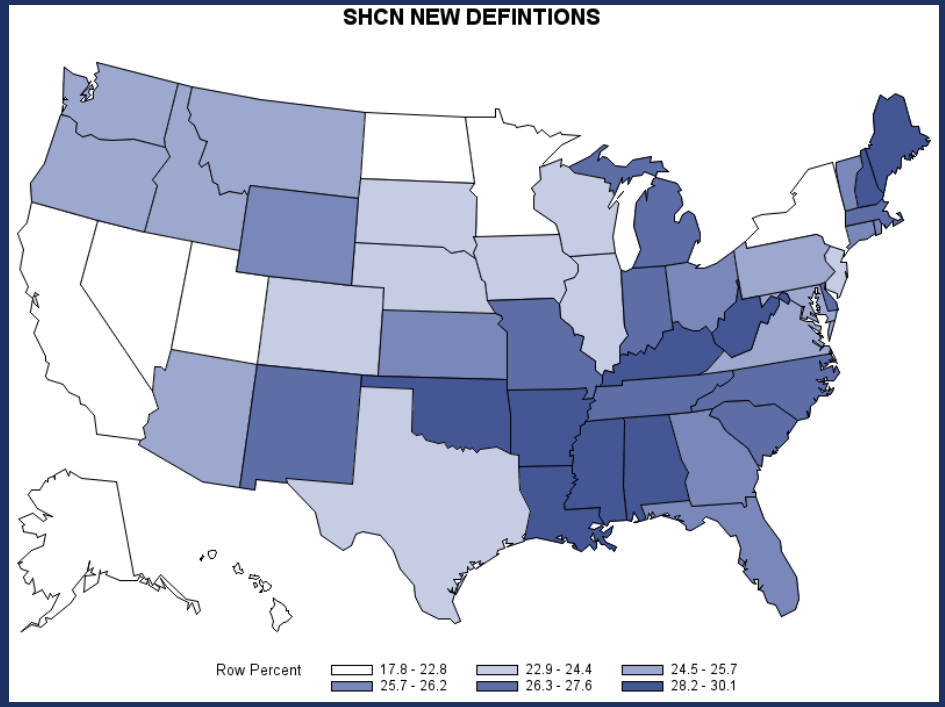
➢ Despite clear utility to the field, the CSHCN Screener demonstrates some important limitations.

# Results: State Prevalence

## Prevalence of CYSHCN – Current Calculation




## Prevalence of CYSCHN – Expanded Calculation

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# Critical Populations within CYSHCN

| | Class 1 | Class 2 | Class 3 | Class 4 |
|---|---|---|---|---|
| Need help coordinating | ↑ | | | ⇧ |
| Problems paying for care | ⇧ | | | ↑ |
| Time delivering health care at home | ↑ | | | |
| Time coordinating care | ⇧ | | | |
| Need medical specialists | ↑ | | | ↑ |
| ED visits | ⇧ | | | ↑ |
| Hospitalizations | | | | ⇧ |
| Behavioral impact | ↑ | | | |
| Developmental impact | ↑ | | ↑ | |
| Intellectual impact | ⇧ | | | |
| Language impact | ↑ | | ↑ | |
| Learning impact | ↑ | | ↑ | |
| Consistent and great deal ADL impact | ↑ | | ↑ | ↑ |
| Global health assessment (good-excellent) | | | | |

Needs

Health Care Use

Fxn Limitations

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# Critical Populations within CYSHCN:
## *Making sense of a larger prevalence number*

**1. CMC**
- Both medical and functional impact
- **~1.5% of children**, 5% of CSHCN

**2. Low impact**
- **~16% of children**
- 67% of CSHCN

**3. Functional**
- "Behavior & development"
- **~3.5% of children**, 14% of CHSNC

**4. Medical**
- "Medically fragile" – ED and hospital
- **~3.5% of children**, 14% of CSHCN

# Implications for proposed changes?

## Refine How We Count CYSHCN in the NSCH

- Increase CYSHCN from about 19% to about 25% of all children in the US

## Identify Critical Populations within CYSHCN

- Routinely report NSCH data by both total CYSHCN (as current), and according to
- Key populations within the overall CYSHCN population, such as CMC.

NCSH = National Survey of Children's Health

Learn more at https://mchb.hrsa.gov

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# Measuring what Matters: *Discussion*

- How are you currently using the NSCH?
  - If not using the NSCH to inform your work, what data sources are you using?
  - What is your comfort level working with the NSCH?
- If these changes are in place, how does this impact your work?
  - What are the benefits of these proposed changes?
  - What are the potential challenges of changes to NSCH?

# Break

# Family Partnership and Engagement: *Reaching Minoritized Families and Communities*

# Discussion

- How are families engaged in your program and across all MCH?
- How are you building your “bench strength” across family and community engagement?
- How are you working with young families who are new to navigating the system?
- How does your programs’ vision change to prioritize including those hard-to-reach communities and families?

# Population Health and Medical Home: *How do they Align?*

Learn more at https://mchb.hrsa.gov

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# Population Health and Medical Home: How do they Align?

## *Federal State Title V Partnership Meeting*

November 5, 2023

Debra Waldron, MD, MPH, FAAP
Senior Vice President,
Healthy and Resilient Children Youth and Families
Alex Kuznetsov, Senior Manager
Disabilities and Special Health Care Needs
American Academy of Pediatrics

American Academy of Pediatrics
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# Acknowledgement

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.

# Agenda

- Introduce the National Center for a System of Services for CYSHCN
- Describe how Title V programs measure access to medical home
- Briefly review core tenets of medical home
- Discuss medical home population health approaches
- Engage in information sharing and peer-to-peer learning; identify technical assistance needs

# National Center for a System of Services for CYSHCN

**Goal:** Advance systems of services for CYSHCN through Blueprint implementation.

## What We Do

One-on-one technical assistance

Tools

Training

Strategies

Connections to peers and experts

# Why does the medical home matter?

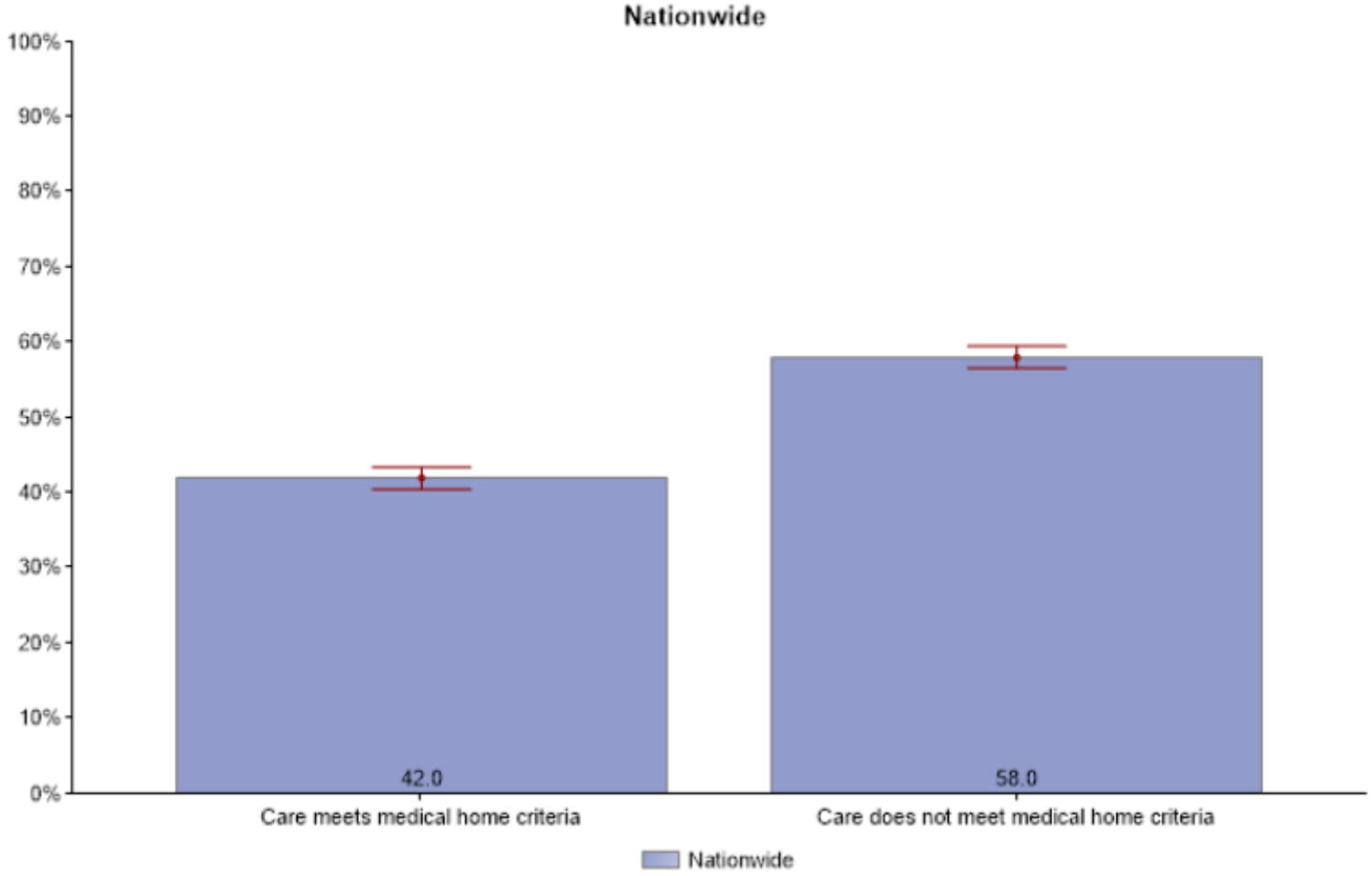
- Standard of care for all children, including CYSHCN
- Key driver of comprehensive system of services for CYSHCN
- Proposed universal national performance measure (NPM) for Title V Programs
  - Focus on access and quality of primary and preventive care
  - Intended to drive improvement in CYSHCN systems of care national outcome measure

# NPM 11: Medical Home (Proposed Universal Measure)

- % of children with and without special health care needs, ages 0 through 17, who have a medical home
- Composite measure based on five components constructed from a total of 16 survey items.
  - Personal doctor or nurse
  - Usual source of sick care
  - Family-centered care
  - Problems getting needed referrals
  - Effective Care Coordination when needed
- **Blueprint for Change efforts can fall within the medical home NPM**

## NPM 11: Percent of children with special health care needs who have a medical home

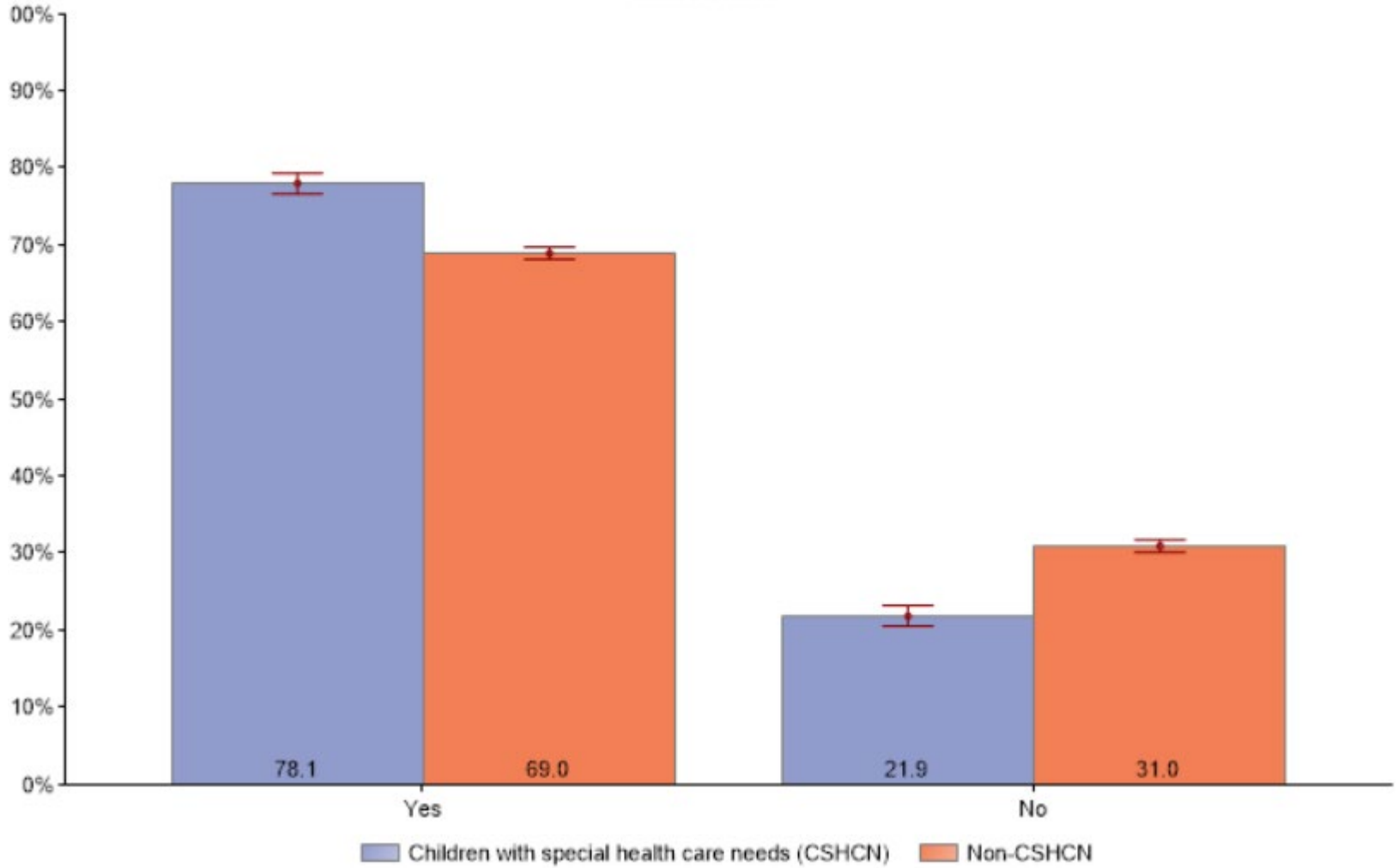
Children with special health care needs ages 0-17 years



## Medical Home Component: Children with a personal doctor or nurse

Children age 0-17 years

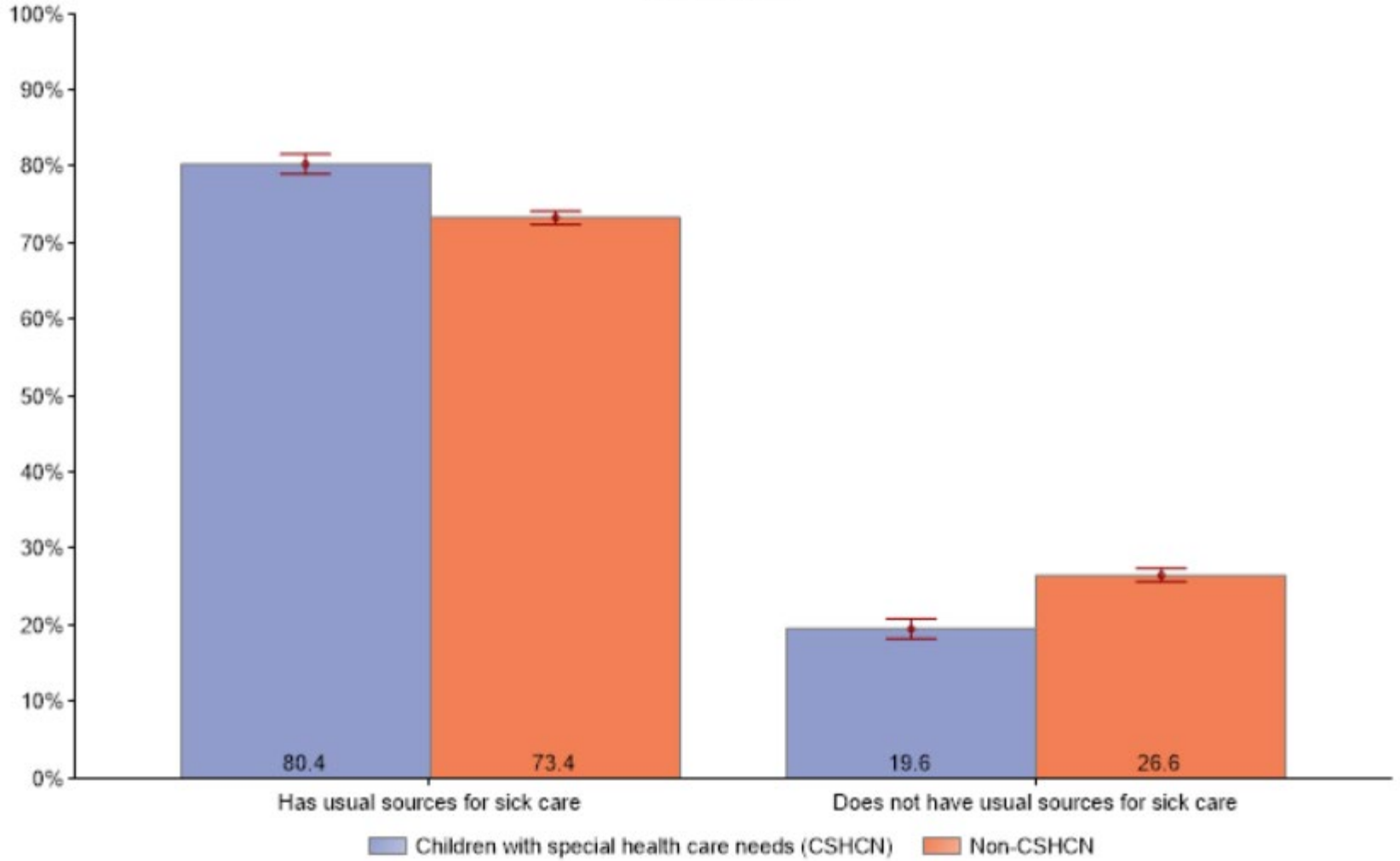
Nationwide



## Medical Home Component: Usual source for sick care

Children age 0-17 years

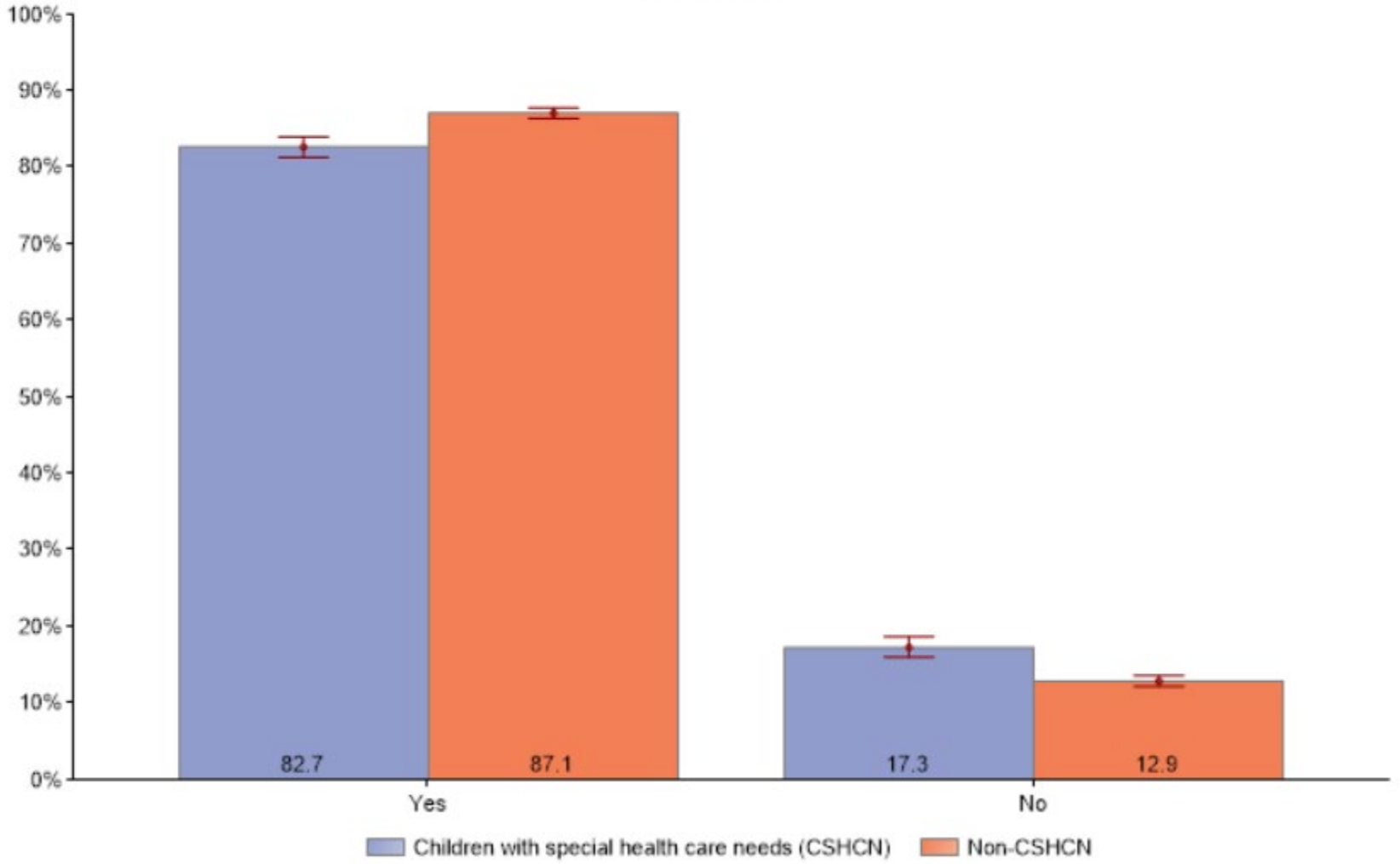
Nationwide



## Medical Home Component: Family-centered care

Children age 0-17 years who had a health care visit in the past 12 months

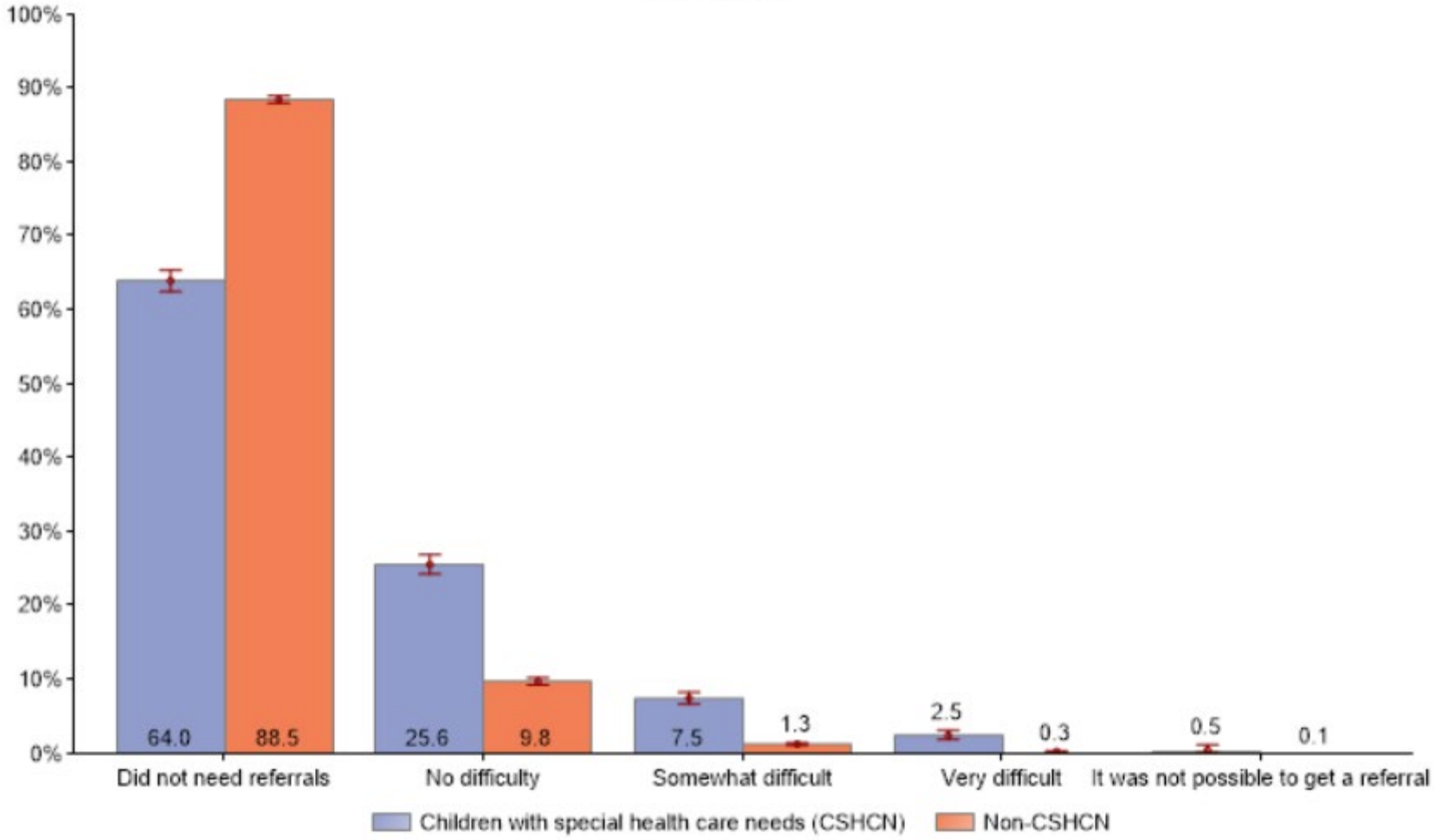
**Nationwide**



## Medical Home Component: Difficulties getting referrals to see any doctors or receive any services

Children age 0-17 years

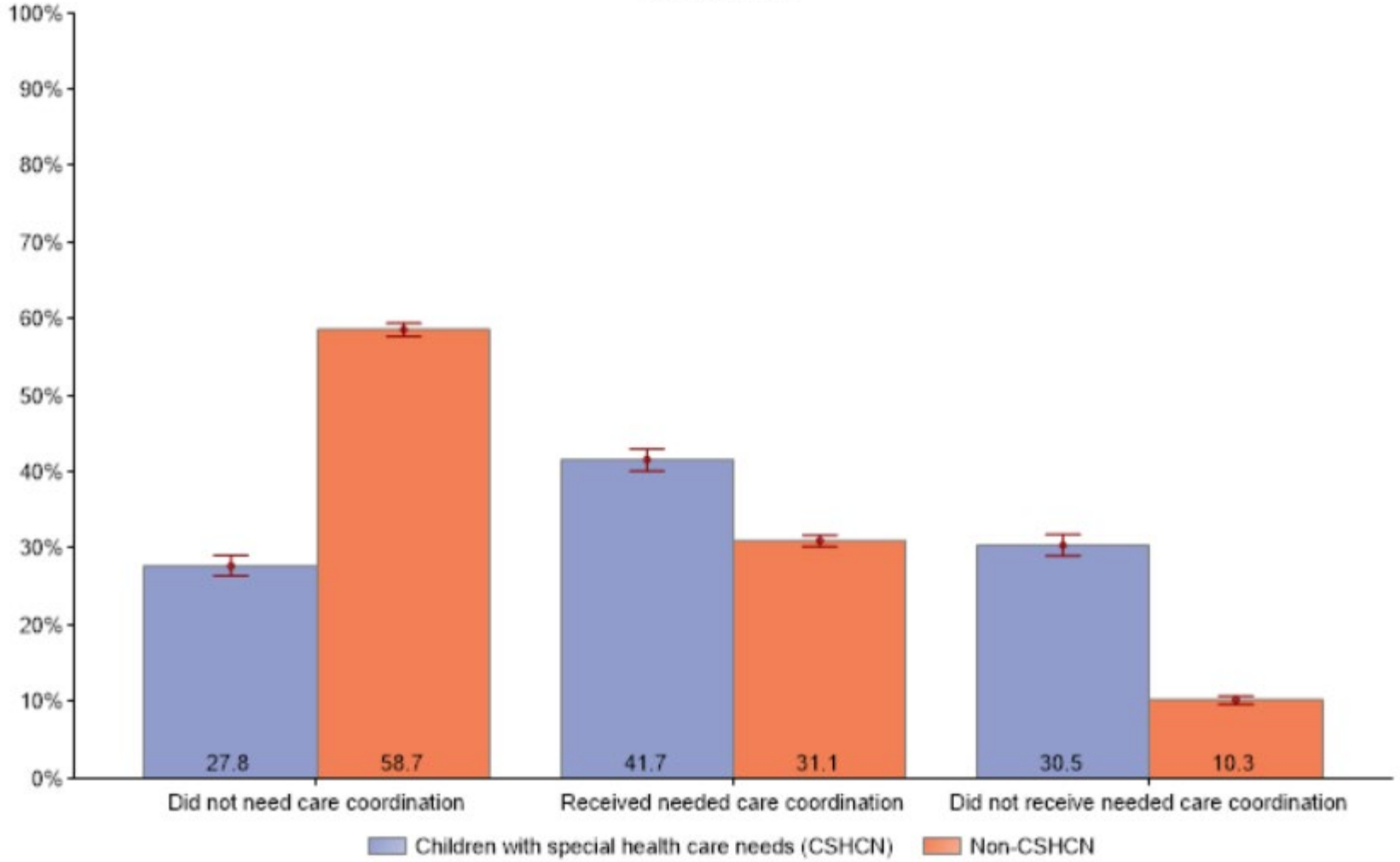
Nationwide



## Medical Home Component: Effective care coordination

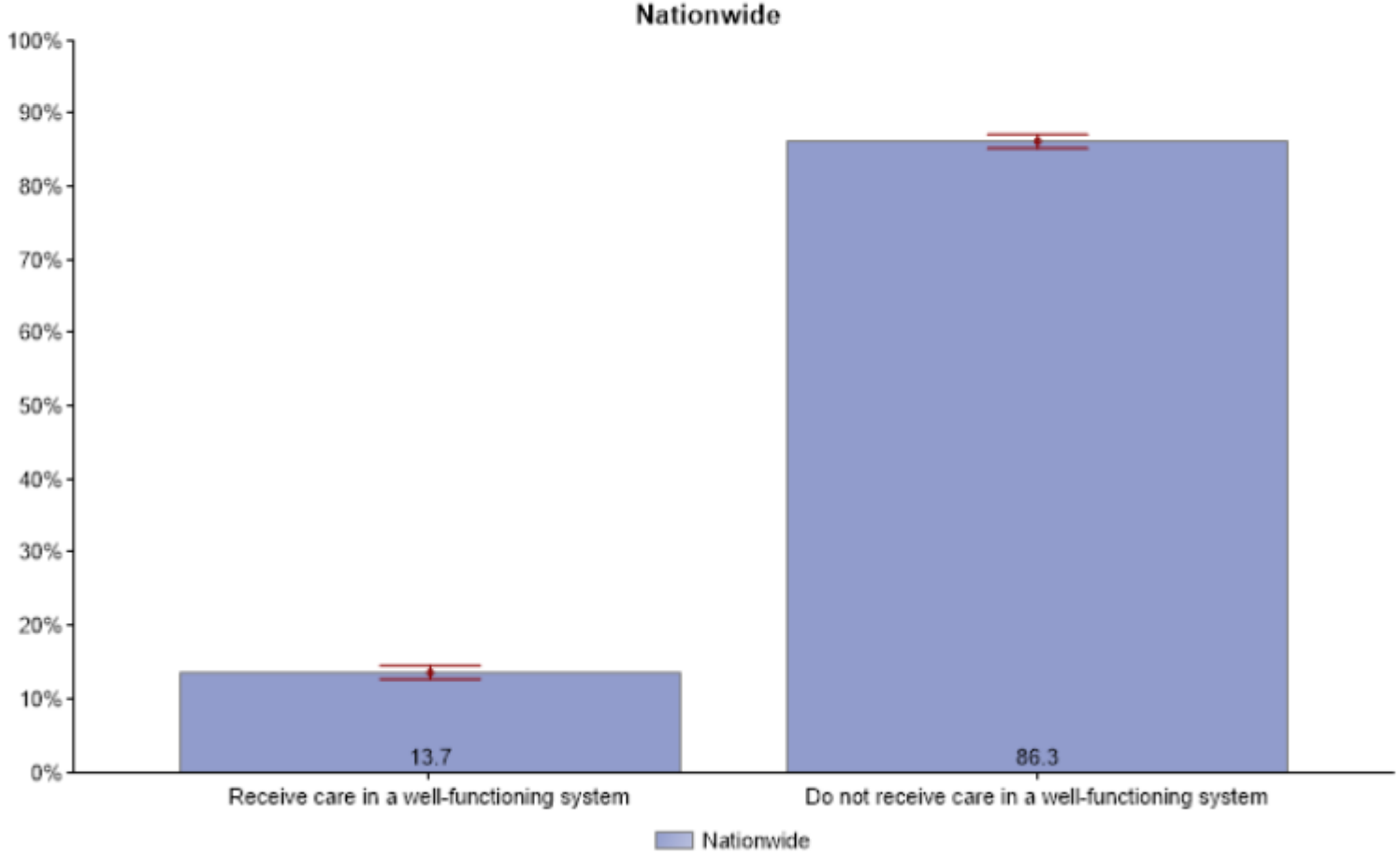
Children age 0-17 years

Nationwide

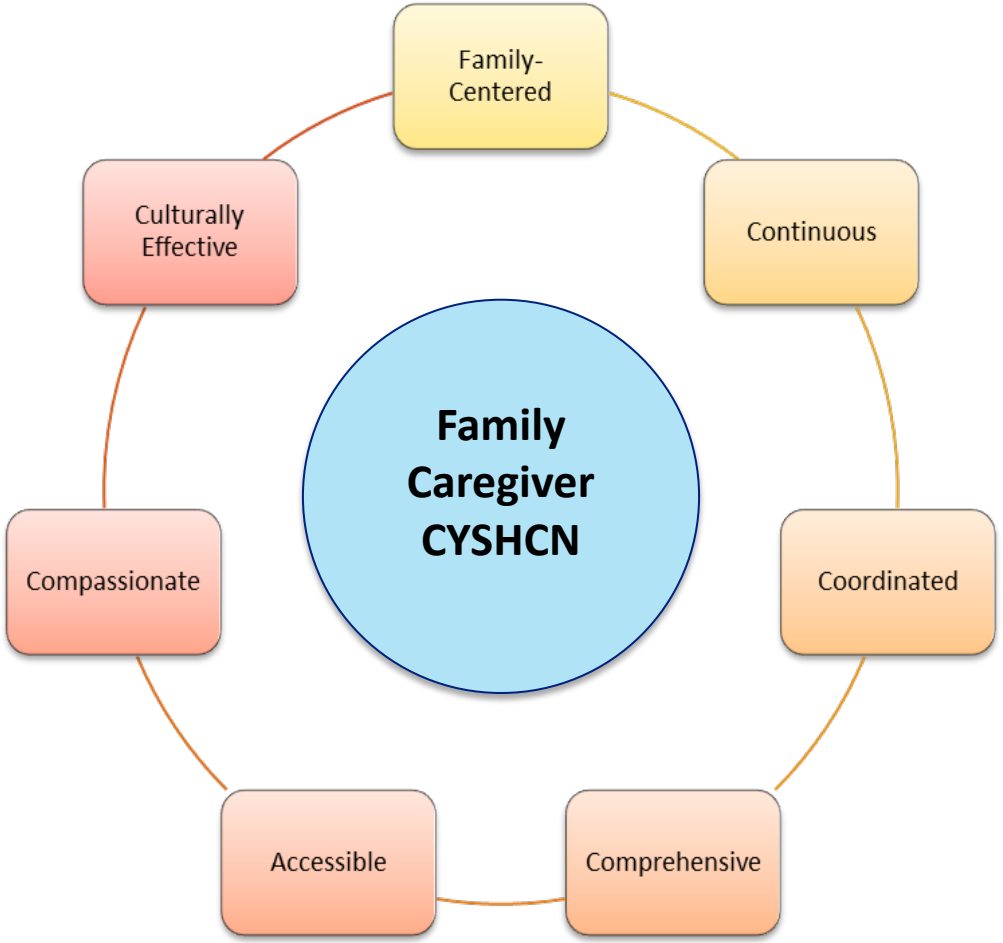


## NOM 17.2: Percent of children with special health care needs who receive care in a well-functioning system

Children with special health care needs ages 0-17 years



# Core Tenets of the Medical Home Model



# Medical Home Implementation Advances the Blueprint for Change

- A Title V program educates families/caregivers on how to access non-emergency medical transportation through Medicaid for CYSHCN medical appointments.
  - Blueprint: Access to care, financing, equity
  - Medical home: Accessible, family-centered care, coordinated
- A Title V program provides training for pediatric providers on disability justice and anti-ableism.
  - Blueprint: Access to care, equity, quality of life
  - Medical home: culturally effective, accessible, family-centered

# Population Health Strategies for CYSHCN

- **Definition:** Population health strategy for CYSHCN intends to improve the health and well-being of an entire group or subgroup. These strategies occur at the policy or systems level and are measurable over time. They are designed to improve health equity and often focus on social and environmental factors.

# Medical Home and Population Health

- Community health workers
- Connections to peer supports/lived expertise organizations
- Advisory groups/steering committees at the state level
- Collaborating with Medicaid
- Non-emergency medical transportation access
- Language access
- Workforce development

# Medical Home and Population Health

- Community referral system for families and providers
- Statewide registry to track screening
- Educational campaigns for providers, health systems, families
  - Particularly around emerging public health needs (example: COVID-19, Medicaid Unwinding, immunizations, etc.)
- **Our National Center can help Title V programs with medical home population health approaches. What support would be helpful to you?**

# We Can Help!

- National Center for a System of Services for CYSHCN
- Blueprint4CYSHCN@aap.org
- No wrong door – feel free to contact us or any of our Consortium partners:
  - AAP
  - Family Voices
  - Got Transition
  - Catalyst Center

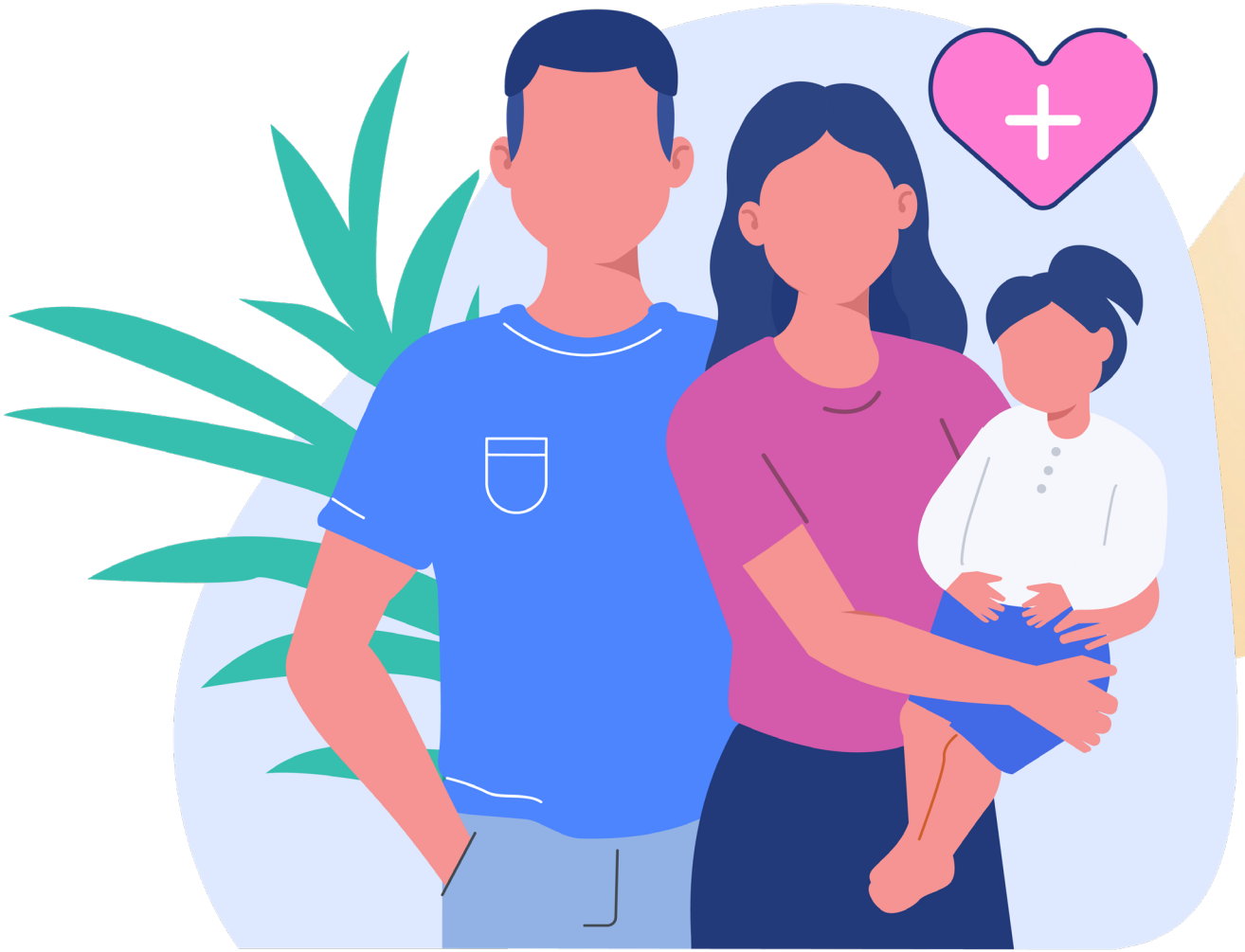
# Discussion Questions

- What are you states/jurisdictions currently doing around medical home population health approaches?
- What challenges are you encountering?
- How have you begun to think about Blueprint Implementation in the context of the medical home?

# Interactive Activity: Medical Home and the MCH Pyramid of Services

- Use sticky notes to share your work related to medical home
- Place sticky notes with activities along the corresponding level of services on the MCH pyramid:
  - Direct
  - Enabling
  - Population health services and systems

# Wrap-up and Next Steps



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