



Blueprint for Change: EHDI as a Role Model for a Well-Functioning System of Services for CYSHCN

2023 Early Hearing Detection & Intervention Conference

March 6, 2023

Jeffrey P. Brosco, MD, PhD

Director, Division of Services for Children with Special Health Needs

Maternal and Child Health Bureau

Vision: Healthy Communities, Healthy People



Outline

1. Who am I?
2. Why EHDI?
3. What are we (MCHB and you) doing?
Blueprint for Change
4. Where are we (MCHB and you) going?
5. How will we (MCHB and you) get there?



Outline

1. Who am I?

2. Why EHDI?

3. What are we (MCHB and you) doing?

Blueprint for Change

4. Where are we (MCHB and you) going?

5. How will we (MCHB and you) get there?



From the Outside to the Inside (Jeff)

- Pediatrician - General pediatrics and developmental-behavioral pediatrics
- Maternal and Child Health Bureau (MCHB) Related Experience
 - State (non-government): LEND Director (Miami), PMHCA, etc.
 - National: ACHDNC Member, NBS Translational Research Network (NBSTRN), Blueprint Workgroup, CMC CollN, etc.
- State Government Experience
 - Deputy Secretary of Health (FL); Title V CYSHCN Director (FL)
- Scholarship – History and Health Policy



Outline

1. Who am I?
- 2. Why EHDI?**
3. What are we (MCHB and you) doing?
Blueprint for Change
4. Where are we (MCHB and you) going?
5. How will we (MCHB and you) get there?



Why EHDI as Role Model for CYSCHN System?

- Every year:
 - 1-3 of every 1,000 children are born deaf or hard of hearing in one or both ears.¹
 - By kindergarten, the prevalence of children identified as deaf or hard of hearing increases to approximately 3-6 out of every 1,000 children.²
 - Over 90% of deaf and hard of hearing children are born to hearing parents.³
- The first few years of a child's life are the most important time for a child to learn language.
- Hearing difficulties can impact a child's language, social-emotional, and cognitive development during this critical period.

1: Centers for Disease Control and Prevention. (2022, September 29). 2020 Summary of Diagnostics Among Infants Not Passing Hearing Screening. Centers for Disease Control and Prevention. Retrieved from <https://www.cdc.gov/ncbddd/hearingloss/2020-data/06-diagnostics.html>. 2: Bamford J, Fortnum H, Bristow K, Smith J, Vamvakas G. (2007). Current practice, accuracy, effectiveness and cost-effectiveness of the school entry hearing screen. *Health Technology Assessment*, 11(32). 3: Mitchell RE, Karchmer MA. Chasing the mythical ten percent: Parental hearing status of deaf and hard of hearing students in the United States. *Sign Language Studies*. 2004;4(2):138-163.



EHDI Legislative Authority

- 2022 Reauthorization:
 - Reauthorizes EHDI through 2027
 - Includes GAO study of EHDI programs



Early Hearing Detection and Intervention Act of 2022, Public Health Service Act, Title III, Section 399M (as added by P.L. 106-310, Sec. 702 and reauthorized by P.L. 117-241, Sec. 2)

EHDI's Impact



98 percent of U.S.-born infants are now screened for hearing loss usually before leaving the hospital



Since 2005 over 84,000 D/HH infants in the U.S. have been identified early



\$200 million in education costs are saved each year in the U.S. due to newborn hearing screening



Center for Disease Control and Prevention. (2022). *CDC's Progress in Detecting Infant Hearing Loss* [Fact sheet]. <https://www.cdc.gov/ncbddd/hearingloss/documents/hearing-factsheet-508.pdf>

Ongoing Challenges

1. Timeliness of diagnosis and enrollment into early intervention
2. Family engagement and D/HH adult consumer involvement
3. Provider knowledge about the EHDI system and 1-3-6 guidelines
4. Coordination with EI programs and other community-based services and supports
5. States and territories experience unique, local challenges
6. Long-term outcome data for D/HH children
7. Geographic, racial, and socioeconomic disparities



Biggest Challenge?

“Language access for children who are deaf or hard of hearing in the early years. . . can have such a lasting impact on a child’s language and cognitive skills.”

Day Al-Mohamed, Director of Disability Policy
Domestic Policy Council, White House



Outline

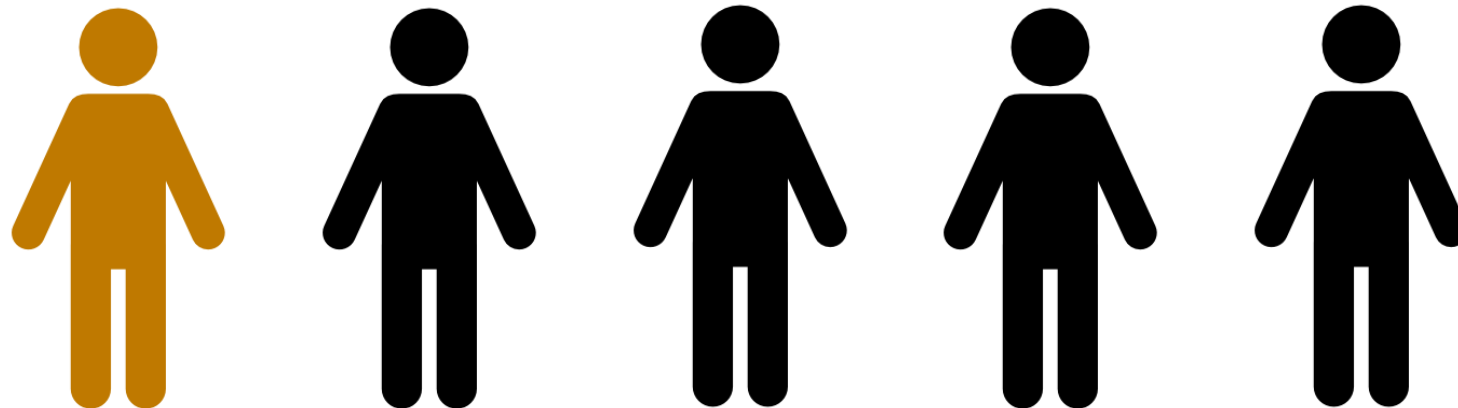
1. Who am I?
2. Why EHDI?
- 3. What are we (MCHB and you) doing?
*Blueprint for Change***
4. Where are we (MCHB and you) going?
5. How will we (MCHB and you) get there?



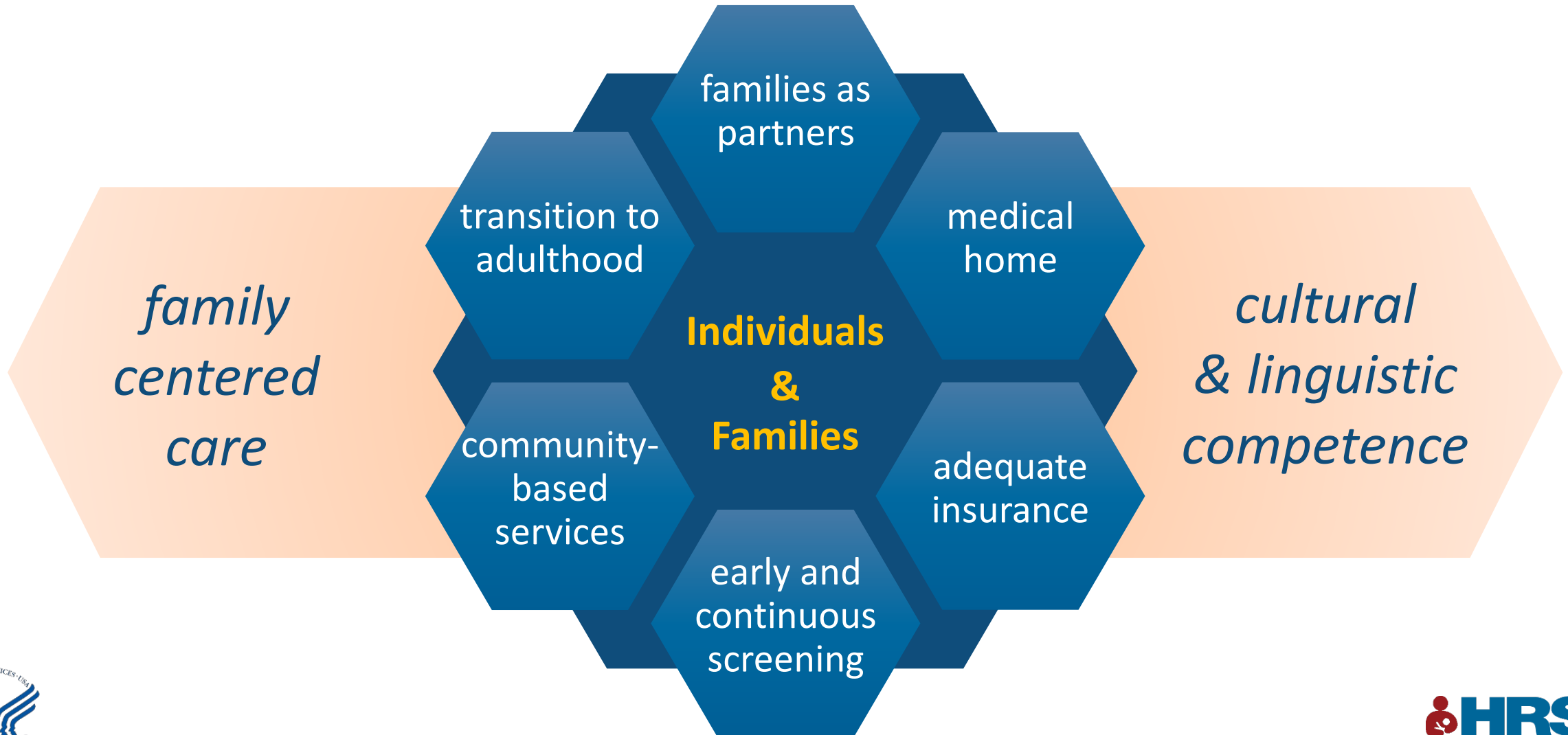
D/HH Are One Key Population Within CYSHCN

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.



Six Indicators of a Well-Functioning System



MCHB Strategic Plan

Mission

To improve the health and well-being of America's mothers, children, and families.

Vision

Our vision is an America where all mothers, children, and families thrive and reach their full potential.

MCHB Goals

ACCESS

Assure access to high-quality and equitable health services to optimize health and well-being for all MCH populations.

EQUITY

Achieve health equity for MCH populations.

CAPACITY

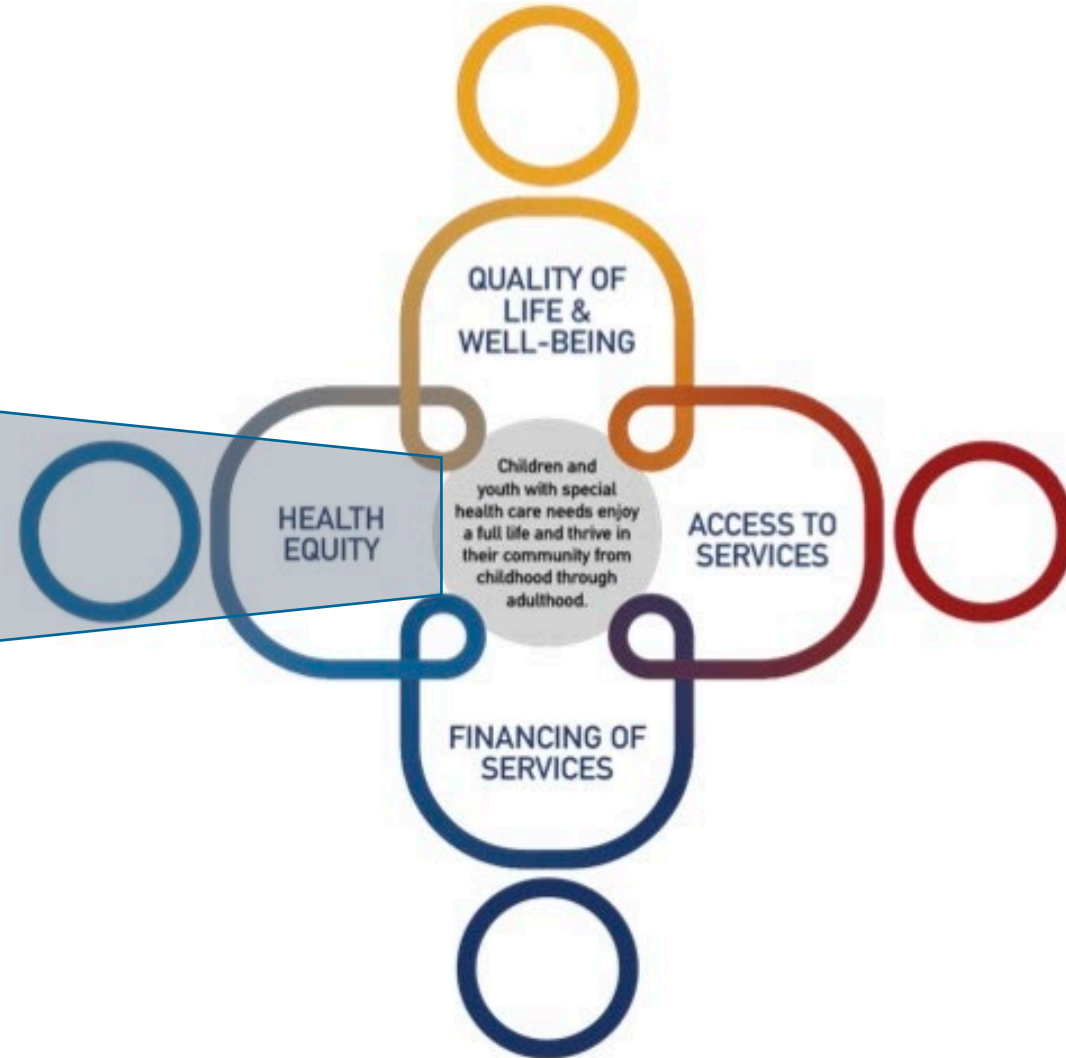
Strengthen public health capacity and workforce for MCH.

IMPACT

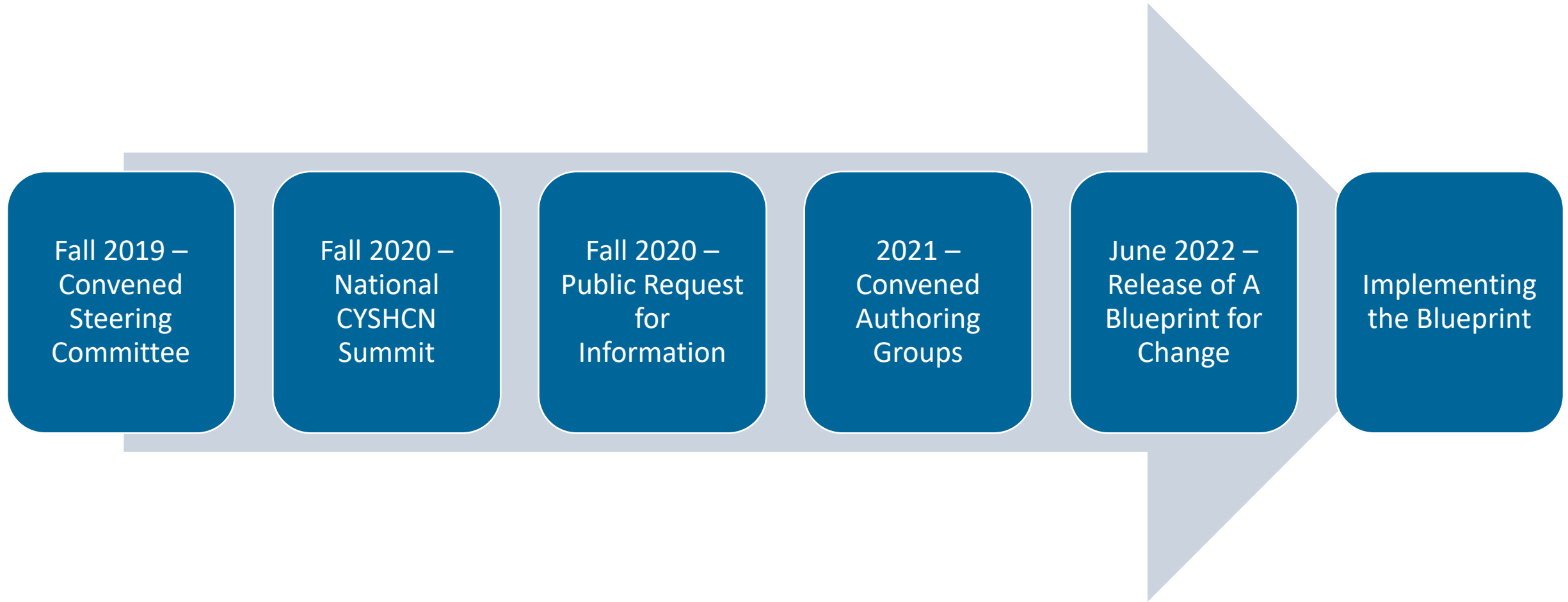
Maximize impact through leadership, partnership, and stewardship.

MCHB *Blueprint for Change for CYSHCN*

Children and youth with special health care needs enjoy full lives and thrive in their communities from childhood through adulthood

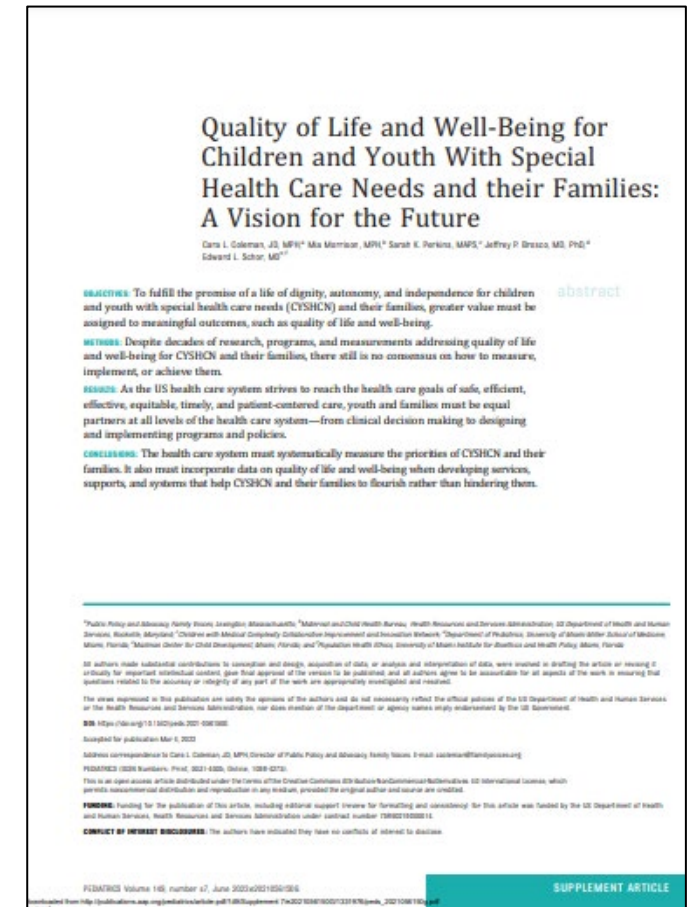


Development of the Blueprint



What's New in the Blueprint? Quality and Equity

- **QOL: Child and caregiver well-being**
 - What families tell us really matters
 - Children thrive when caregivers are healthy
 - Appropriate measures/outcomes point the system in the right direction, even if imperfect
- **EQUITY: Every child is thriving**
 - Fair and equitable outcomes
 - One approach: “targeted universalism”
 - Ensure that historically underserved and/or marginalized populations have equitable outcomes



Coleman et al, “Quality of Life and Well-Being for CYSHCN and their Families” *Pediatrics* June 2022; Houtrow et al., “Health Equity for CYSHCN” *Pediatrics* June 2022.



***Blueprint* GOAL: Plain Language Version**

**Every child gets the services they need,
so that they can play, go to school,
and grow up to become a healthy adult.**

(And so grown-ups and siblings can thrive too.)

Original language: “Children and youth with special health care needs enjoy full lives and thrive in their communities from childhood through adulthood.”



Plain Language Version = Equity and QOL

Every child gets the services they need, = **Equity** (Tawara Goode)

so that they can play, go to school, = **Child thriving**

and grow up to become a healthy adult. = **Transition**

(And so grown-ups and siblings can thrive too.) = **Caregiver well-being**

What do we do? “Measure What Matters”

1. QOL

- Universal measures: child thriving, kindergarten readiness, healthy weight, successful transition to adulthood, caregiver well-being
- At least one condition-specific measure

2. Populations

- Systems-level
 - What % of children/caregivers achieve the measures?
- Equity
 - Do the demographics of numerator match those of the denominator?

3. Accountable

- All organizations plan, track, explain (some SDOH/HRSN in their control)
 - Some rewarded for increased % of people achieving measures?
- Universal measures in NOFOs, Title V, Medicaid, NSCH, CDC, etc.



Summary: *Blueprint for Change*

- ***What is it?***
 - ✓ A vision for how the system of care should work for CYSHCN
- ***Who created it?***
 - ✓ Families/youth, experts in CYSCHN, government agencies, etc.
- ***Why did we do this?***
 - ✓ We can do better by working with stakeholders towards a common vision
 - ✓ Build on the Six Core Components of a well-functioning system and on the Standards for a Well-functioning System and Care Coordination (NASPH)
- ***What's new?***
 - ✓ Address access and financing through lens of equity and quality of life
- ***Why does it matter?***
 - ✓ If we **Measure What Matters**, we can be sure that every child gets what they need to play, go to school, and become a healthy adult.



Outline

1. Who am I?
2. Why EHDI?
3. What are we (MCHB and you) doing?
Blueprint for Change
- 4. Where are we (MCHB and you) going?**
5. How will we (MCHB and you) get there?

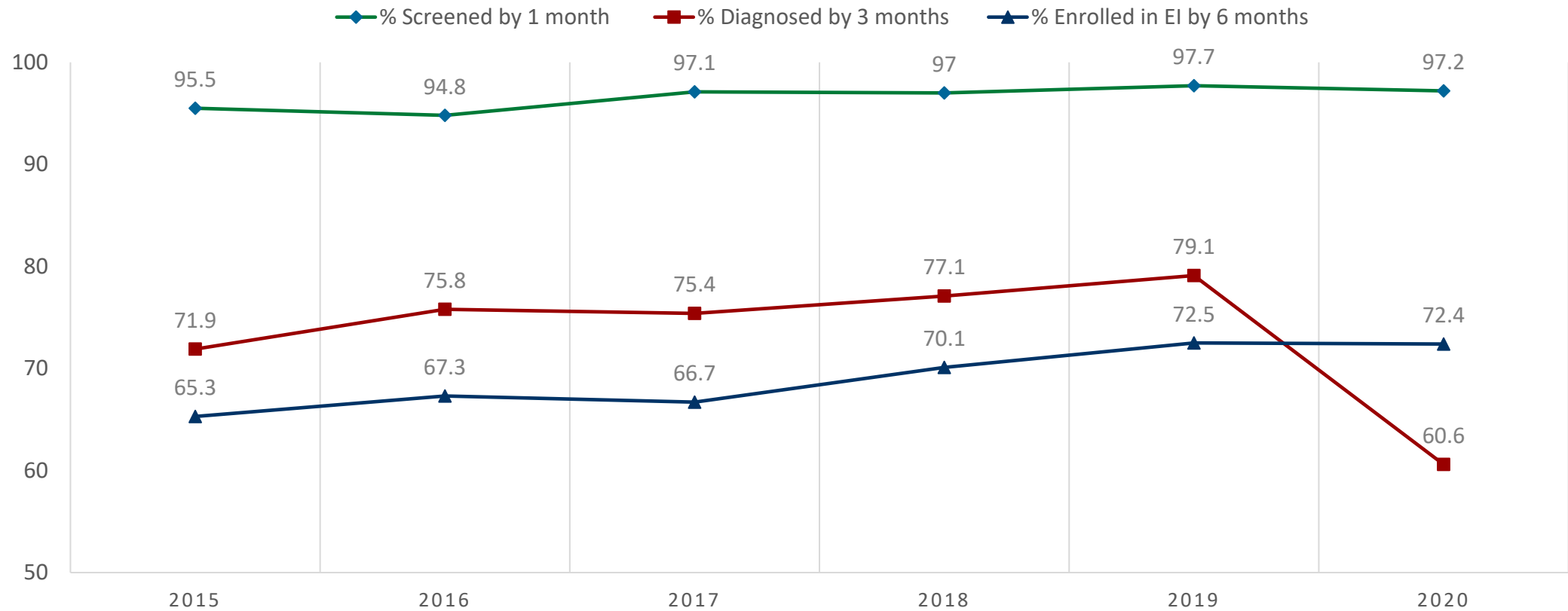


1-3-6



EHDI 1-3-6 Data: 2015-2020

EHDI 1-3-6 DATA: 2015-2020



Data Source: <https://www.cdc.gov/ncbddd/hearingloss/ehdi-data.html>



Disruptions During COVID-19

- Factors influencing 1-3-6 benchmarks:
 - Specialty provider shortages
 - Facility protocols
 - Delayed services
 - Staff diversions

The image shows the cover of the journal article. At the top, there is a blue header with a white waveform graphic and the text 'JEHDI The Journal of Early Hearing Detection and Intervention'. Below this, the article title 'Likely Impact of the COVID-19 Pandemic on Newborn Hearing Screening and Follow-up Services in the United States in 2020' is prominently displayed. The authors' names are listed to the right of the title. The abstract, keywords, acronyms, disclosures, acknowledgments, and correspondence information are provided in smaller text below the title. The journal's name and issue information are at the bottom.

Likely Impact of the COVID-19 Pandemic on Newborn Hearing Screening and Follow-up Services in the United States in 2020
Kelly Dundon, AuD, MPH¹
Suhana Ema, MPH²
Xidong Deng, PhD³
Mia Morrison, MPH⁴
Treeby Brown, MA⁵
Karl White, PhD⁶
Linda Hazard, EdD⁷
Marcia Fort, AuD⁸
Kirsten Coverstone, AuD⁹
Craig A. Mason, PhD¹⁰
Marcus Gaffney, MPH¹¹

Abstract
This perspective aims to highlight aspects of the Early Hearing Detection and Intervention (EHDI) newborn hearing screening and follow-up processes that were impacted by the COVID-19 pandemic and considers factors that likely impacted follow-up after failing newborn hearing screening among infants born in the United States during 2020. Efforts to minimize the potential impact of missed or delayed identification of hearing loss in infants and young children will also be discussed to help guide future program improvement activities.

Keywords: COVID-19, Newborn Hearing Screening

Acronyms: CDC = Centers for Disease Control and Prevention; DHH = deaf or hard of hearing; EHDI = Early Hearing Detection and Intervention; EHDI-IS = Early Hearing Detection and Intervention-Information System; HRSA = Health Resources and Services Administration; HSFS = Hearing Screening and Follow-up; LFU/LTD = lost to follow-up/lost to documentation

Disclosures: Jurisdictional EHDI data related work was supported under the current Centers for Disease Control and Prevention (CDC) Cooperative Agreement DD20-2006, "Improving Timely Documentation, Reporting and Analysis of Diagnostic and Intervention Data through Optimization of EHDI Surveillance Practices and Information Systems." The findings and conclusions in this report are those of the authors and do not necessarily represent the official position of the Centers for Disease Control and Prevention or the Health Resources and Services Administration.

Acknowledgments: The authors would like to thank the jurisdictional EHDI Programs who continue to share information on the hearing status of infants and young children throughout the United States with the CDC and partners.

Correspondence concerning this article should be addressed to: Kelly Dundon, AuD, MPH, GenTech Associates.
Phone: (678) 431-2096; Email: kxo2@cdc.gov

The Early Hearing Detection and Intervention (EHDI) Act (S. 852, PL 115-71) authorizes the Health Resources and Services Administration (HRSA) and the Centers for Disease Control and Prevention (CDC) to support EHDI activities at state and territorial levels to help ensure infants receive recommended services according to established national benchmarks (i.e., hearing screening before one month of age, diagnosis before three months of age, and enrollment in early intervention before six months of age (JCIH, 2019). Late identification of a child as deaf or hard of hearing (DHH) can adversely affect their ability to develop communication, language, cognitive, and social skills (Morton & Nance, 2006; Vohr, 2003). In March 2020, the United States declared a national emergency in response to the COVID-19 pandemic (Executive Office of the President, 2020).

The Journal of Early Hearing Detection and Intervention 2022: 7(3) 1



Dundon, K. ALAM, S. Deng, X. Morrison, M. BROWN, T. White, K. R. Hazard, L. Fort, M. Coverstone, K. R. Mason, C. & Gaffney, M. (2022). Likely Impact of the COVID-19 Pandemic on Newborn Hearing Screening and Follow-up Services in the United States in 2020. Journal of Early Hearing Detection and Intervention, 7(3), 1-5. DOI: <https://doi.org/10.26077/bdtm-7v57>



1-3-6 → Developmental Outcomes

- Receiving early intervention services before 6 months of age can help children who are born deaf or hard of hearing (D/HH) get ready for kindergarten.
- When identified soon after birth, babies who are D/HH can begin intervention early and are more likely to achieve language, cognitive, and social development on par with typically developing peers.



Christine Yoshinaga-Itano C, Sedey A.L, Wiggin M, Chung W. Early Hearing Detection and Vocabulary of Children with Hearing Loss. Pediatrics. 2017; 140(2): e20162964; DOI: <https://doi.org/10.1542/peds.2016-2964>

The Big Picture

“The goals of early hearing detection and intervention (EHDI) are to **maximize language and communication competence, literacy development, and psychosocial well-being** for children who are deaf or hard of hearing.”

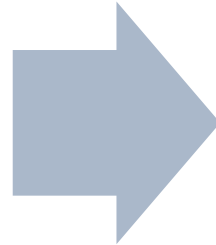
Joint Committee on Infant Hearing (JCIH)
2019 Position Statement



Focusing on Long-term Outcomes

Short-term Outcomes

- Screened by 1 month
- Diagnosed by 3 months
- Referred to EI by 6 months
- Families enrolled in family support services
- Providers reporting confidence in caring for D/HH children



Long-term Outcome

Increase % of 3-year-old children achieving language acquisition milestones

What do we do? “Measure What Matters”

1. QOL

- Universal measures: child thriving, kindergarten readiness, healthy weight, successful transition to adulthood, caregiver well-being
- At least one condition-specific measure

2. Populations

- Systems-level
 - What % of children/caregivers achieve the measures?
- Equity
 - Do the demographics of numerator match those of the denominator?

3. Accountable

- All organizations plan, track, explain (some SDOH/HRSN in their control)
 - Some rewarded for increased % of people achieving measures?
- Universal measures in NOFOs, Title V, Medicaid, NSCH, CDC, etc.



Working Towards a Common Goal

- CDC Hearing Screening and Follow-up Survey (HSFS)
 - 1-3-6
 - Collecting family-to-family support information
- Outcomes and Developmental Data Assistance Center for EHDI (ODDACE) Programs
- EHDI Outcomes Committee



EHDI as Exemplar for all MCHB Programs

1. QOL

- Condition-specific measure: “language acquisition at age 3 years”

2. Populations

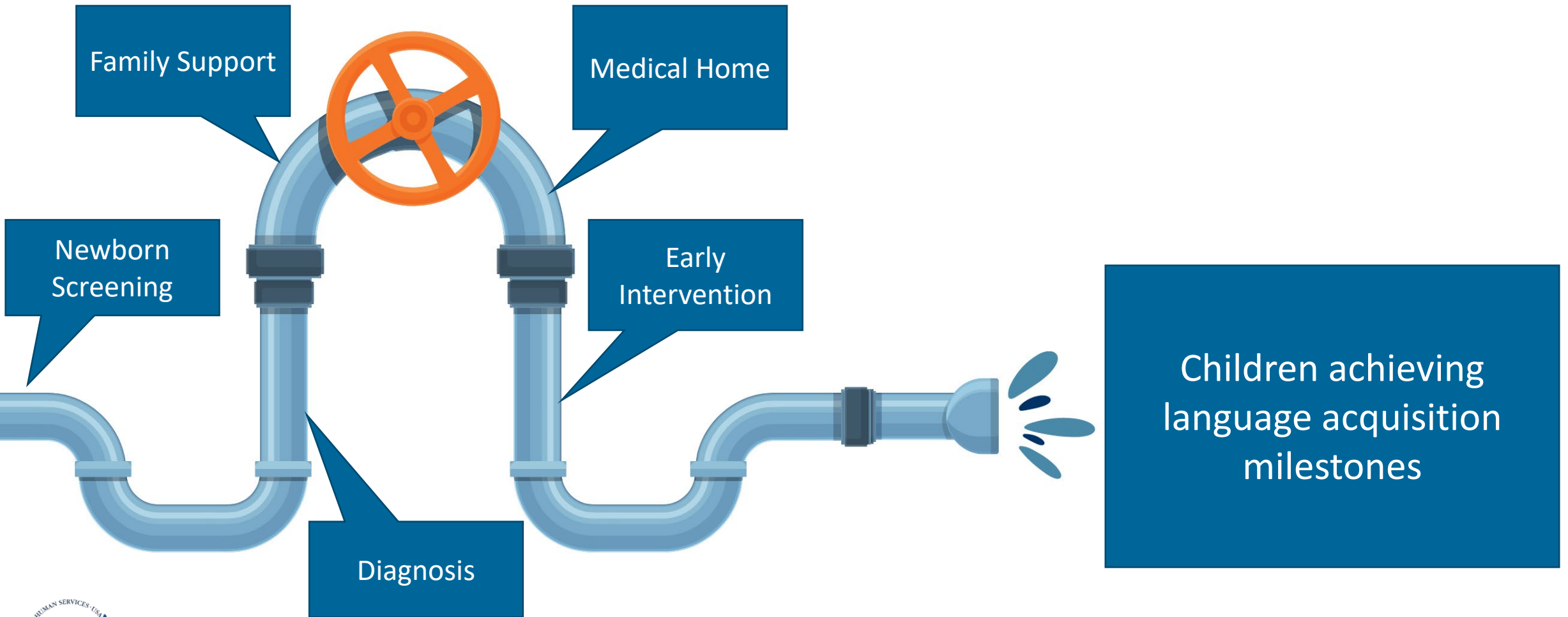
- What % of D/HH children in the state achieving the language goal?
- Are all populations having the same success? (race/ethnicity, rural, etc.)

3. Accountable

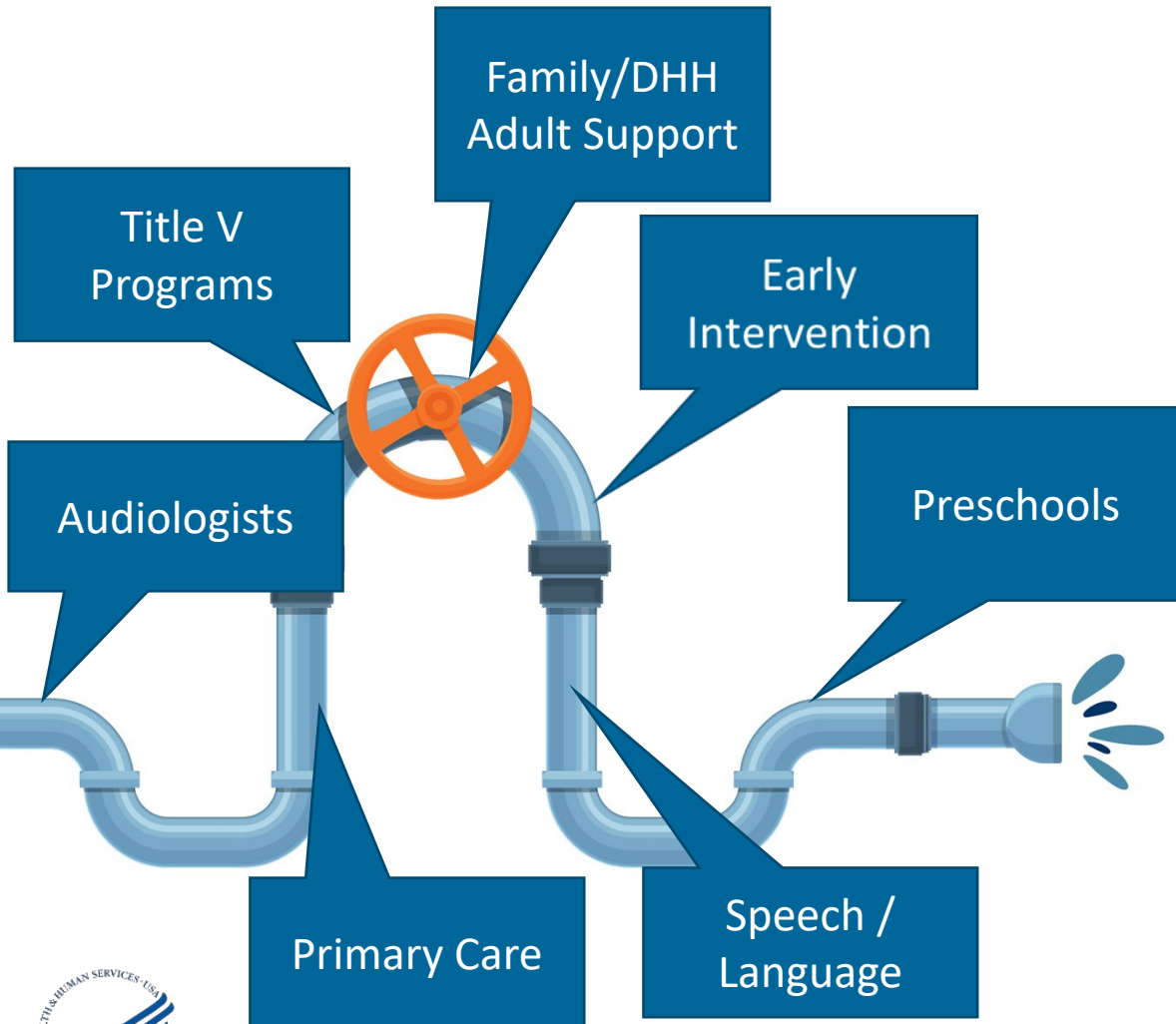
- Job of the **state coordinator**: create a “pipeline” graphic of all children in the state from birth to 3 years of age showing “leaks” towards the goal; convene stakeholders to create/update a plan to address issues
- Job of the **national coordinating center**: help states with tools of continuous QI, implementation science, address common needs, etc.
- Job of **all of us** is to hold ourselves accountable to common measures



EHDI Pipeline



Everyone Helps Identify/Address the Leaks



SYSTEMS LEVEL

Health equity, legislative support, financing systems, care integration . . .

PROVIDER LEVEL

1-3-6 knowledge, workforce capacity, communication with families, guidance available, database capacity . . .

PATIENT / FAMILY LEVEL

Competing needs, support network, financial support . . .

Role of EHDI Programs: Continuous Quality Improvement

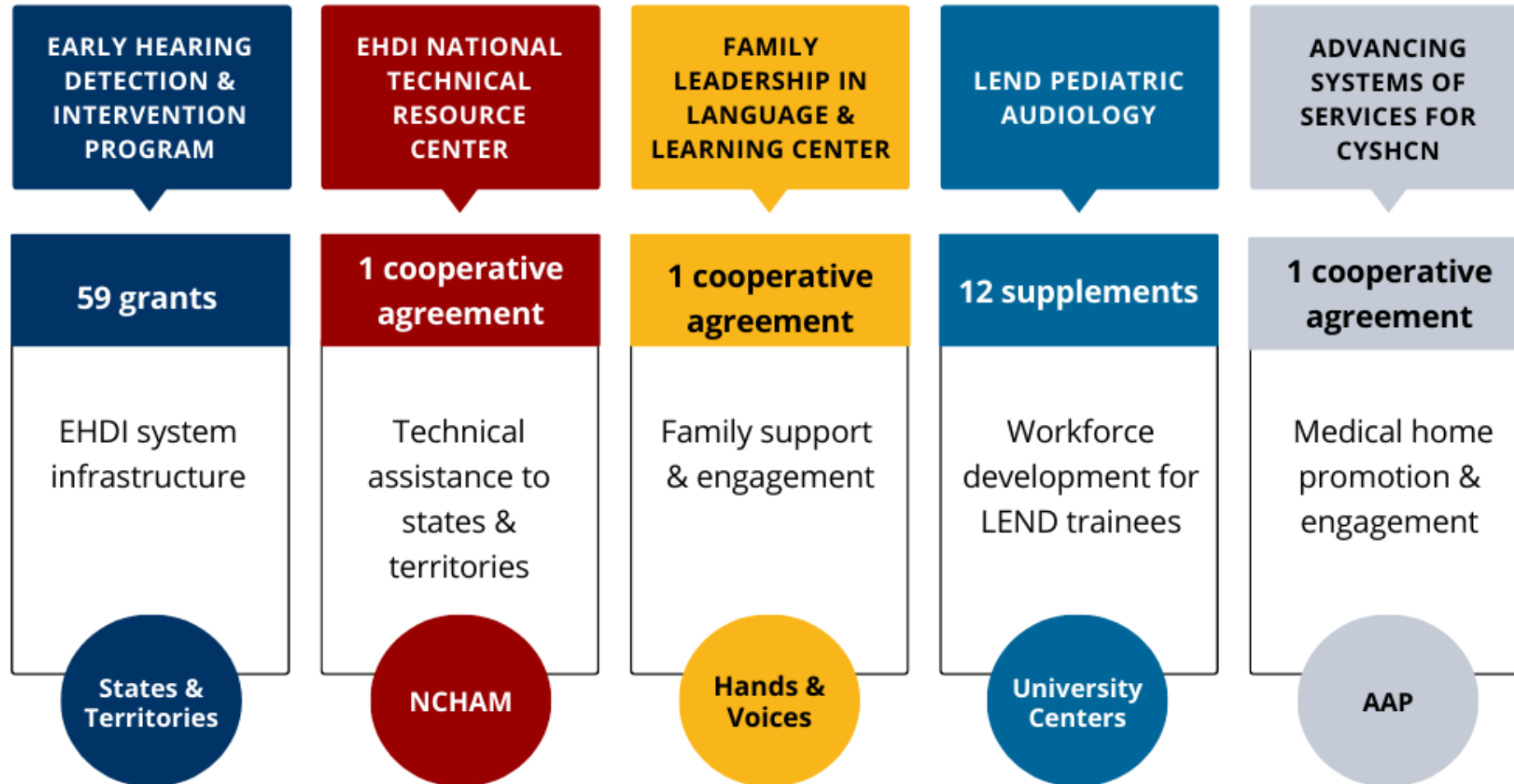


Outline

1. Who am I?
2. Why EHDI?
3. What are we (MCHB and you) doing?
Blueprint for Change
4. Where are we (MCHB and you) going?
- 5. How will we (MCHB and you) get there?**



Current Support from HRSA



Technical Assistance

EHDI TA CENTERS

Technical Assistance, Education, & Training


Policy Analysis & Assessment

Partnership Building

Evaluation




Partnerships




Office of Special Education Programs
U.S. Department of Education

PART C EARLY INTERVENTION




FAMILY BASED ORGANIZATIONS



TITLE V PROGRAMS



HEAD START & EARLY HEAD START



CENTERS FOR DISEASE CONTROL AND PREVENTION



MIECHV HOME VISITING

What is YOUR Role?

HELLO THERE!

MY ROLE IS



Contact Information

Jeffrey P. Brosco MD PhD

**Director, Division of Services for Children
with Special Health Needs (DSCSHN)**

Maternal and Child Health Bureau (MCHB)

Health Resources and Services Administration (HRSA)

jbrosco@hrsa.gov

Blueprint for Change:

[Blueprint for Change | MCHB \(hrsa.gov\)](https://www.hrsa.gov/mchb/blueprint-for-change)

MCHB Website: [mchb.hrsa.gov](https://www.mchb.hrsa.gov)



Connect with HRSA

Learn more about our agency at:

www.HRSA.gov



[Sign up for the HRSA eNews](#)

FOLLOW US:



Bonus Slides

- Slides that may be useful during the Q&A/Discussion



ARTICLES

Introducing the Blueprint for Change: A National Framework for a System of Services for Children and Youth With Special Health Care Needs

Treeby W. Brown et al

A Blueprint for Change: Guiding Principles for a System of Services for Children and Youth With Special Health Care Needs and Their Families

Sarah E. McLellan et al

Children and Youth With Special Health Care Needs: A Profile

Reem M. Ghandour et al

Progress, Persistence, and Hope: Building a System of Services for CYSHCN and Their Families

Michael D. Warren et al

Health Equity for Children and Youth With Special Health Care Needs: A Vision for the Future

Amy Houtrow et al

Quality of Life and Well-Being for Children and Youth With Special Health Care Needs and their Families: A Vision for the Future

Cara L. Coleman et al

Access to Services for Children and Youth With Special Health Care Needs and Their Families: Concepts and Considerations for an Integrated Systems Redesign

Dennis Z. Kuo et al

Financing Care for CYSHCN in the Next Decade: Reducing Burden, Advancing Equity, and Transforming Systems

Jeff Schiff et al

<https://publications.aap.org/pediatrics/issue/149/Supplement%207>

A SUPPLEMENT TO PEDIATRICS

Blueprint for Change: A National Framework for a System of Services for Children and Youth with Special Health Care Needs

Treeby W. Brown, MA, Sarah E. McLellan, MPH, Marie Y. Mann, MD, MPH, FAAP, and Joan A. Scott, MS, CGC, Guest Editors

Funding for the publication of this article, including editorial support (review for formatting and consistency) for this article was funded by the US Department of Health and Human Services, Health Resources and Services Administration under contract number 75R60219D00014.

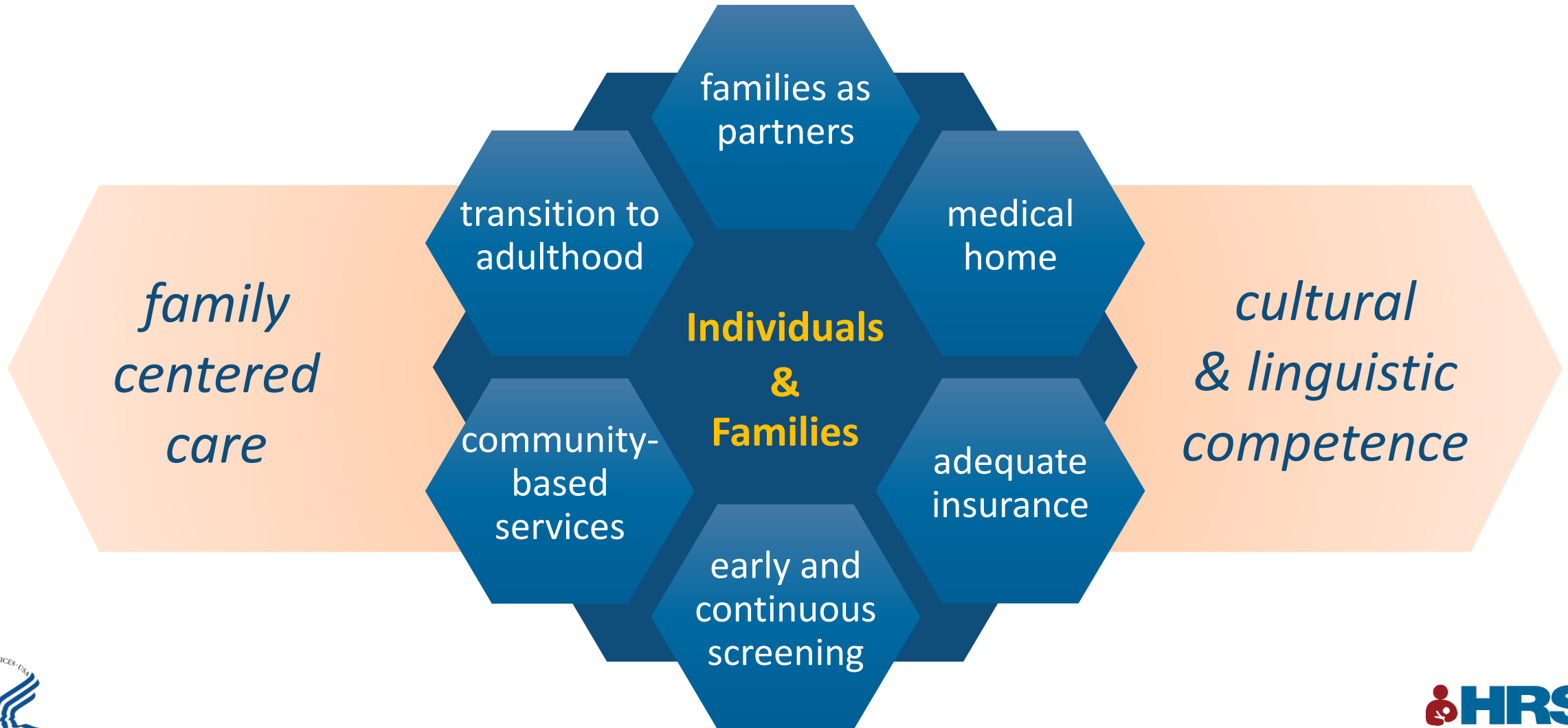
The views expressed in this publication are solely the opinions of the authors and do not necessarily reflect the official policies of the US Department of Health and Human Services or the Health Resources and Services Administration, nor does mention of the department or agency names imply endorsement by the US Government.

American Academy
of Pediatrics



DEDICATED TO THE HEALTH OF ALL CHILDREN®

Six Indicators of a Well-Functioning System



National Standards for Systems of Care for CYSHCN



<https://nashp.org/wp-content/uploads/2018/09/Standards-for-Systems-of-Care-for-Children-and-Youth-with-Special-Health-Care-Needs-Version-2.0.pdf>

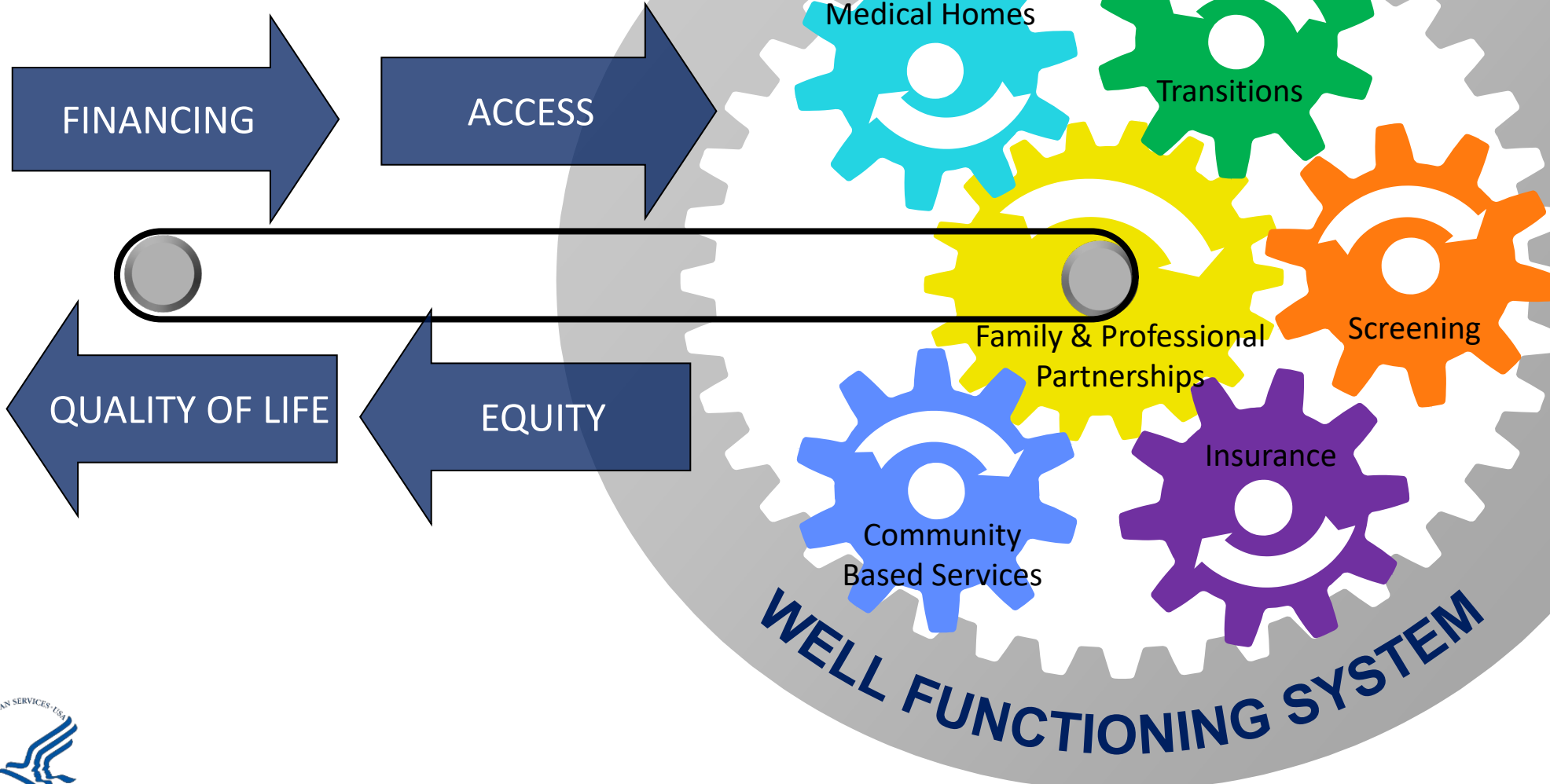
<https://www.nashp.org/national-care-coordination-standards-for-children-and-youth-with-special-health-care-needs/>



AMCHP

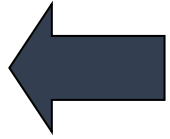
HRSA
Maternal & Child Health

Blueprint for Change



Every child gets what they need, so that they can play, go to school, and grow up to become a healthy adult.

Example Uses: Blueprint, 6 Core Outcomes, Standards



- If you are aiming to improve equity in your Title V programs, you can use the Blueprint article on equity for a framework and for specific strategies.
 - [Health Equity for Children and Youth With Special Health Care Needs: A Vision for the Future | Pediatrics | American Academy of Pediatrics \(aap.org\)](#)



- If you are measuring the system of care for CYSHCN, you can use the six core outcomes of a well-functioning system.
 - [National Survey of Child Health
National Survey of Children's Health - Data Resource Center for Child and Adolescent Health \(childhealthdata.org\)](#)



- If you are working on a contract for a managed care organization to provide care coordination, you can use National Care Coordination Standards for CYSHCN.
 - [NASHP Releases National Care Coordination Standards for Children and Youth with Special Health Care Needs - NASHP](#)

Most Children in the US are Healthy (Chronic conditions per 100)

Allergies	9	Learning disability	8.2
Asthma	8	ADHD	7.5
Diabetes	0.1	Depression	3.3
Sickle cell	0.1	Intellectual disability	1.5
Child cancers	0.02	Autism	1.1
Liver transplant	0.0004	Hearing loss	0.4
		Visual loss	0.4
		Cerebral Palsy	0.3
		Down Syndrome	0.15

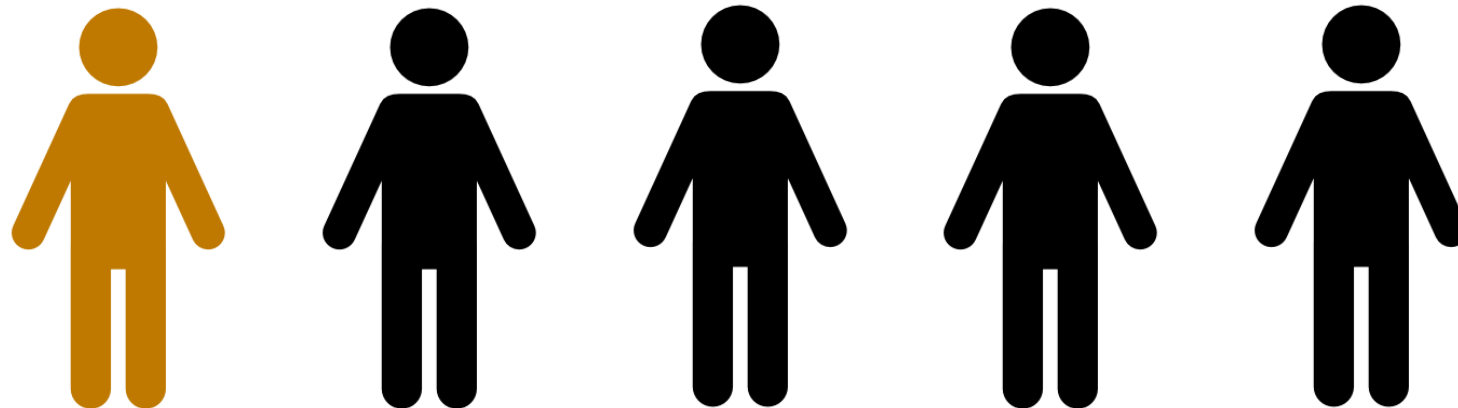
**13,000 more
(rare) conditions**



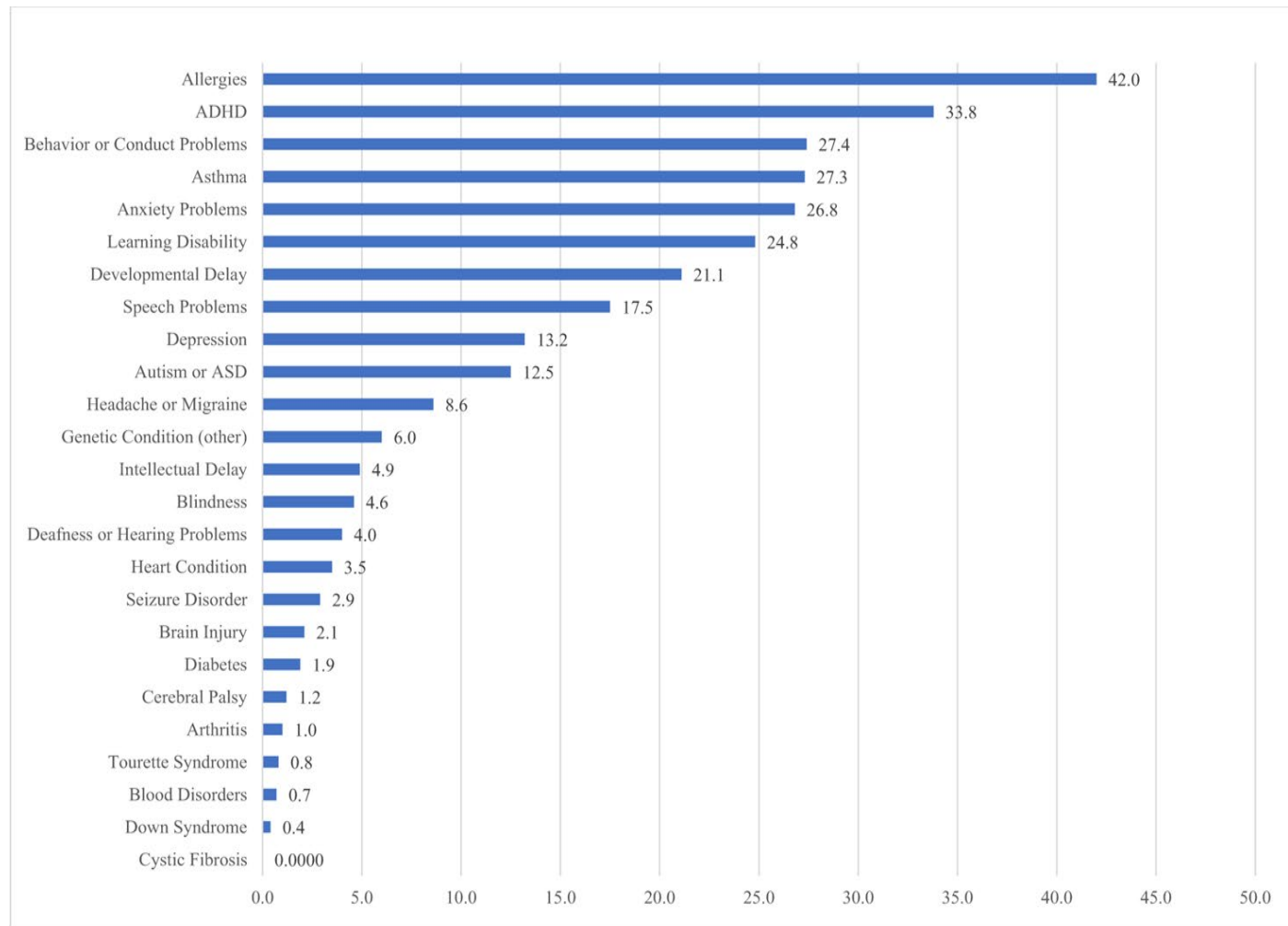
Definition of CYSHCN, 1998

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.



Prevalence of Selected Conditions among CYSHCN



National Survey of Children's Health, 2016-19. Pediatrics. 2022;149(Supplement 7). doi:10.1542/peds.2021-056150D



Children with Medical Complexity

- Serious and chronic medical conditions
- Multiple specialists/medical technology/home health
- Require tertiary/quaternary medical care
- **1-2% of children, but 1/3 of spending and 40% of deaths**
 - Prevalence ranges from 1% (SSI) to 5% (NSCH)
- **ACE Kids Act** = Section 1945A of the Social Security Act
 - August 1, 2022 guidance to state Medicaid directors
 - Authorizes states to cover an optional health home as a state plan benefit for Medicaid-eligible CMC

Cohen E et al Pediatrics 2017; Status Complexicus
<https://www.medicaid.gov/federal-policy-guidance/downloads/smd22004.pdf>



Children in the US

- **CYSHCN** = children and youth with special health care needs (20% of all children)
 - 13,000 different conditions
 - Asthma, allergies, ADHD, anxiety, depression, autism
- **CMC** = children with medical complexity (< 1-2% of all children)
 - Subset of the CYSHCN population

