HRSA
Health Resources & Services Administration

Children and Youth with Special Health Care Needs

Blueprint for Change: Implementation Update

May 24, 2023

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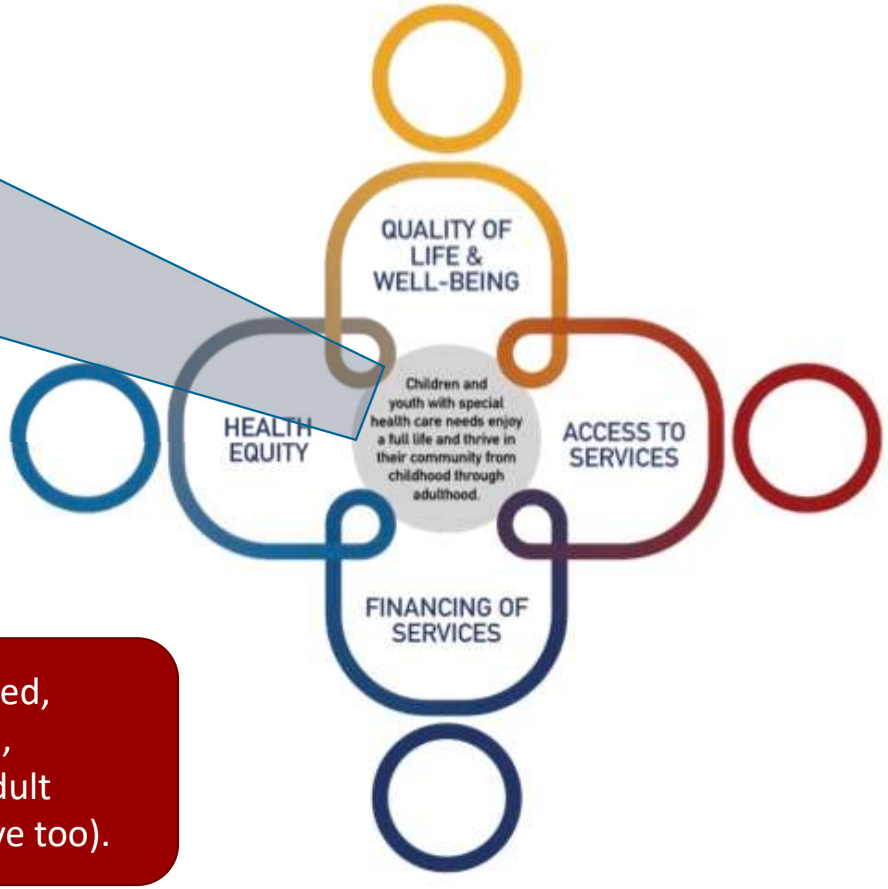
Vision: Healthy Communities, Healthy People

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



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).

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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.

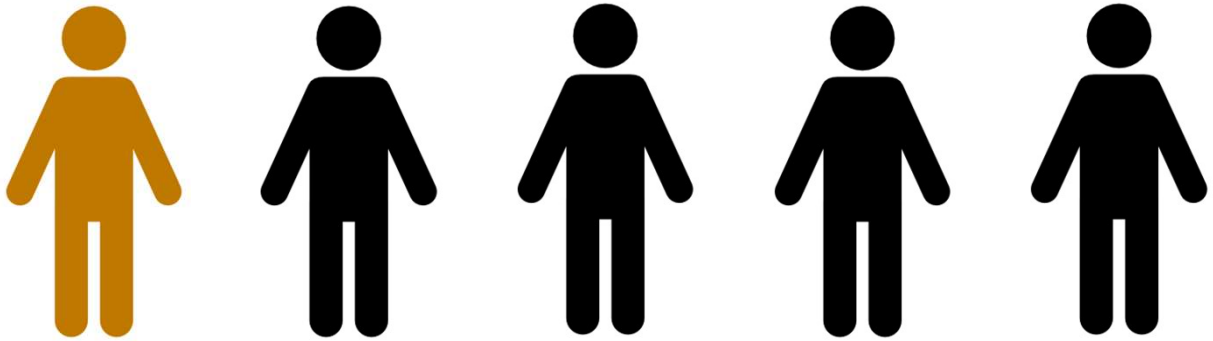
IMPACT

Maximize impact through leadership, partnership, and stewardship.

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.



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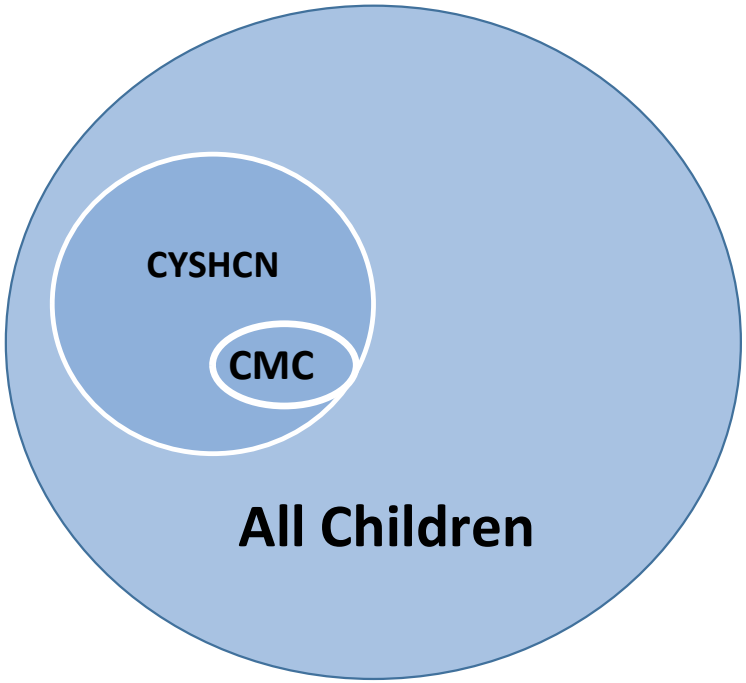
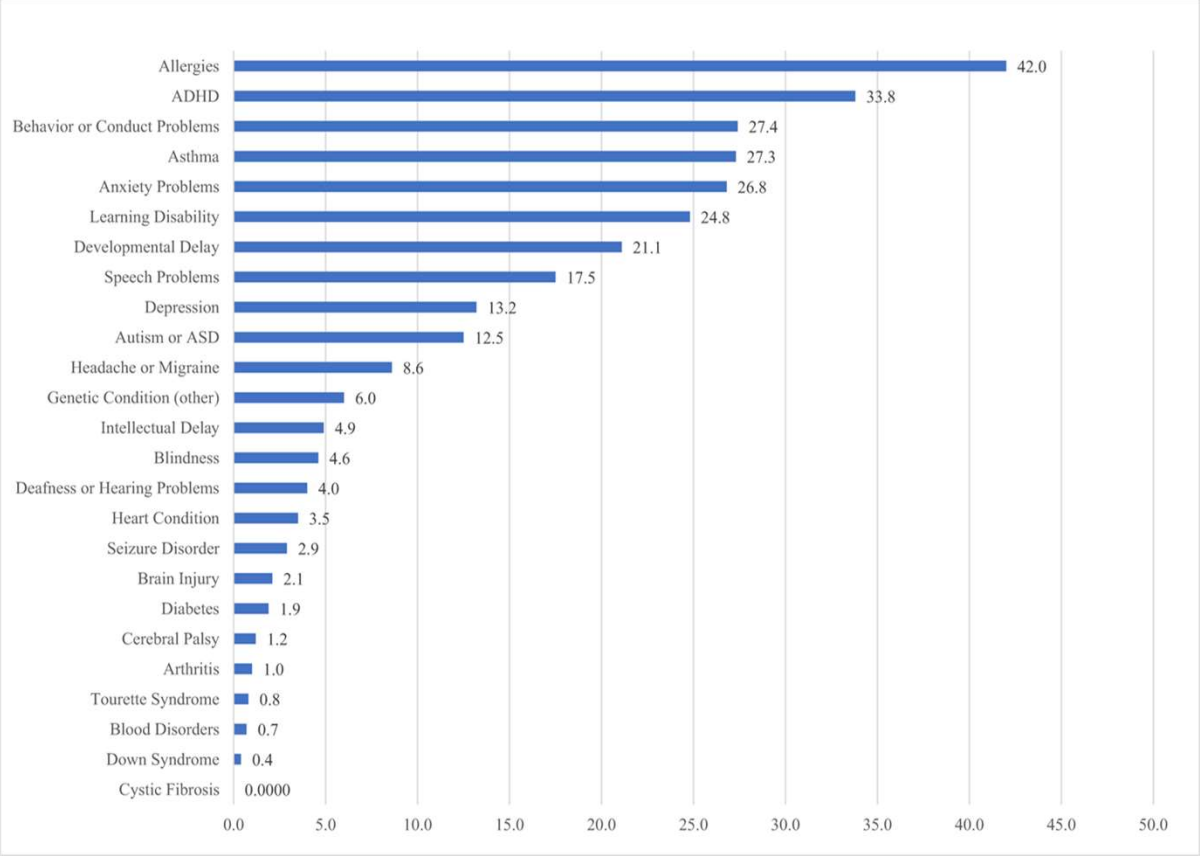
Children in the US

- **CYSHCN** = 20%
  - 13,000 different conditions
  - Asthma, allergies, ADHD, anxiety, depression, autism
- **CMC** = Children with Medical Complexity (< 5%)
  - Subset of the CYSHCN population



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

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CYSHCN and Social Determinants of Health

1. Greater dependence on health care system

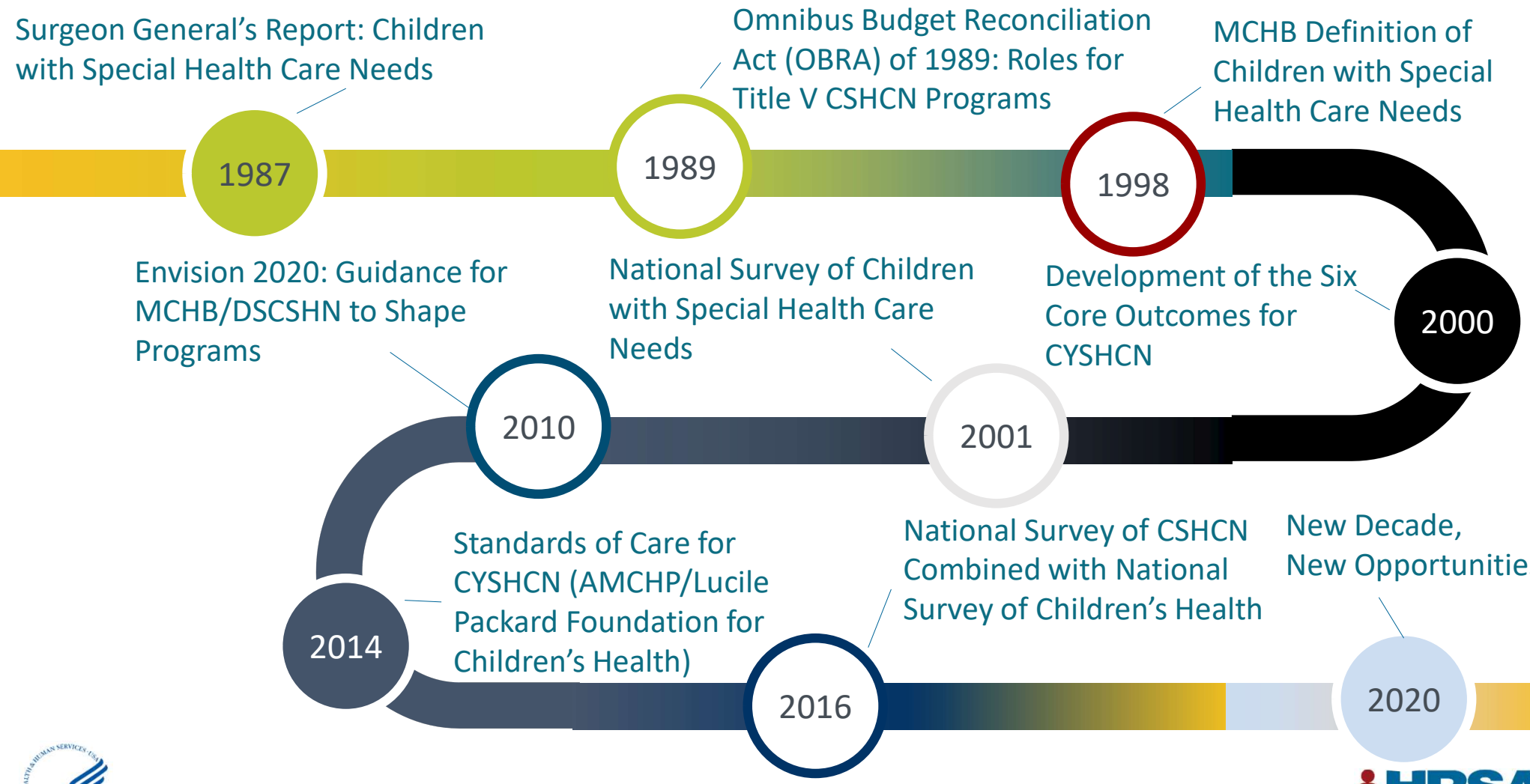
- Laboratory research, tertiary care hospitals, clinicians, equipment

2. Triply vulnerable to social determinants of health

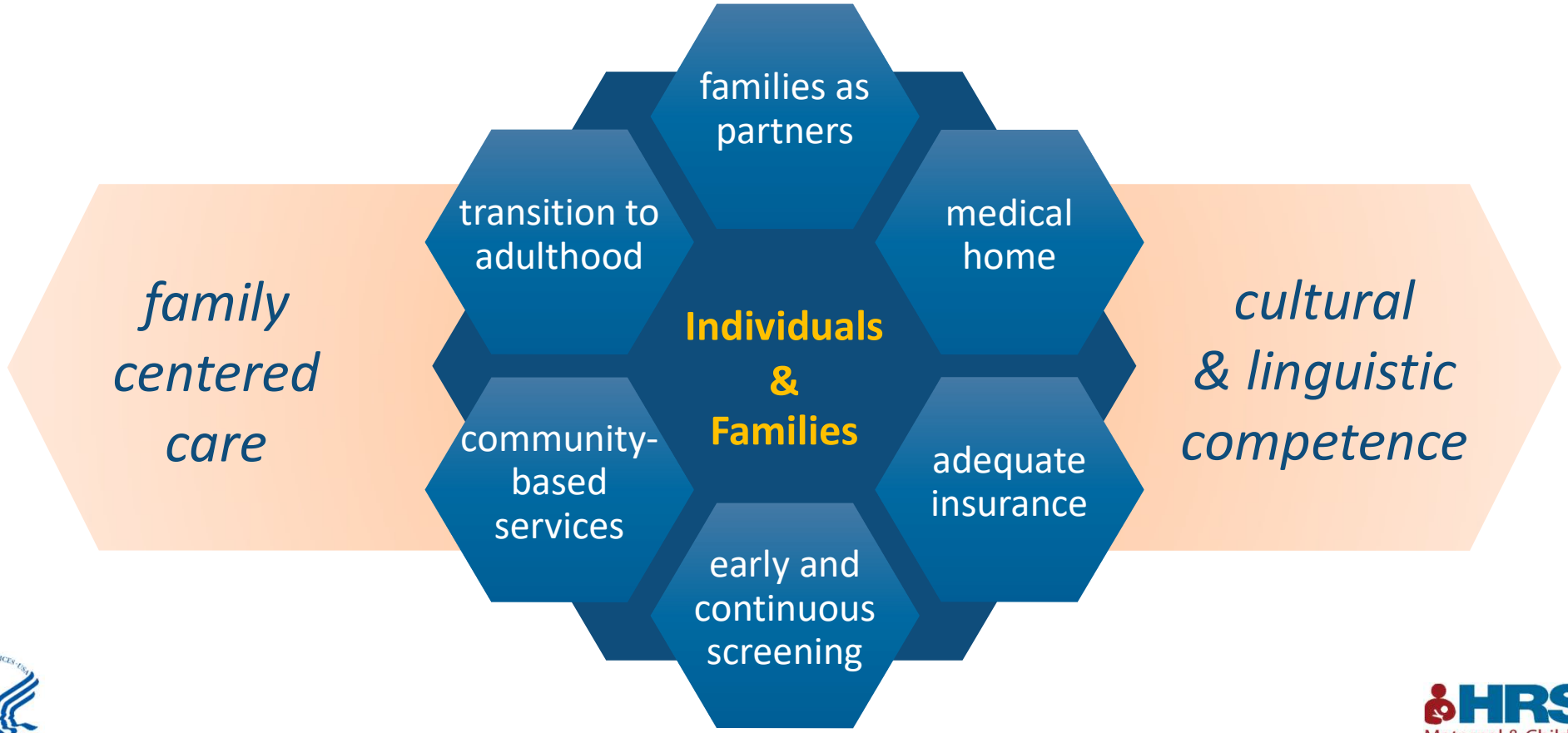
- e.g. child with asthma harmed by air pollution
- e.g. lack of transportation limits access to health care they need more of
- e.g. chronic medical conditions increase economic burden

3. Small numbers, high impact

- CYSHCN < 20%; Children with Medical Complexity < 5%
- Require more resources; high impact on health outcomes


Surgeon General's Report: Children with Special Health Care Needs
1987
Omnibus Budget Reconciliation Act (OBRA) of 1989: Roles for Title V CSHCN Programs
1989
MCHB Definition of Children with Special Health Care Needs
1998
2000
Development of the Six Core Outcomes for CYSHCN
National Survey of Children with Special Health Care Needs
2001
Envision 2020: Guidance for MCHB/DSCSHN to Shape Programs
2010
Standards of Care for CYSHCN (AMCHP/Lucile Packard Foundation for Children's Health)
2014
National Survey of CSHCN Combined with National Survey of Children's Health
2016
New Decade, New Opportunities
2020

Six Indicators of a Well-Functioning System



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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

AMCHP

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

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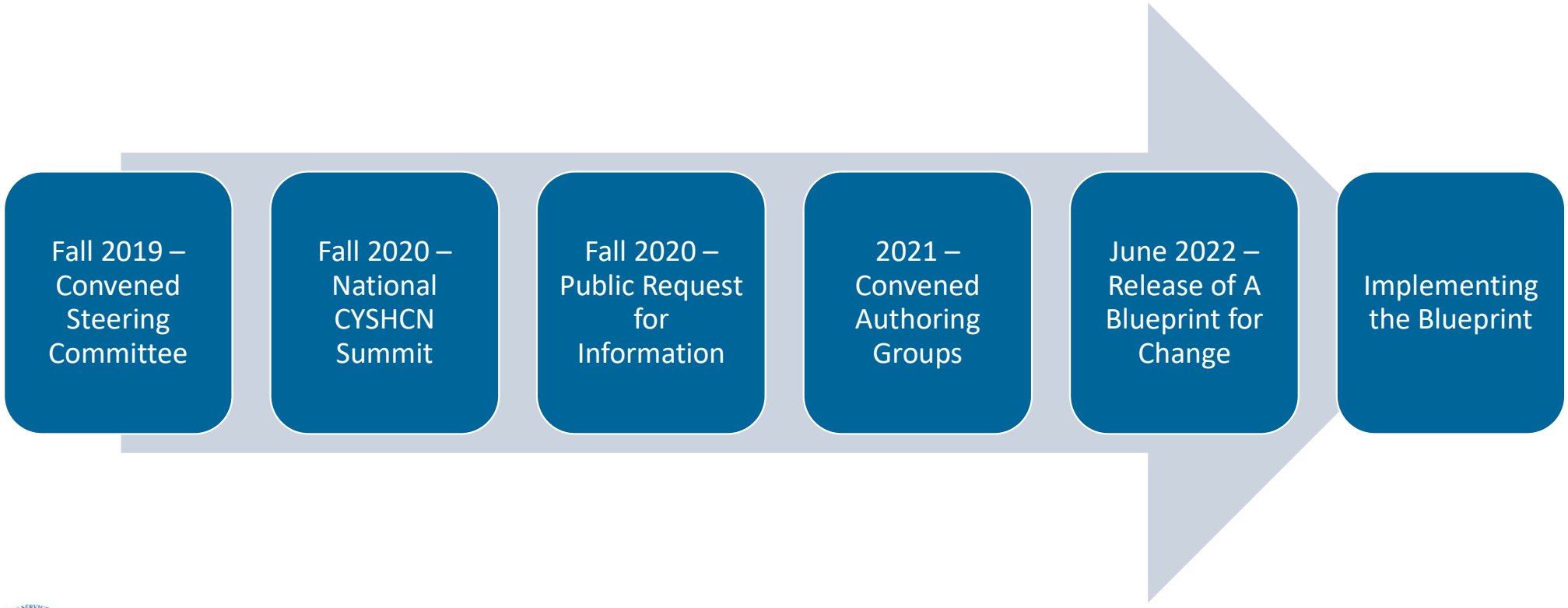
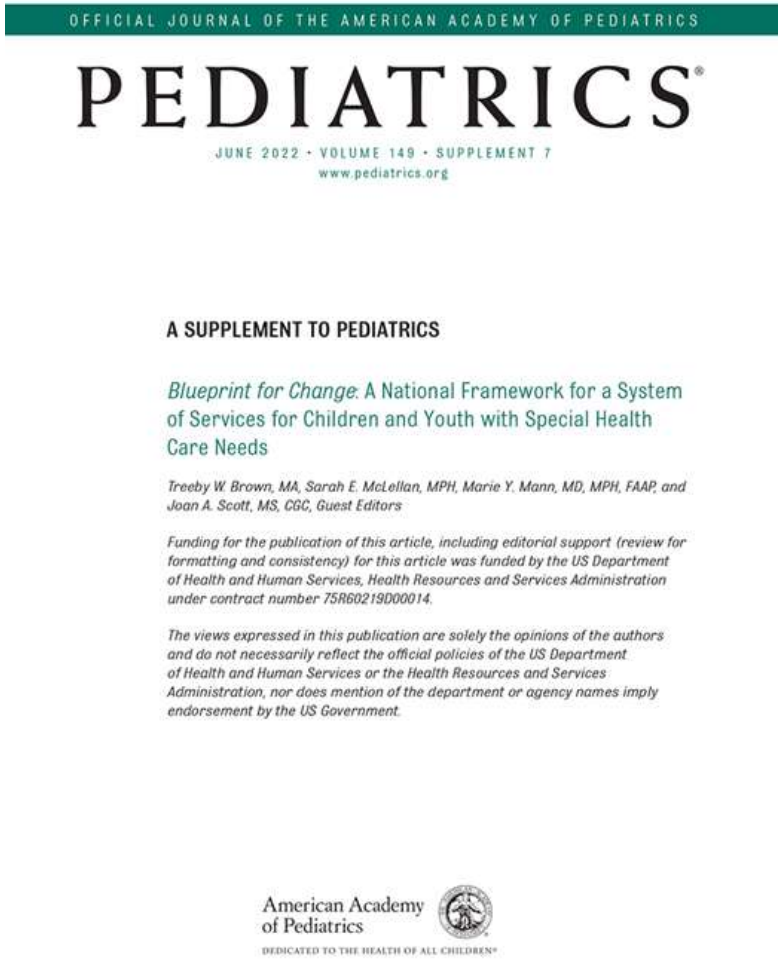
Development of the Blueprint

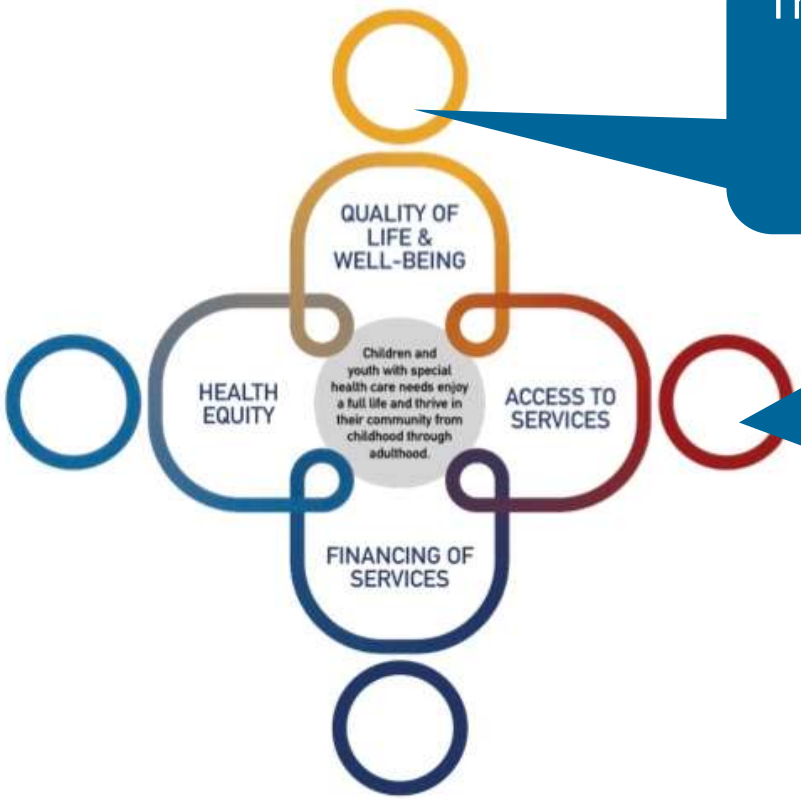


ARTICLES

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



Focus Area Visions



The service system prioritizes **quality of life**, well-being, and supports flourishing for CYSHCN and their families.

CYSHCN and their families have timely **access** to the integrated, easy-to-navigate, high-quality health care and supports they need, including but not limited to physical, oral, and behavioral health providers; home and community-based supports; and care coordination throughout the life course.

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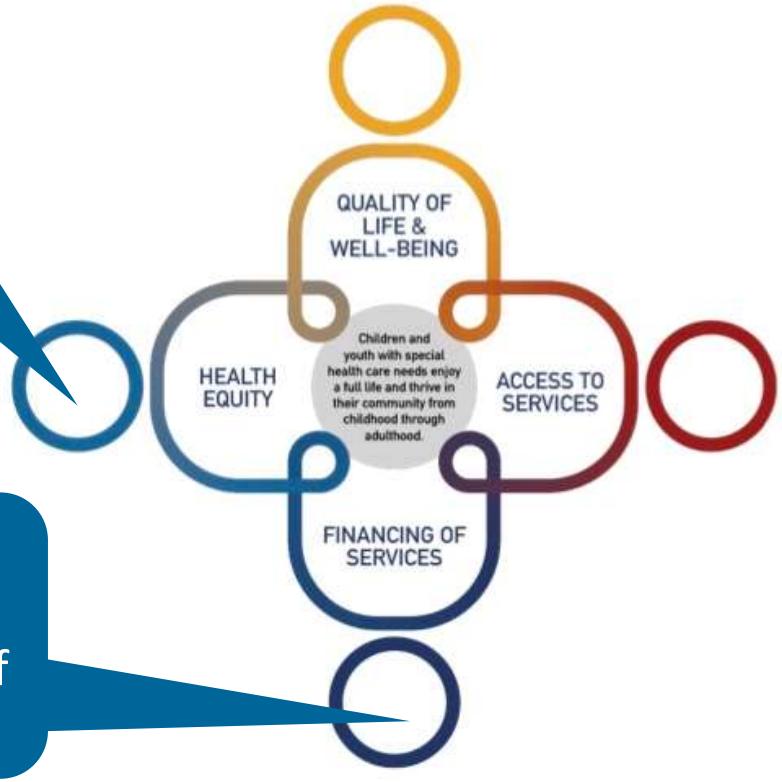
Focus Area Visions

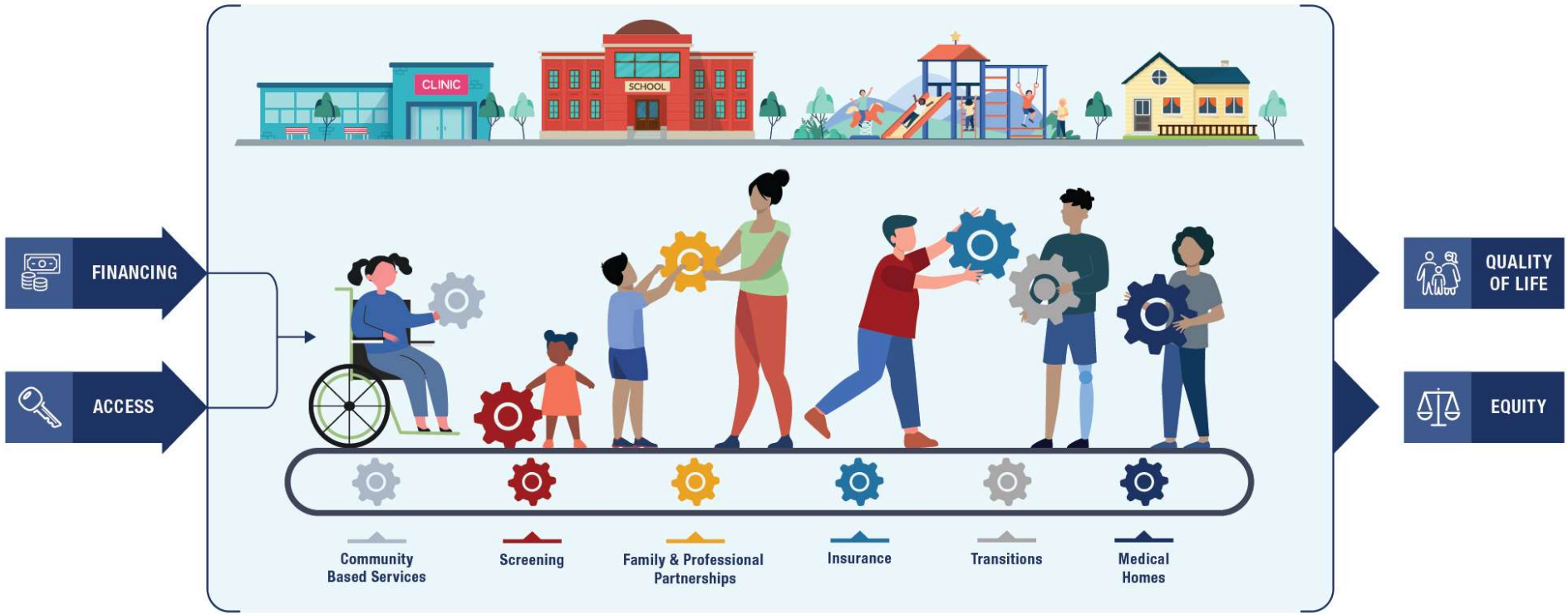
All CYSHCN have a **fair and just** opportunity to be as healthy as possible and thrive throughout their lives (eg, from school to the workforce), without discrimination, and regardless of the circumstances in which they were born or live.



Health care and other related services are accessible, **affordable**, comprehensive, and continuous; they prioritize the well-being of CYSHCN and families.

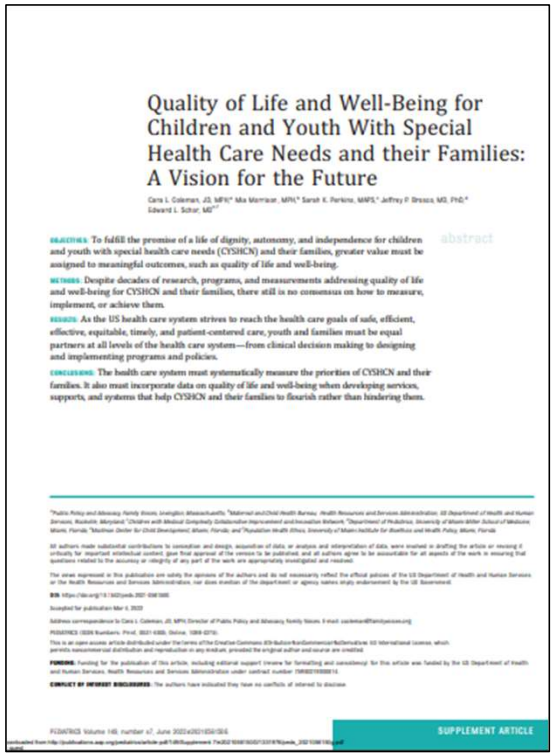
CYSHCN Blueprint for Change

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



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



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

SUPPLEMENT ARTICLE

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.

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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."

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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”

QOL	Population level	Accountable	Consensus

• Child thriving, kindergarten readiness, healthy weight, successful transition to adulthood, caregiver well-being, other “universal” measures
• At least one condition-specific measure
	• Systems-level thinking – “population health 2.0”
	  • What % of children/youth/caregivers achieving the universal measures?
	• Equity – “targeted universalism”
	  • Do the demographics of numerator match those of the denominator?
		• 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?
			• Universal measures in NOFOs, Title V, Medicaid, NSCH, CDC, etc.

What do we do? “Measure What Matters”

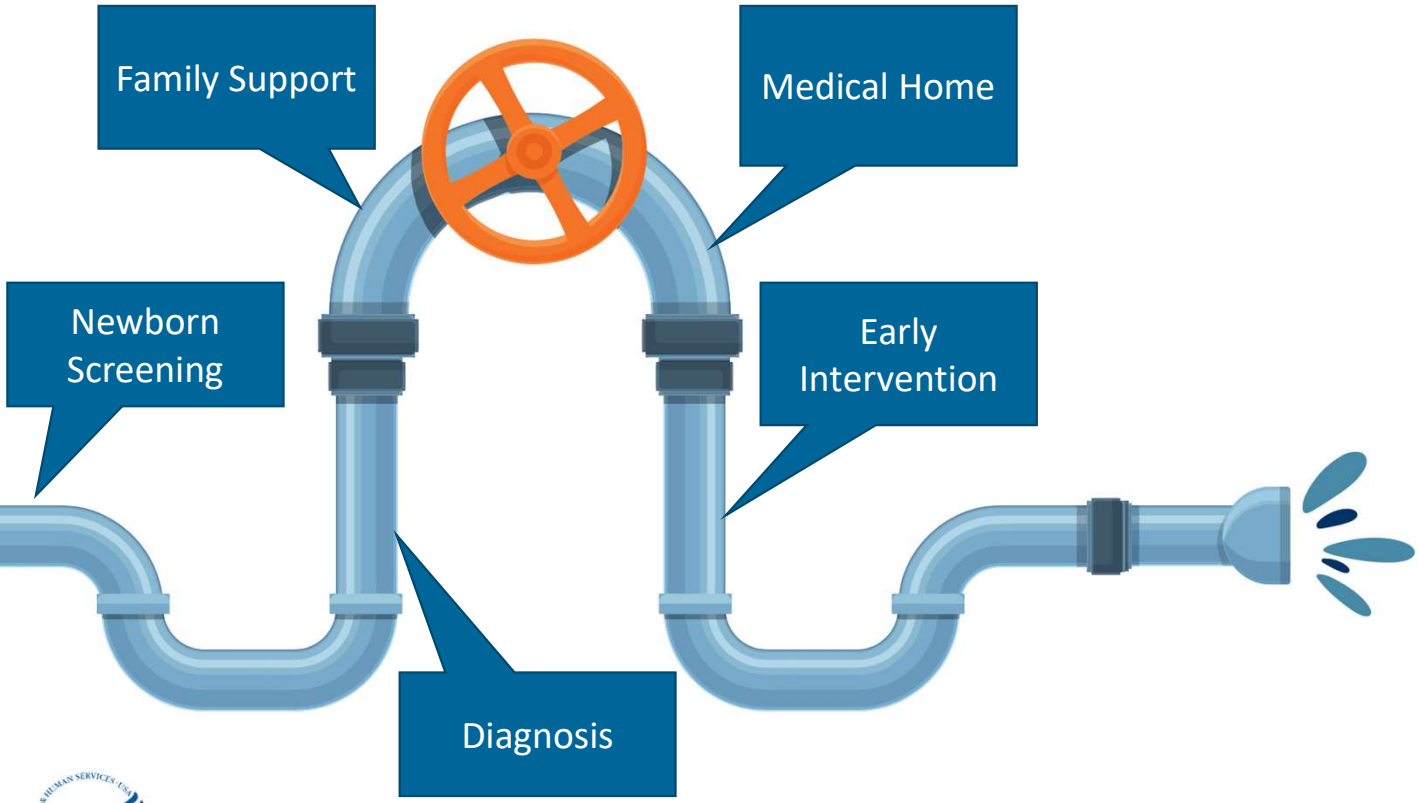
1. **QOL**
   - Universal measures: successful transition to adulthood and other stages of life, increasing comprehensive care visits for the underserved, high school/GED attainment, reducing absenteeism.
   - Condition-specific measure: increasing the number of infants identified with an NBS Condition who are thriving at 3 years of age
2. **Populations**
   - Systems-level: What % of persons age 12 and up have health care transition plans?
   - Equity
     - Do the demographics of numerator match those of the denominator?
3. **Accountable**
   - All organizations plan, track, explain their role.
   - Universal measures in NOFOs, NHIS, NSCH, CDC/Healthy People, etc.

EXAMPLE: Early Hearing Detection/Intervention 1-3-6

Example: Early Hearing Detection/Intervention (EHDI)

1. **QOL** for children who are deaf/hard of hearing (D/HH)
   - 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

EXAMPLE: EHDI Pipeline for D/HH Children



Children achieving language acquisition milestones

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.

What's Next? Implementing the Blueprint

CYSHCN Blueprint for Change
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Blueprint for Change

A national framework for a system of services for children and youth with special health care needs (CYSHCN) where they enjoy a full life and thrive in their community from childhood through adulthood

Scan to learn more!

Contact Information

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