

Charting a New Course for CYSHCN: Introducing a New National Center for a System of Services

Virtual Town Hall

Moderator: Debbi Harris, MS, MA

American Academy of Pediatrics

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FUNDING ACKNOWLEDGEMENT

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CONFLICT OF INTEREST

- The moderator and panelists have no conflicts of interest to report.
- The views presented in this discussion do not necessarily represent the views and opinions of the AAP.



AGENDA

- Welcome and opening remarks
 - *Moderator: Debbi Harris*
- Overview of the Blueprint for Change
 - *Faculty: Jeff Brosco*
- Overview of the National Center for a System of Services for CYSHCN
 - *Faculty: Debra Waldron*
- Panel Discussion
 - *Moderator: Debbi Harris*
 - *Panelists: Nathaniel Beers, Cara Coleman, Amy Houtrow, Jeff Schiff*
- Closing Remarks
 - *Moderator: Debbi Harris*





Children and Youth with Special Health Care Needs
MCHB Welcome – *Charting a New Course for CYSHCN:*
Introducing a New National Center for a System of Services
July 27, 2023

Jeffrey P. Brosco, MD, PhD

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

Maternal and Child Health Bureau (MCHB)

Vision: Healthy Communities, Healthy People



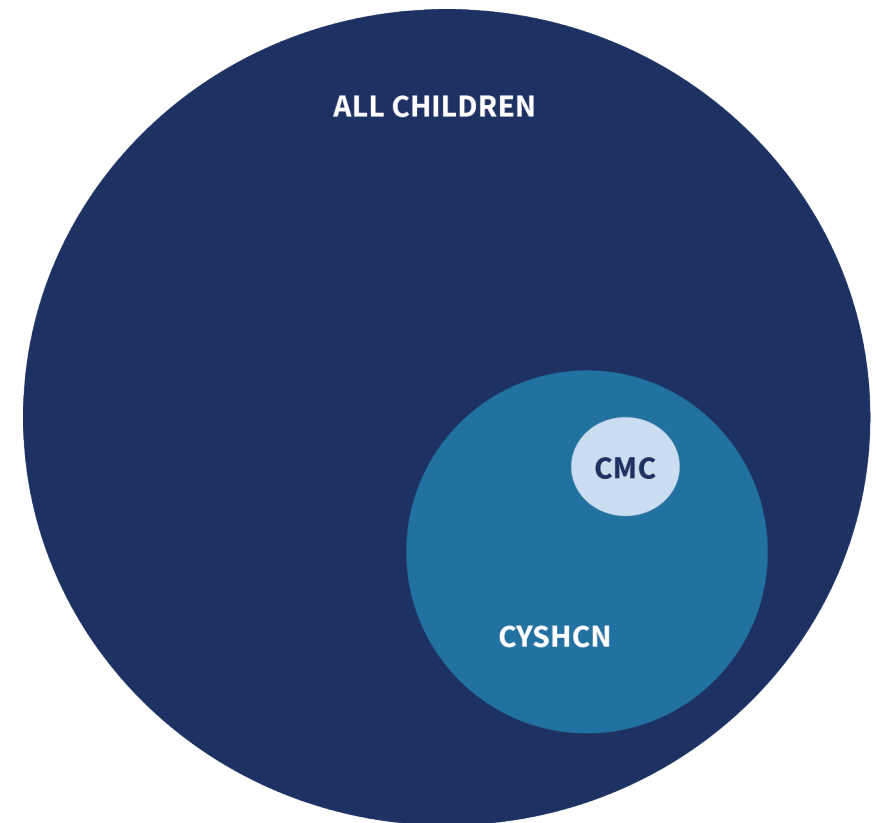
CYSHCN
Blueprint for Change

HRSA
Maternal & Child Health



CHILDREN IN THE US

- **CYSHCN** = children and youth with special health care needs (20%)
 - 13,000 different conditions
 - Asthma, allergies, ADHD, anxiety, depression, autism
- **CMC** = children with medical complexity (< 5%)
 - Subset of the CYSHCN population



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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

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

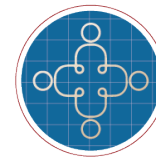
BLUEPRINT GOAL: PLAIN LANGUAGE VERSION

**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.)

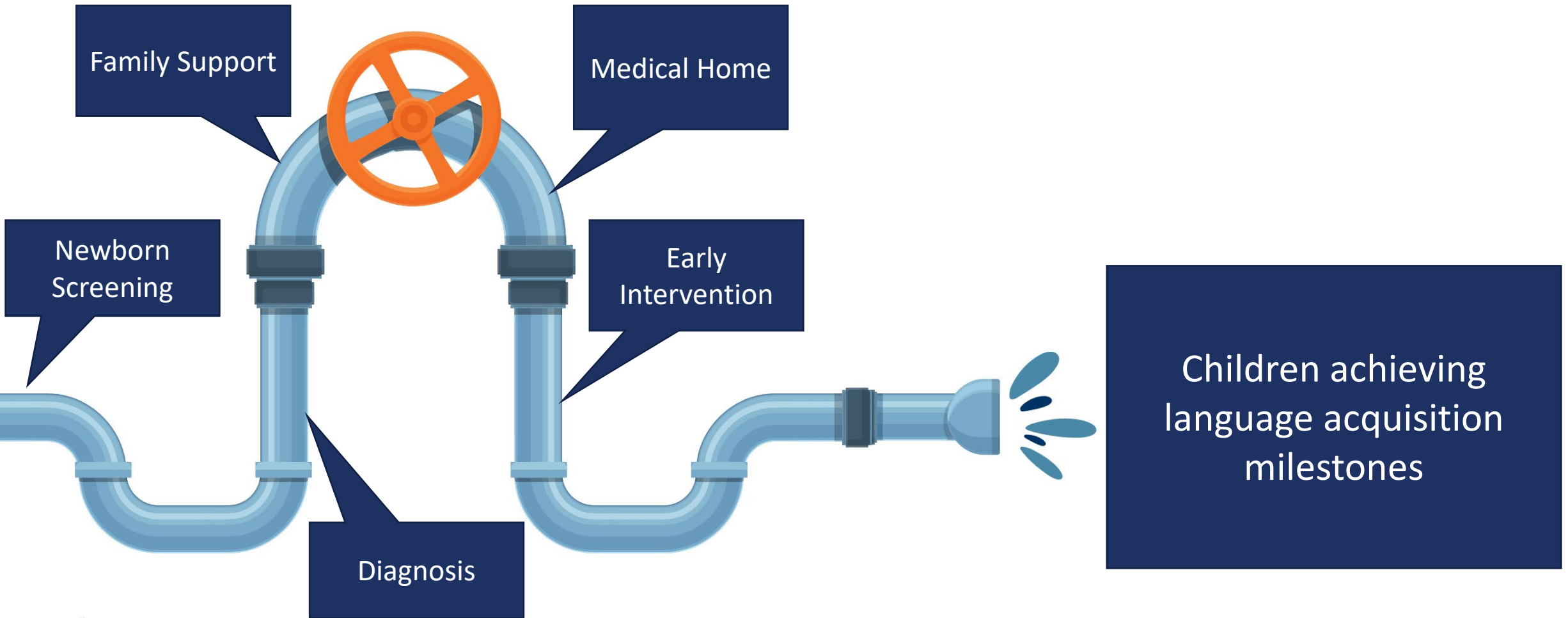
Original language: “Children and youth with special health care needs enjoy full lives and thrive in their communities from childhood through adulthood.”

BLUEPRINT IN PRACTICE: Newborn Hearing Screening



CYSHCN
Blueprint for Change

HRSA
Maternal & Child Health



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

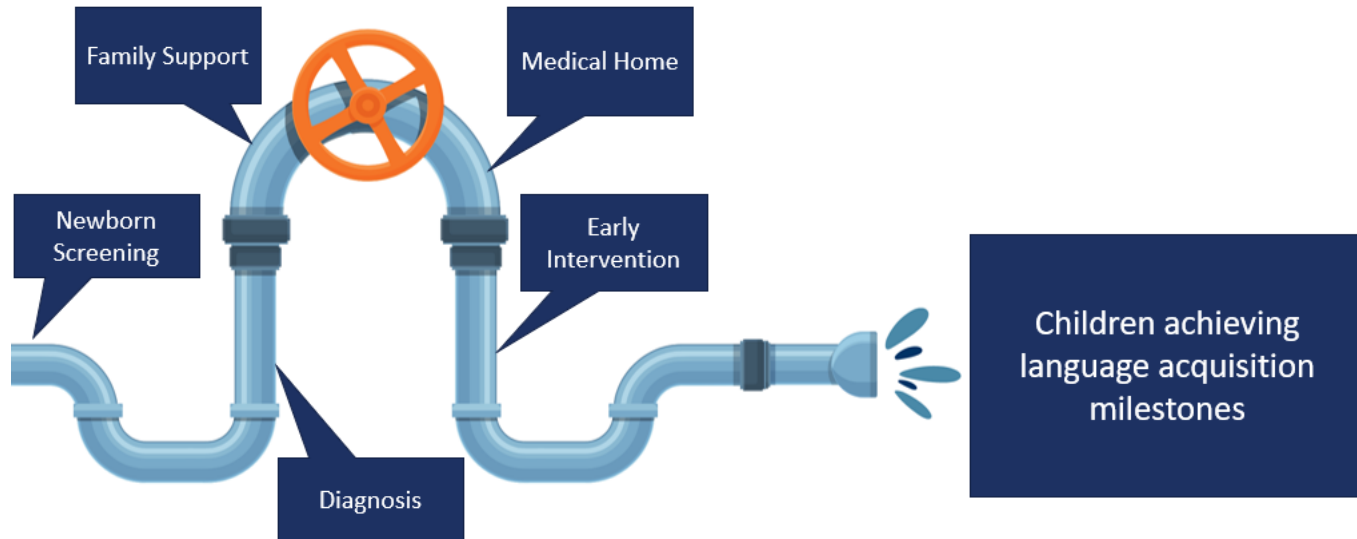
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CHALLENGES

Pipeline



Reality



BLUEPRINT IN PRACTICE: FAMILY JOURNEY



- **Supporting families through the journey**

- 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

- Children and Youth with Special Health Care Needs Research Network (CYSHCNet)—University of Colorado
 - Blueprint focus
 - ✓ Identifying and defining measures of well-being and QoL for CYSHCN and caregivers
 - ✓ Defining and measuring family partnership at the systems level
 - ✓ Understanding integration of models of care
- Family Engagement and Leadership in Systems of Care—Family Voices
 - Blueprint focus
 - ✓ Promoting shared definitions and metrics for family engagement across systems
 - ✓ Achieving health equity for CYSHCN through engaging diverse families in systems of care
- National Center for a System of Services for CYSHCN (Blueprint Center)—AAP
 - AAP (prime) with consortium of partners including Catalyst Center, Family Voices, and Got Transition
 - Center responsible to implement the Blueprint nationally across state Title V programs and other key partners
- Enhancing Systems of Care for Children with Medical Complexity CMC—Academy Health
 - Blueprint Focus
 - ✓ Supporting approaches addressing the elevated social needs and risks of CMC so children and families can thrive
 - ✓ Measuring patient/family experience of care



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://hrsa.gov/blueprint-for-change)

MCHB Website: mchb.hrsa.gov

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



National Center for a System of Services for CYSHCN

*Debra Waldron, MD, MPH, FAAP, Principal Investigator
Senior Vice President, Healthy and Resilient Children, Youth,
and Families*

American Academy of Pediatrics

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NATIONAL CENTER OVERVIEW

- **Goal:** Advance and strengthen the system of services for CYSHCN, their families and caregivers at the community, state, and national levels by supporting implementation of the Blueprint for Change.
- To accomplish this goal, the National Center will:
 - Convene families/caregivers, youth, public health professionals, clinicians, and others to guide all project activities
 - Develop and disseminate a Roadmap to support implementation of the Blueprint for Change
 - Convene state teams co-led by Title V and families/caregivers to test Blueprint implementation strategies
 - Provide technical assistance, training, and support on Blueprint implementation
 - Evaluate all project activities



WHAT DO WE HOPE TO ACCOMPLISH?

- Equitable partnerships with families/caregivers and people with lived experience
- Increase understanding and awareness of the Blueprint for Change
- Increase implementation of core Blueprint domains within states and jurisdictions
- **Long term outcomes:** Integrated health care through the life course for CYSHCN and their families; a fair and just opportunity for CYSHCN to be healthy



NATIONAL CENTER OVERVIEW

- **Timeline:** July 1, 2023 – June 30, 2028
- To implement this work, the AAP established the **National Center Consortium** which includes:
 - Boston University/Catalyst Center
 - Family Voices
 - The National Alliance to Advance Adolescent Health/Got Transition
- Other partners include:
 - UNC Chapel Hill
 - Association of University Centers on Disabilities
 - The Altarum Institute



NATIONAL CENTER STEERING COMMITTEE

- Multidisciplinary group of partners across a variety of sectors serving CYSHCN
 - Families/caregivers
 - Young adults
 - Clinicians
 - Title V
 - Medicaid and other payers
 - Early childhood
 - Education
 - Social work
 - Community health
- Topic specific workgroups will be convened to help lead specific projects under each Blueprint domain, as well as support system integration for sustaining improvement



NATIONAL CENTER: PHASE 1 (YEARS 1-2)

- Technical assistance topics (*this list is not exhaustive*):
 - Understanding the Blueprint for Change and what role you/your organization may have in implementing the Blueprint
 - Understanding how to implement evidence-based/informed strategies across each of the 4 Blueprint domains
 - How to leverage current financing models to support care coordination, case management, and addressing social determinants of health.
 - How clinicians can collaborate with the education system and early childhood system to support CYSHCN



NATIONAL CENTER: PHASE 1 (YEARS 1-2)

- Publish Blueprint Implementation Roadmap
 - A collection of strategies to support implementation of the Blueprint for Change
 - Roadmap intended to be used by CYSHCN system partners to increase implementation of the Blueprint and improve the system of services for CYSHCN
 - Maintain and grow the National Center Web site and accompanying Roadmap Playbook
 - Informed by an environmental scan, feedback from our partners including families, caregivers, people with lived experience



NATIONAL CENTER: PHASE 1 (YEARS 1-2)

- Environmental scan/needs assessment
 - Key informant interviews
 - Focus groups
 - Literature search
 - Review of Title V block grant applications
 - Review of National Survey of Children's Health
 - Review of Medicaid Managed Care contracts



NATIONAL CENTER: PHASE 1 (YEARS 1-2)

- Learning Collaborative
 - Convening multi-disciplinary teams to learn and improve together
 - Method for accelerating change and adopting promising practices together
 - Implement components of the UNC Chapel Hill “Learning Journey” model
 - Participants: Michigan, North Carolina, Rhode Island, Texas, Washington
 - Each team will be co-led by a Title V representative and a family/caregiver
 - Lessons learned and promising practices will inform the Blueprint Implementation Roadmap



NATIONAL CENTER: PHASE 2 (YEARS 3-5)

- Blueprint Implementation Roadmap implementation through:
 - Continued provision of technical assistance
 - Blueprint Cafes
 - Promising practices
 - LEND training curriculum
 - Additional learning collaboratives
 - Stipends available to participating states
 - Innovation awards
 - Evaluation of all National Center activities



CONTACT Us

- Blueprint4CYSHCN@aap.org
- [National Center for a System of Services for CYSHCN Web site](#)
- Remember, there is “no wrong door” to approaching our Consortium for technical assistance!



PANEL DISCUSSION

- Moderator: Debbi Harris
- Panelists:
 - Nathaniel Beers
 - Cara Coleman
 - Amy Houtrow
 - Jeffrey Schiff

