

# AMCHP Family LEAD Committee The Blueprint for Change Part 1

March 21, 2023



Healthy Children. Healthy Families. Healthy Communities.

## Agenda:

- I. Brief Introductions
- II. Overview of Blueprint
- III. Family Perspective
- IV. Question and Answers
- V. Wrap up





# Implementing the Blueprint for Change Where do Families Fit In?

*March 21, 2023*

**Jeffrey P. Brosco, MD, PhD**

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

**Maternal and Child Health Bureau**

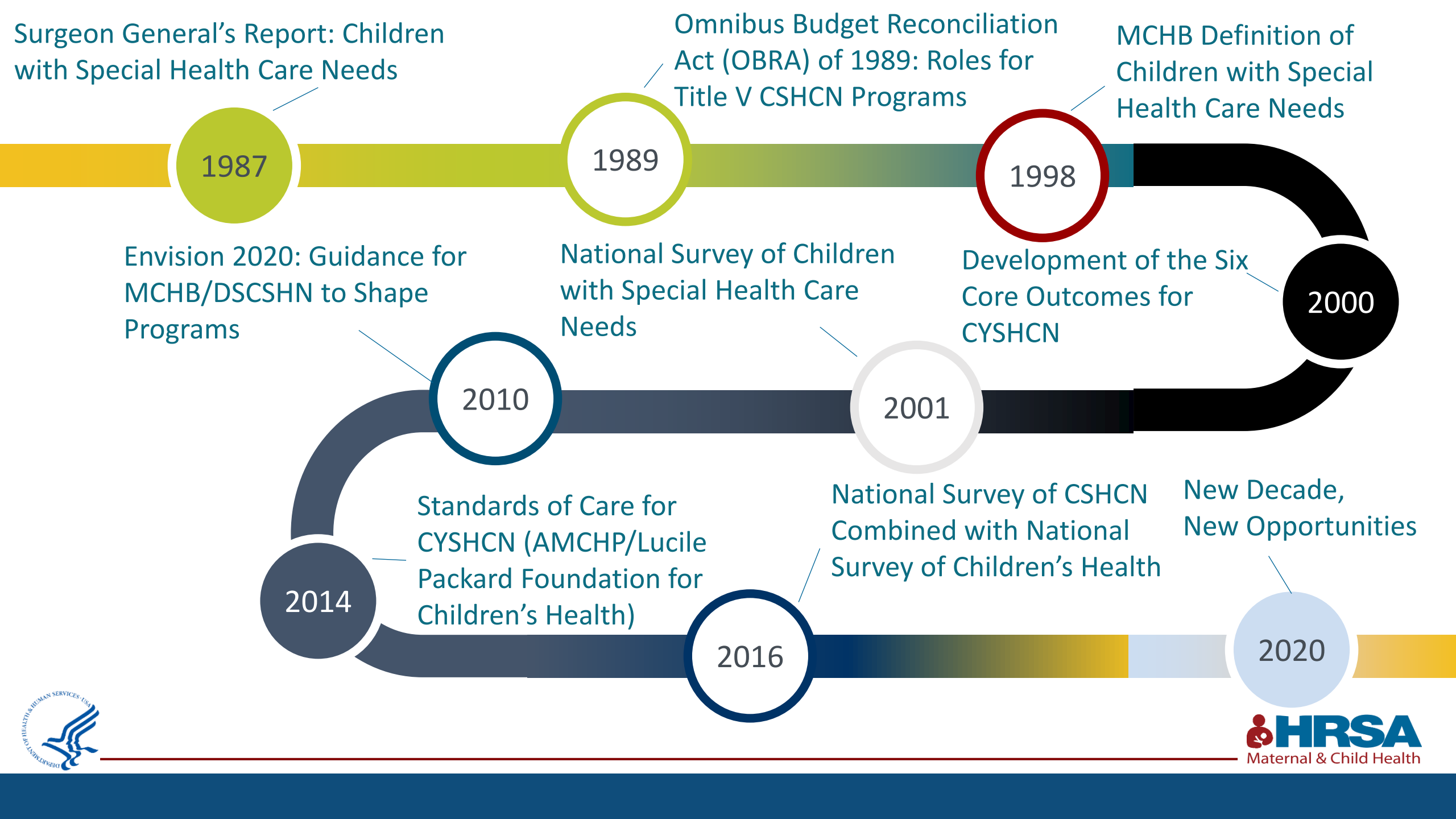
**Vision: Healthy Communities, Healthy People**



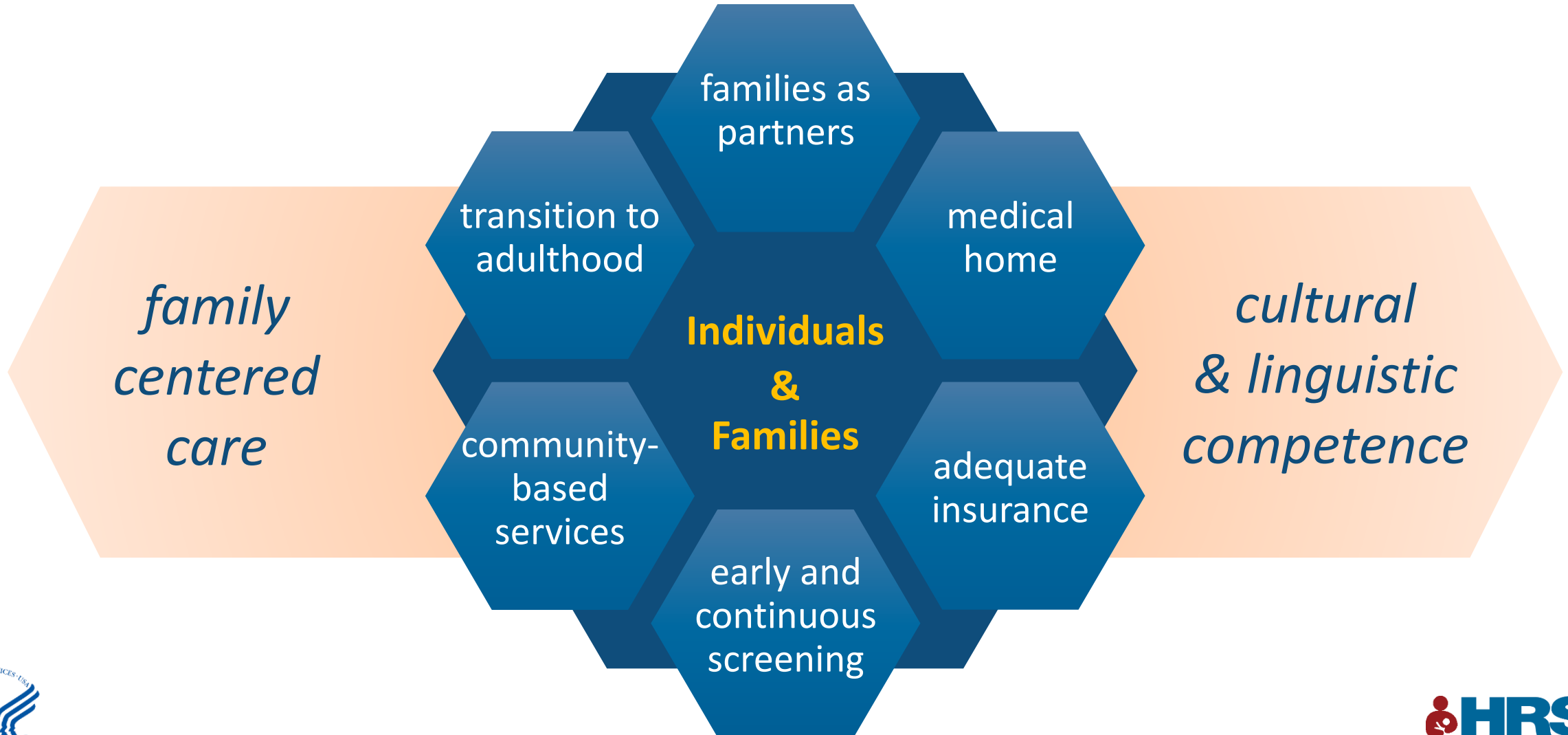
# From the Outside to the Inside (Jeff)

- Pediatrician
  - General pediatrics and developmental-behavioral pediatrics
  - See and talk with children and their families every week
- 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 CoIN, etc.
- State Government Experience
  - Deputy Secretary of Health (FL); Title V CYSHCN Director (FL)
- Scholarship – History, Ethics, and Health Policy





# Six Indicators of a Well-Functioning System





# National Standards for Systems of Care for CYSHCN



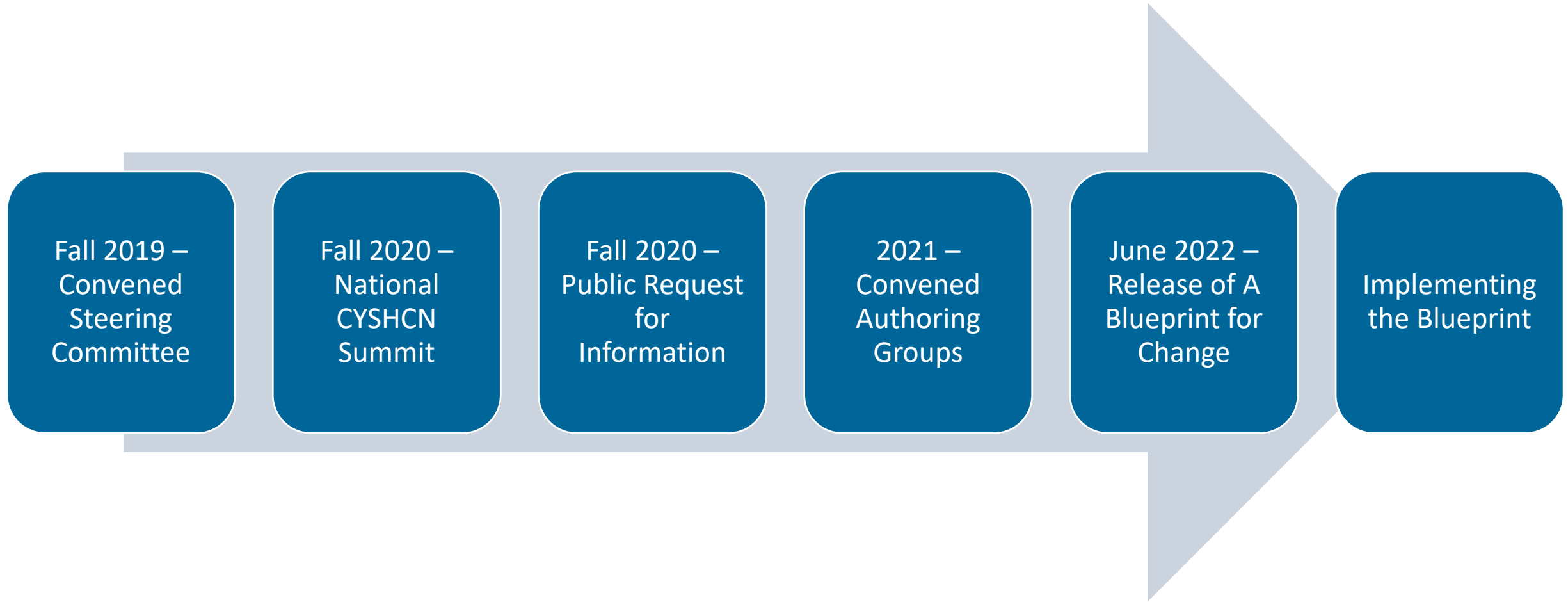
<https://nashp.org/wp-content/uploads/2018/09/Standards-for-Systems-of-Care-for-Children-and-Youth-with-Special-Health-Care-Needs-Version-2.0.pdf>



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

**AMCHP**

# Development of the Blueprint





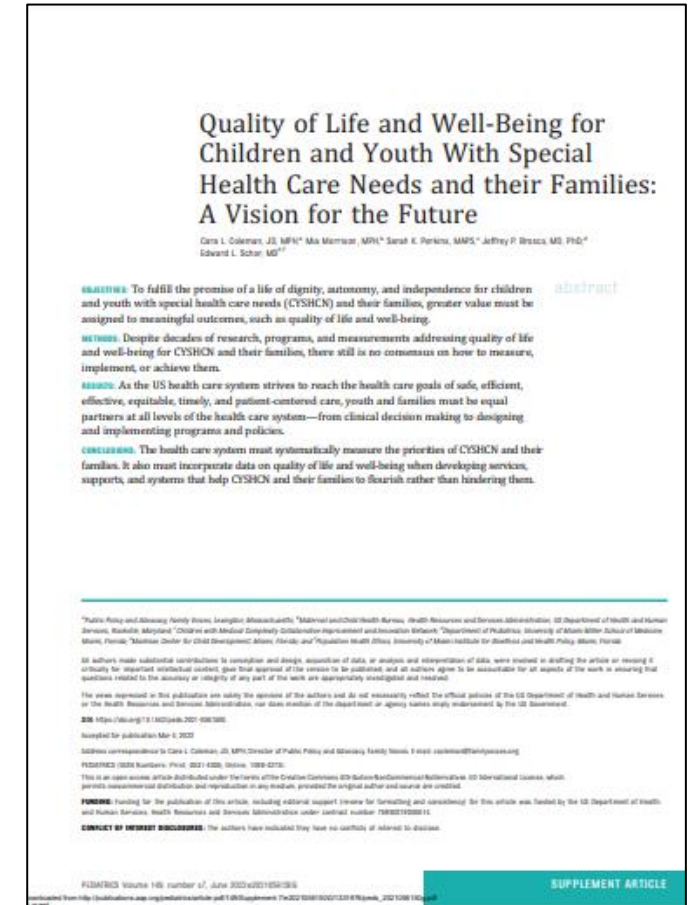
# Blueprint for Change for CYSHCN

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



# 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.



# 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.



National Care Coordination  
Standards for CYSHCN



Standards for Systems  
of Care for CYSCN

FINANCING

ACCESS

QUALITY OF LIFE

EQUITY

Medical Homes

Transitions

Screening

Insurance

Community  
Based Services

Family & Professional  
Partnerships



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

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**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

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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.



# 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.)

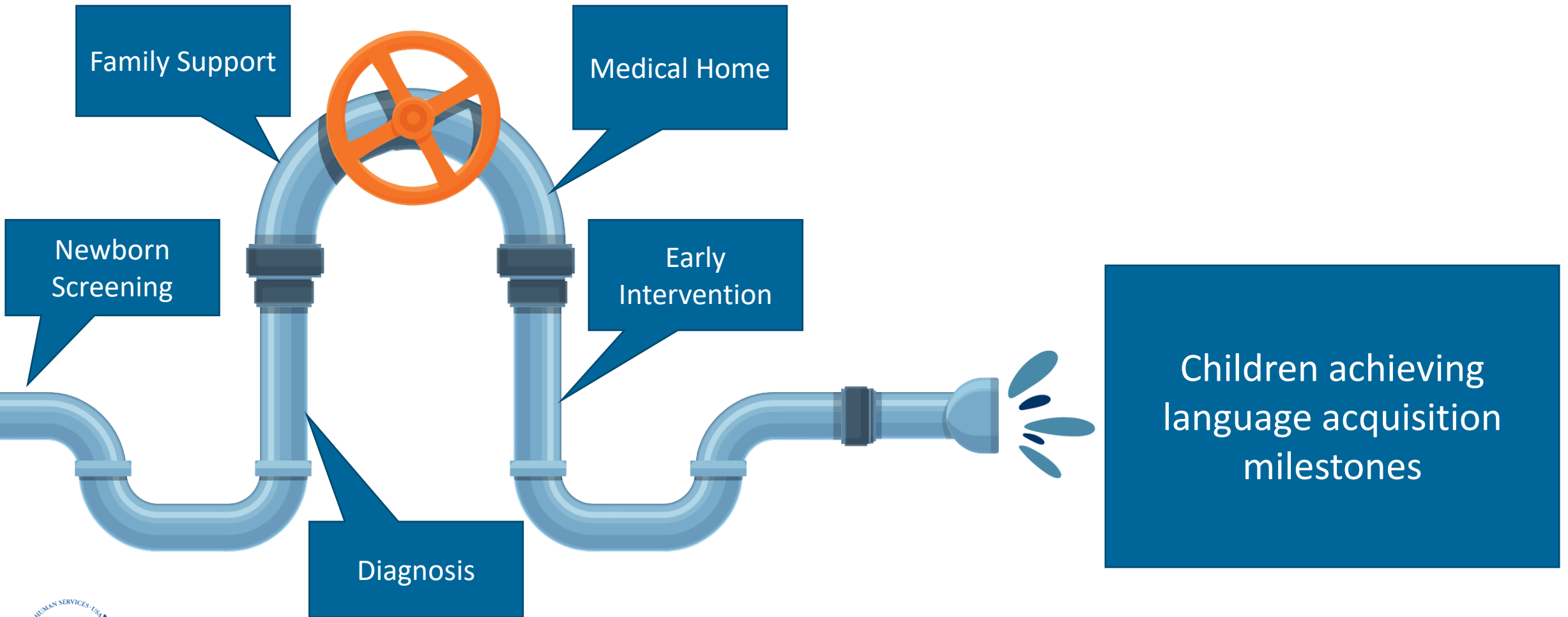
## 3. Accountable

- 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

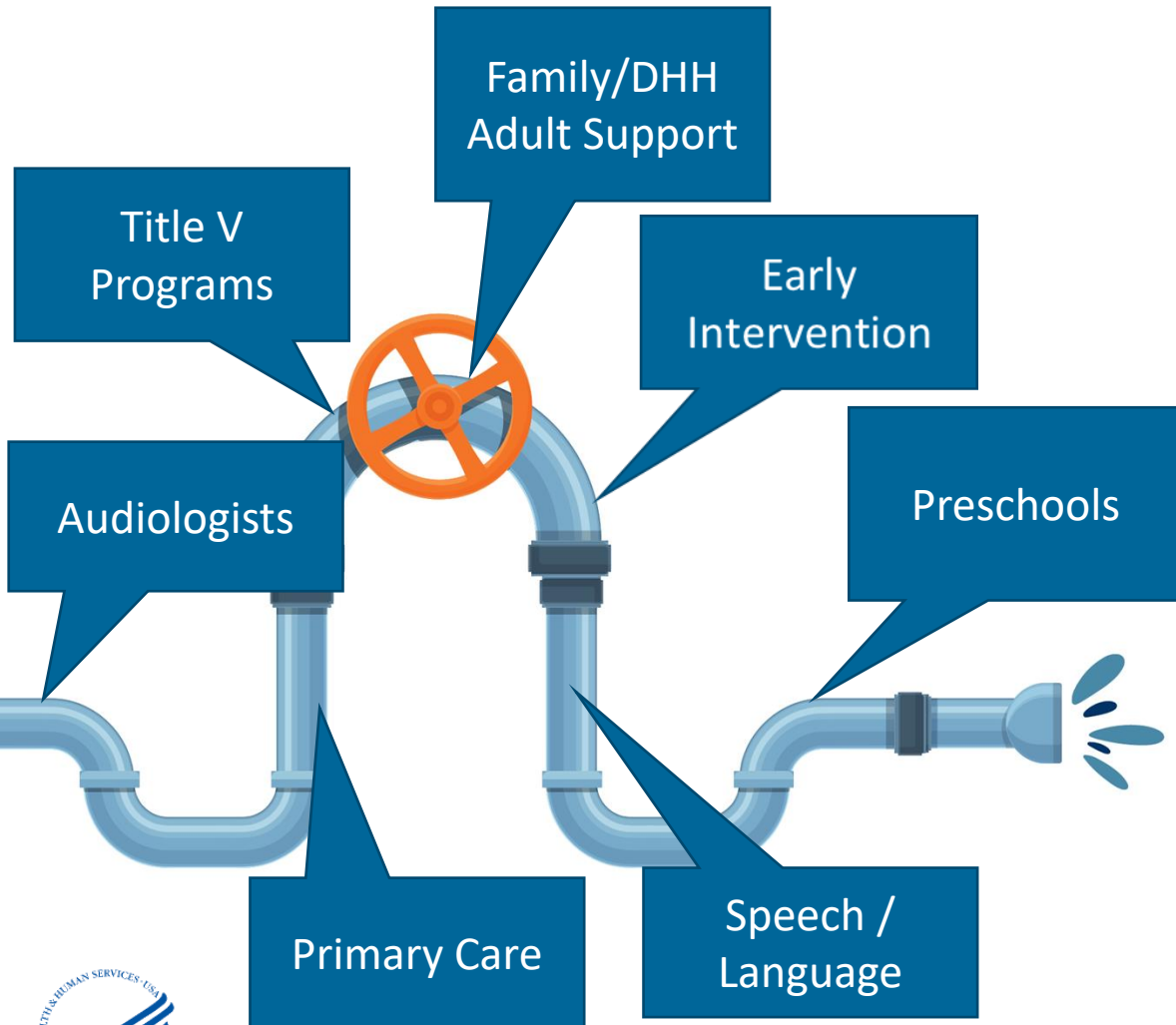




# EHDI Pipeline



# Everyone Helps Identify/Address the Leaks



## SYSTEMS LEVEL

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

## PROVIDER LEVEL

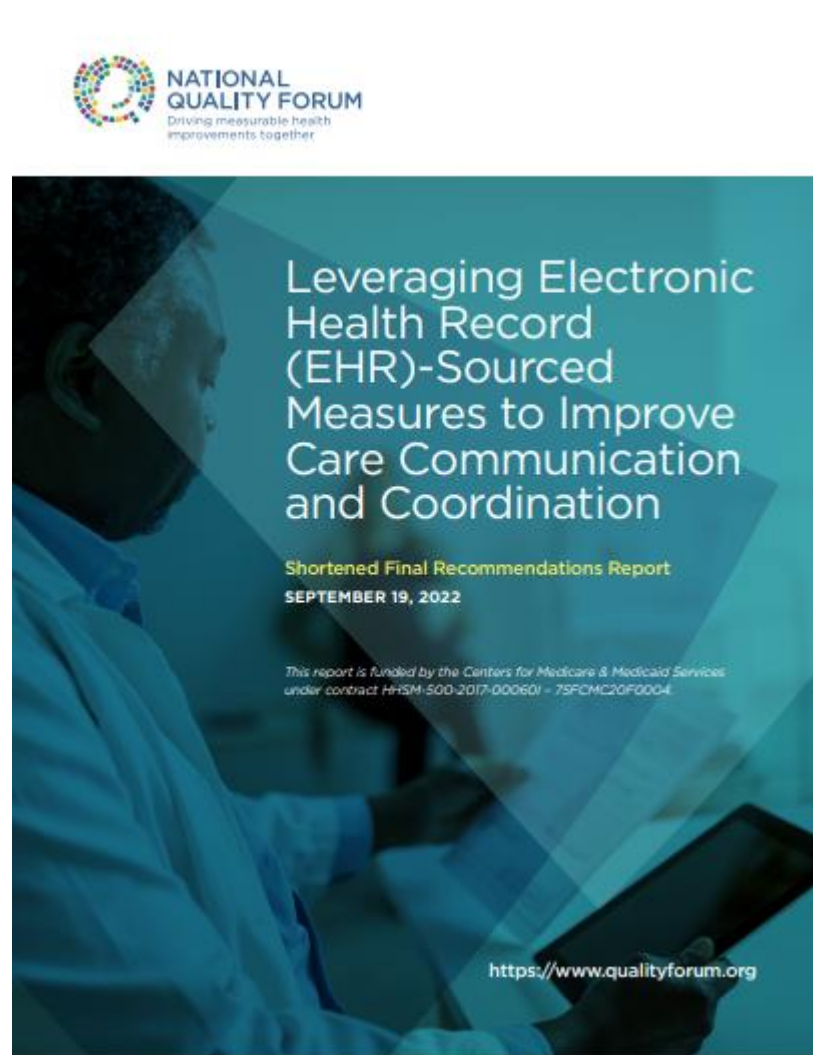
1-3-6 knowledge, workforce capacity, communication with families, guidance available, database capacity . . .

## PATIENT / FAMILY LEVEL

Competing needs, support network, financial support . . .

# Families are Key to Communication

- **Care communication** is the transfer of information for patient care.
- **Care coordination** is the deliberate synchronization of activities and information to improve health outcomes to ensure patients' and families' needs and preferences for healthcare and community services are met over the course of their treatment and 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](mailto:jbrosco@hrsa.gov)

Blueprint for Change:

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

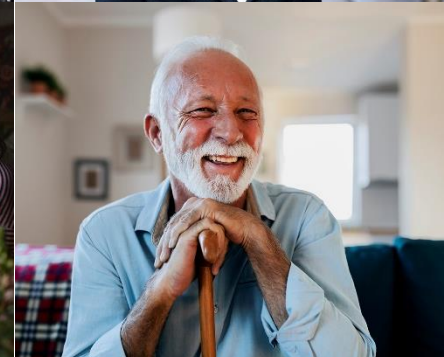
MCHB Website: [mchb.hrsa.gov](https://www.mchb.hrsa.gov)



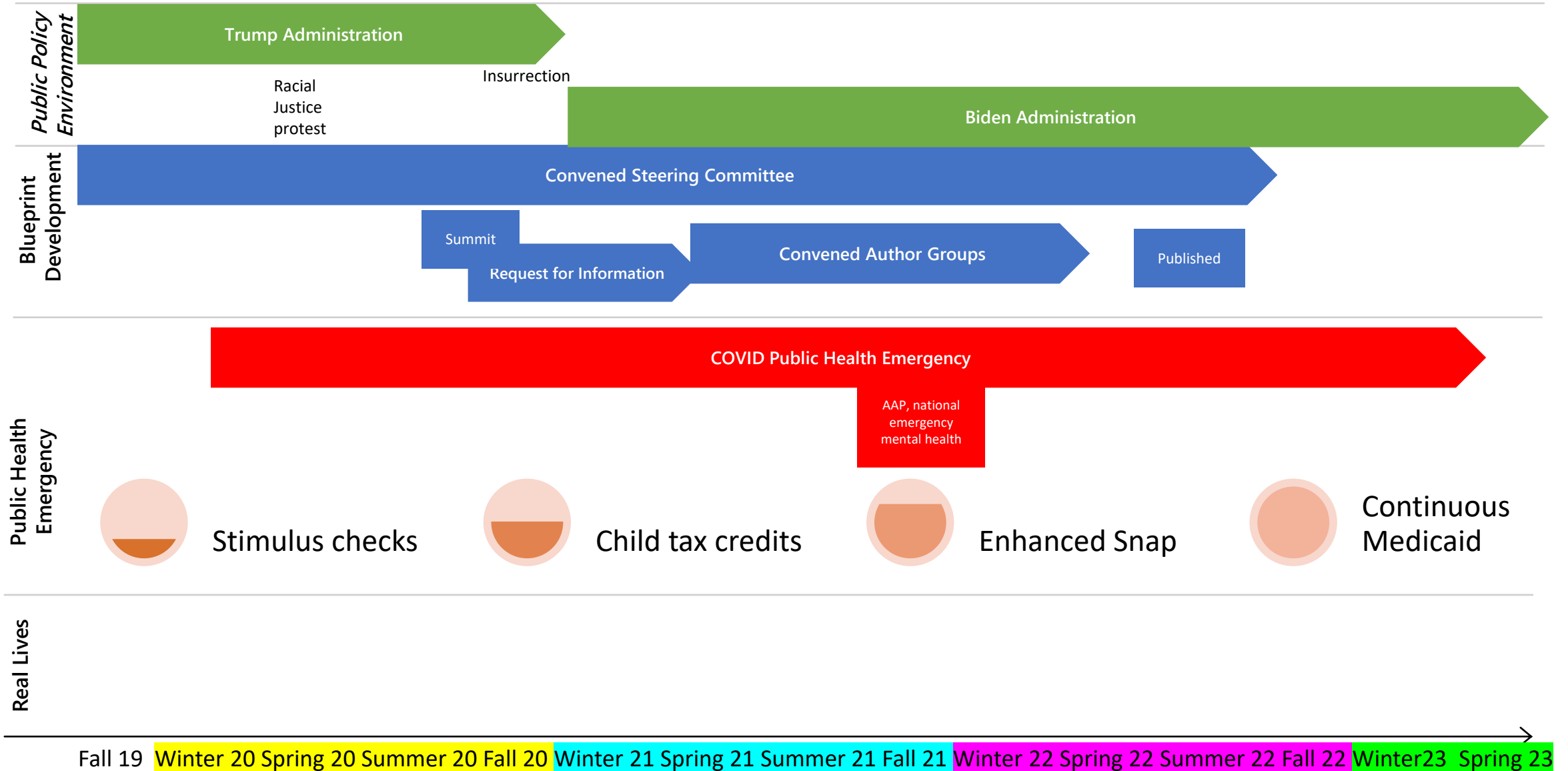




Rylin Rodgers  
[rylinrodgers@microsoft.com](mailto:rylinrodgers@microsoft.com)  
[Rylin Rodgers | LinkedIn](#)

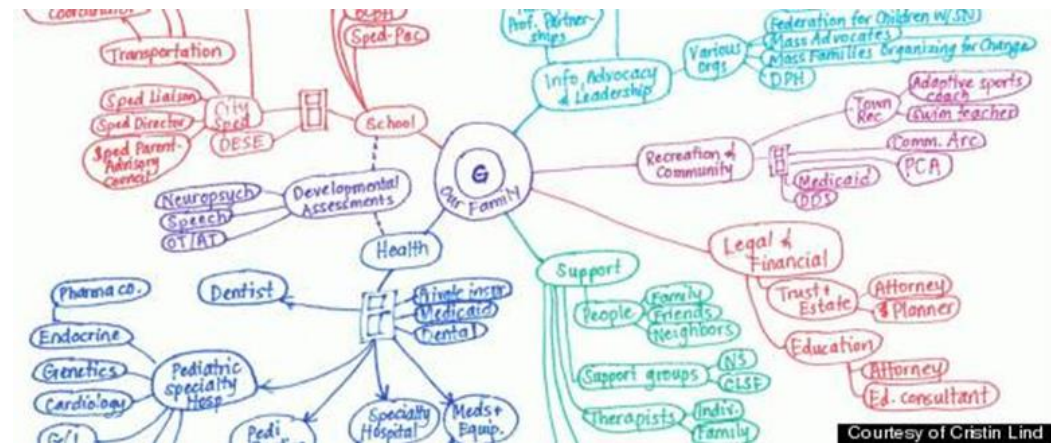
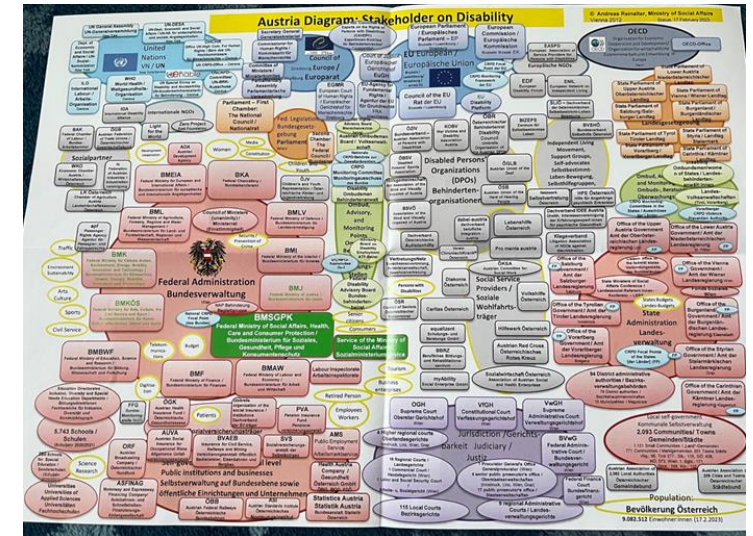


# What is Time....





# Children and Youth are Bigger than MCHB



Courtesy of Cristin Lind



# Blueprint for CHANGE



## Federal

- Budget
- HHS, Education, Housing, Agriculture

## State

- Block Grant Planning
- Budget
- Education planning

## Local

- School board, Social Services Infrastructure

## Provider

- Hospital and medical system, transportation, housing

## Personal

- IEP, IFSP, Waiver Transition

# Question and Answer



Healthy Children. Healthy Families. Healthy Communities.

Thank you!

Join us for Part 2 of this webinar series next Wednesday, March 29, at 3 pm ET

