



# MCHB WELCOME 2024 EHDI GRANTEE MEETING

*March 20, 2024*

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**Maternal and Child Health Bureau (MCHB)**

**Vision: Healthy Communities, Healthy People**



# CHILDREN AND YOUTH WITH SPECIAL HEALTH CARE NEEDS

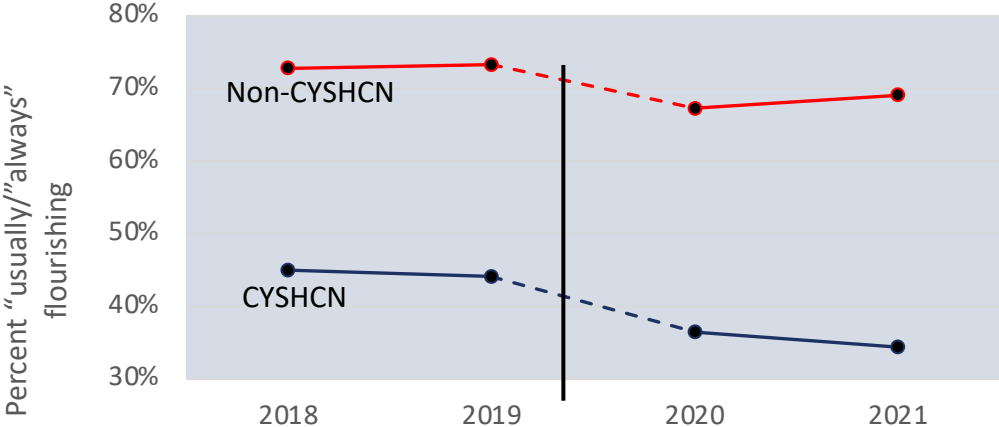
## WHO ARE CYSHCN?

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.

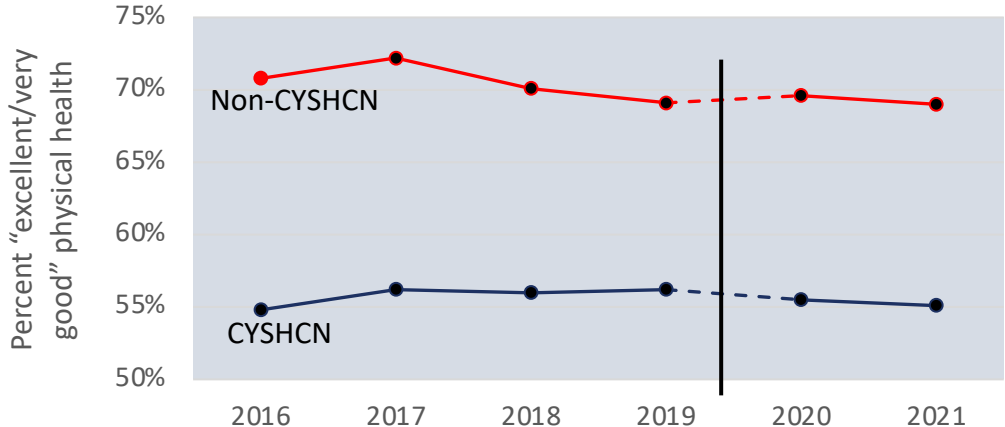


# CYSHCN & Family Quality of Life & Well-Being (MCHB data)

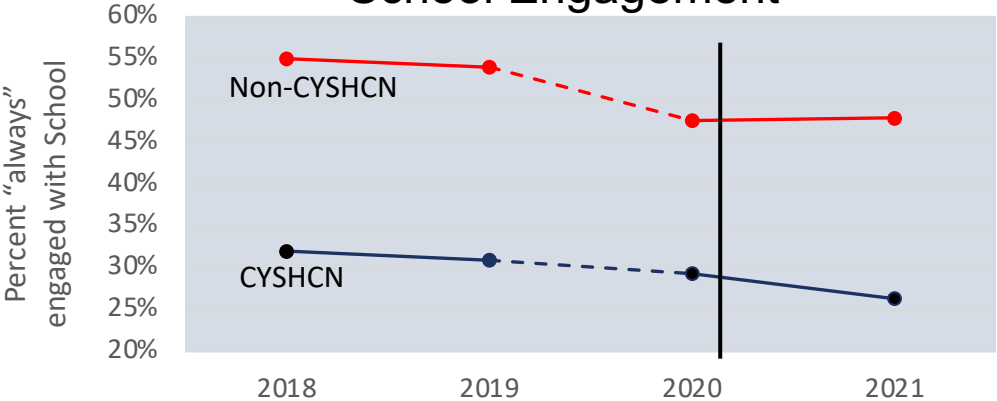
### Flourishing (6-17 years old)



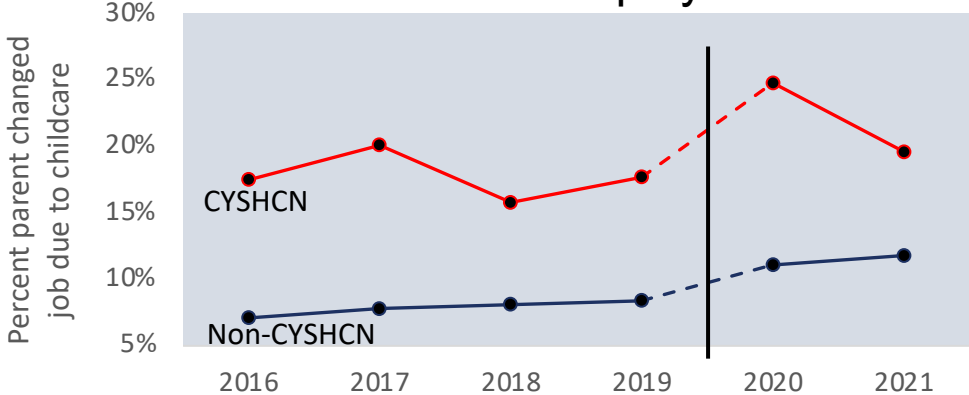
### Parent Physical Health



### School Engagement



### Parent Employment



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



## 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

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American Academy  
of Pediatrics

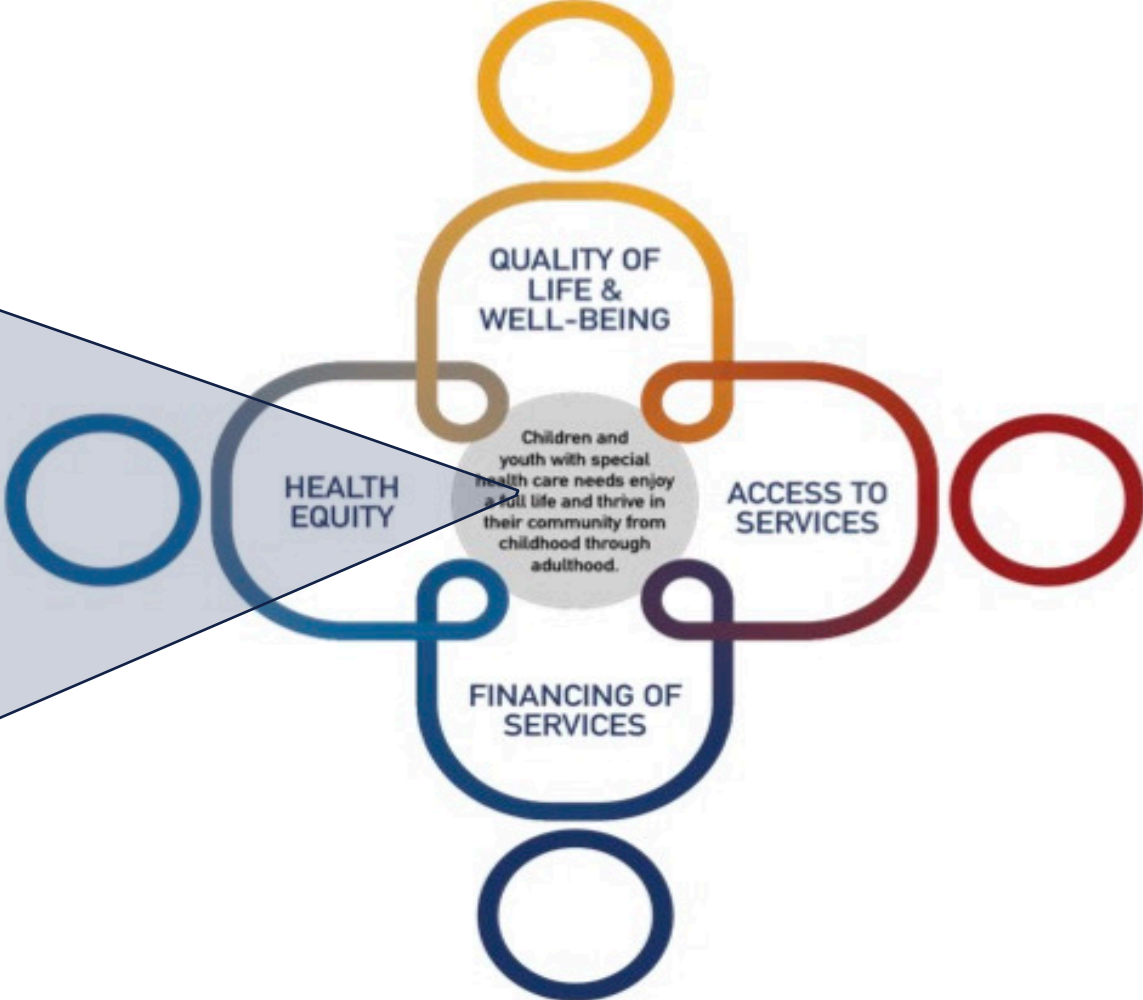


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# BLUEPRINT FOR CHANGE FOR CYSHCN

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
  - Successful transition to adulthood
  - Caregiver well-being
- At least one condition-specific measure
  - **Language acquisition**

## Population

- Systems-level approach
  - What % of all children, youth, caregivers are achieving the universal measures?
- **Equity**
  - 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?

# Language Acquisition

“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.”

- JCIH 2019 Position Statement



[Year 2019 Position Statement: Principles and Guidelines for Early Hearing Detection and Intervention Programs](#)

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

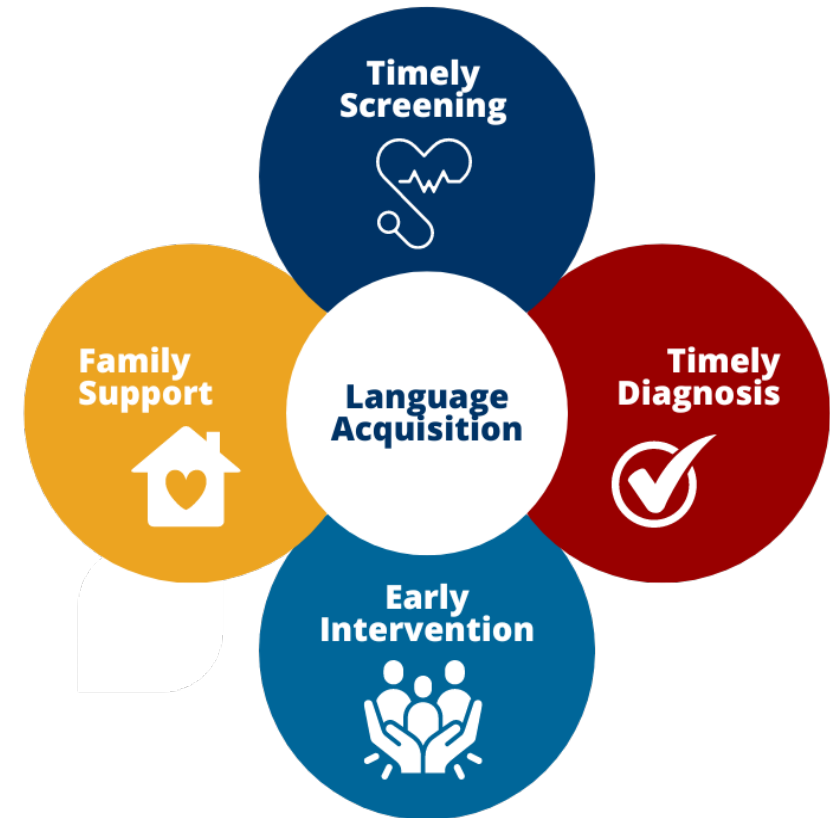


# OUR VISION FOR EHDI

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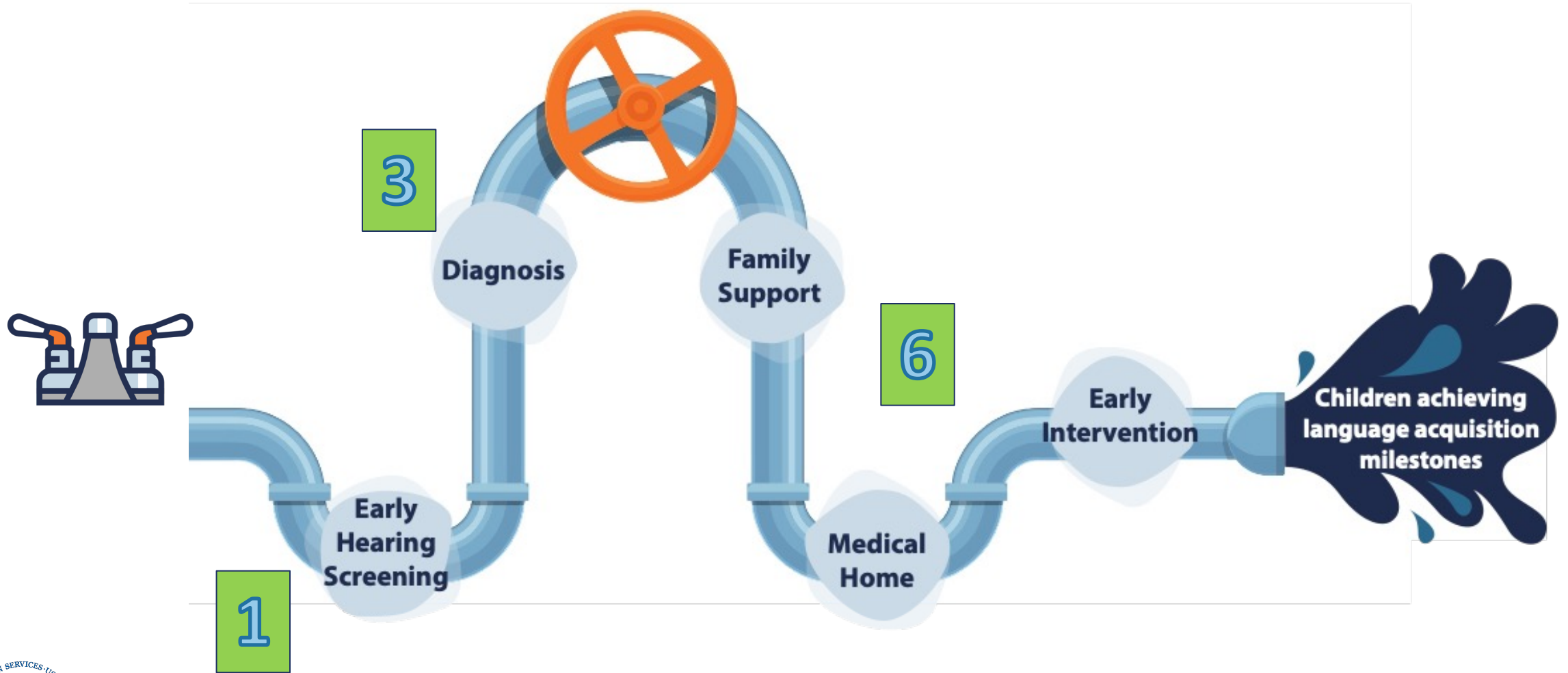
"The purpose of this program is to enhance the state/territory EHDI system infrastructure to improve language acquisition for deaf and hard-of-hearing (DHH) children up to age 3."

- HRSA State/Territory EHDI Program





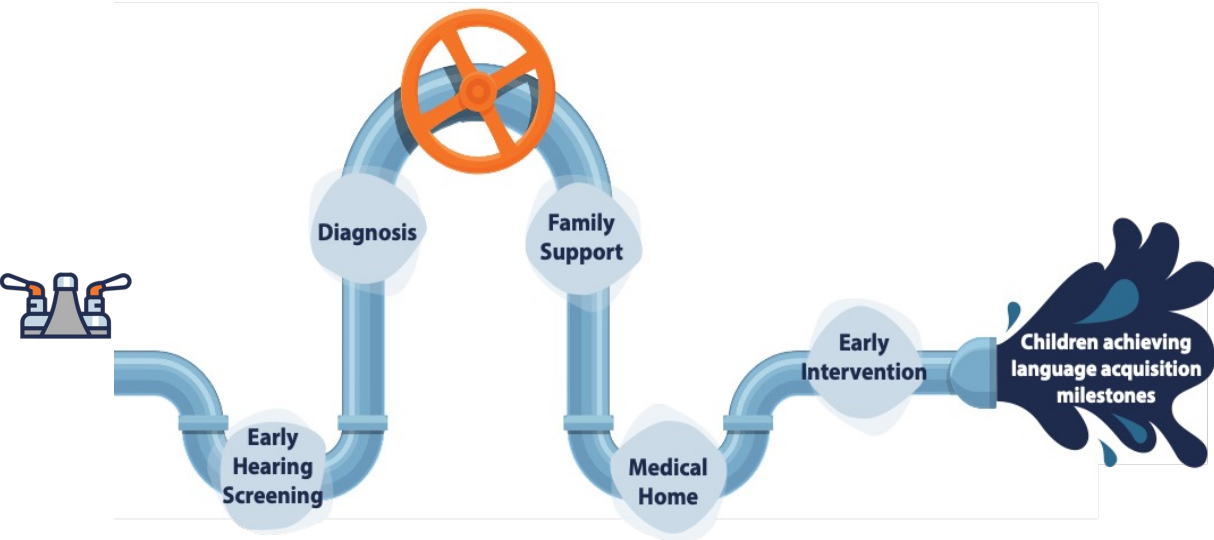
# THE EHDI PIPELINE



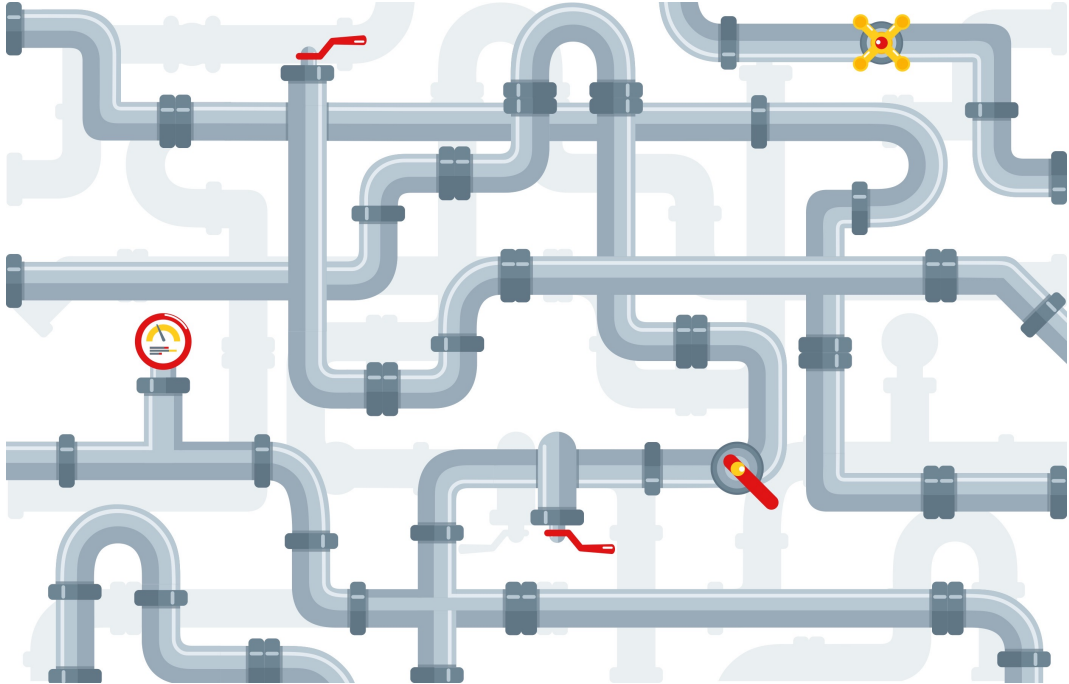
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# CHALLENGE # 1. What does your state look like?

## Ideal Pipeline



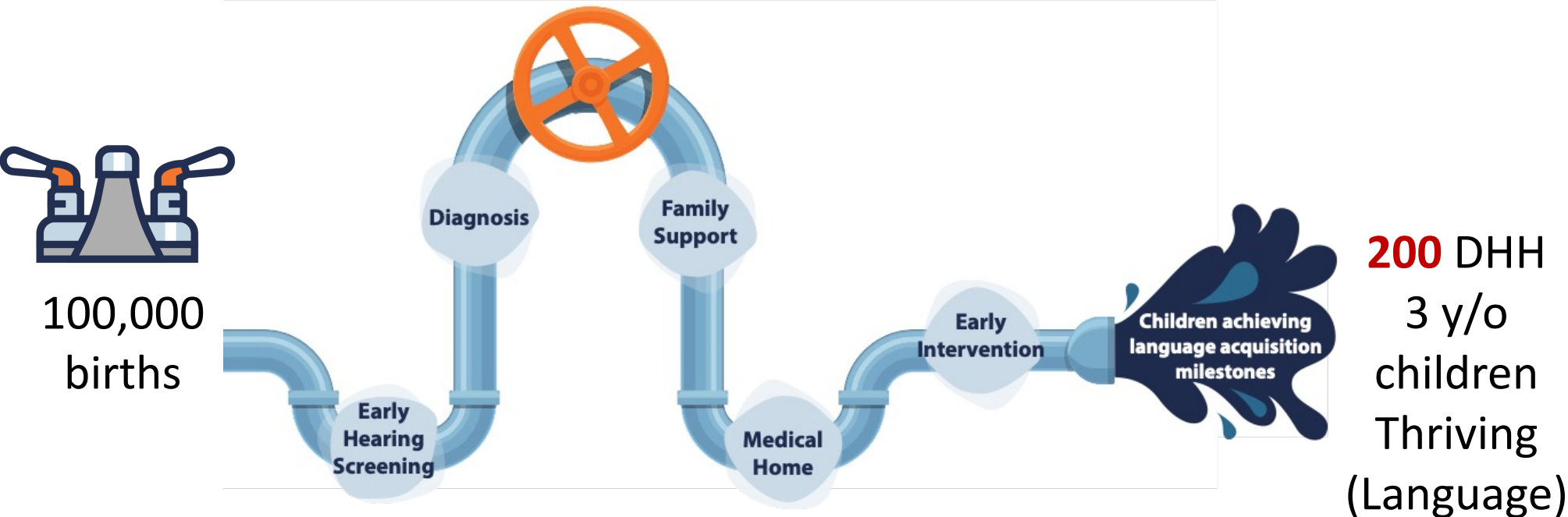
## Reality



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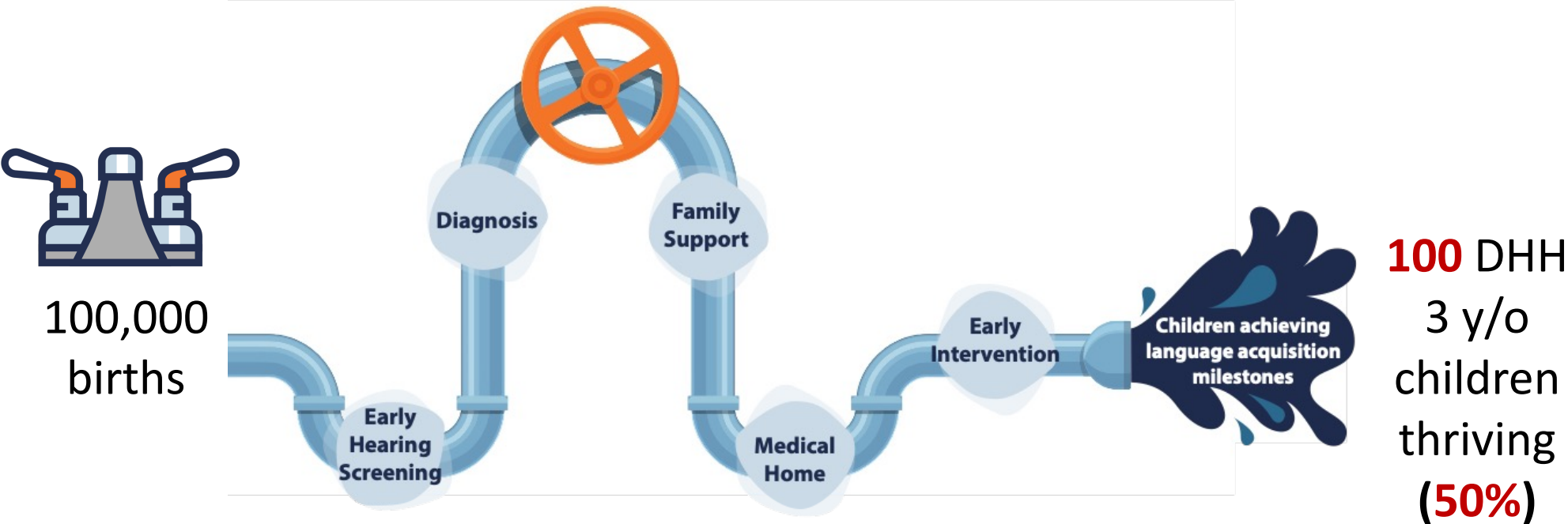
# CHALLENGE # 2. Is the system working?



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# EHDI PIPELINE

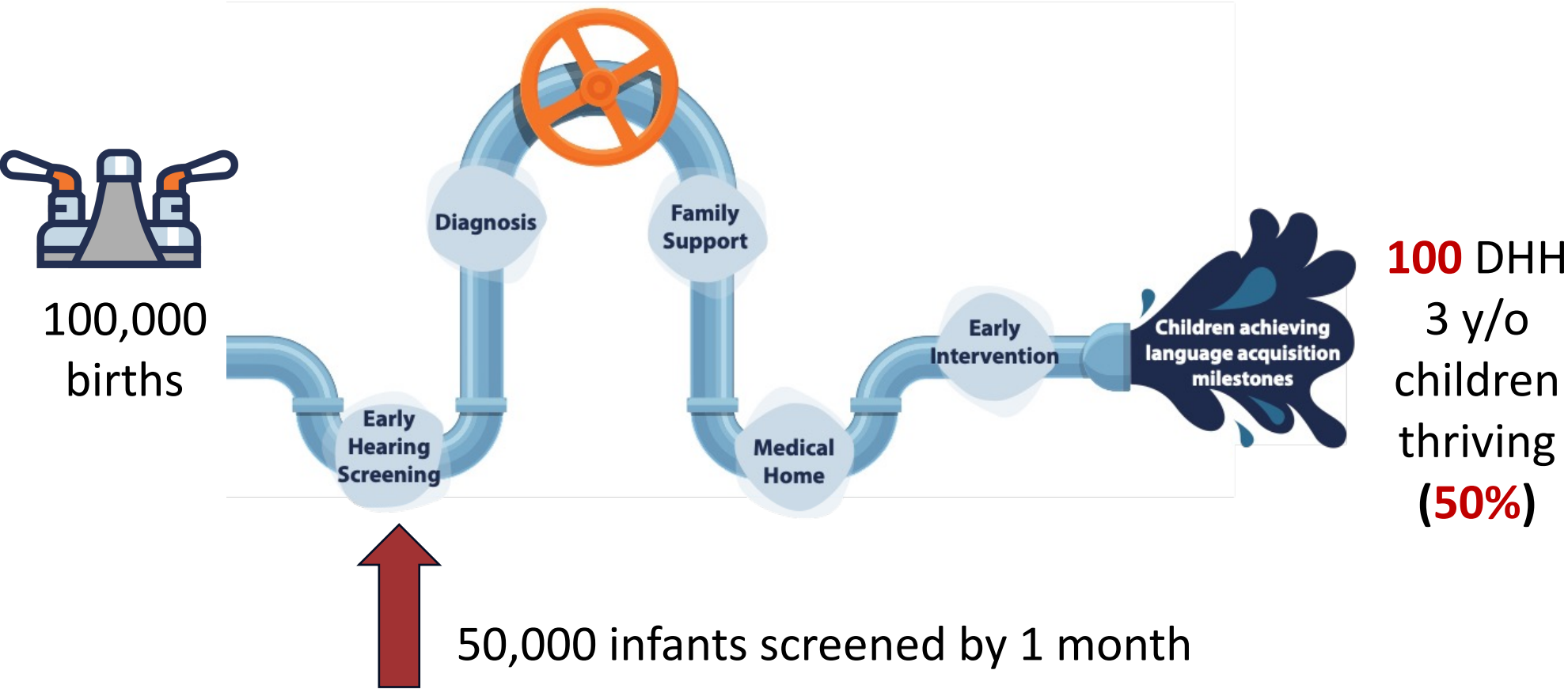
# A Really Good System



Where's the leak in the system?

# EHDI PIPELINE

# State A – Screening by 1 Month

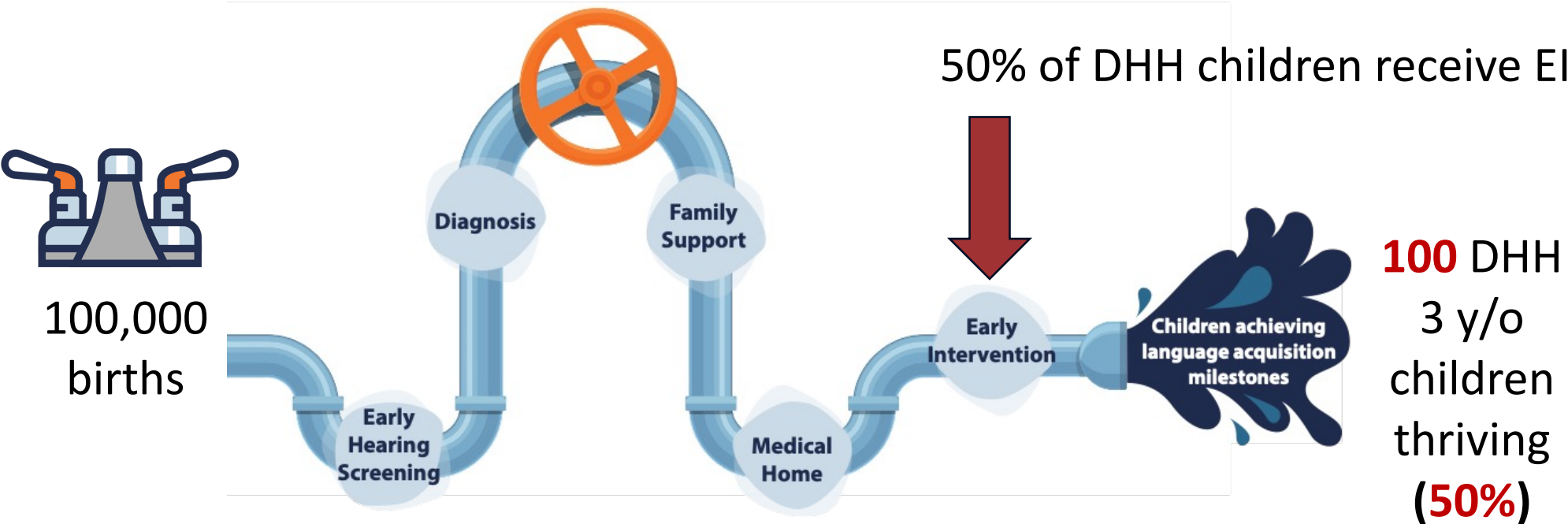


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# EHDI PIPELINE

# State B – Early Intervention

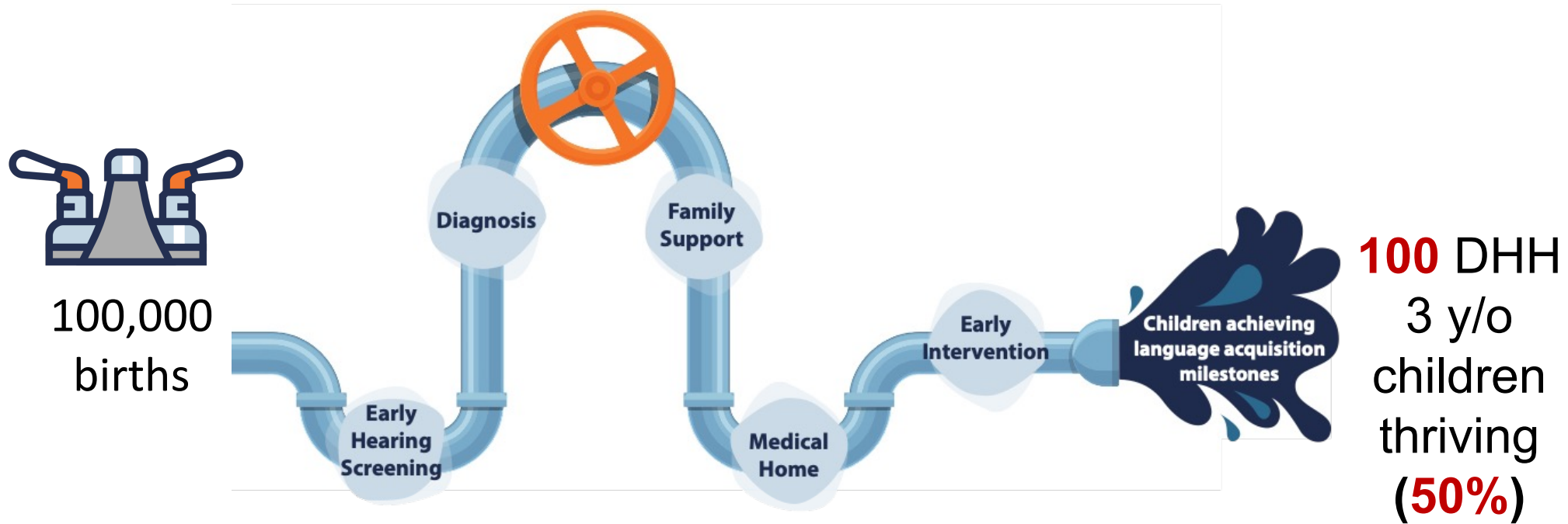


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# EHDI PIPELINE

## State C – Equity



**95% of urban children  
50% among rural**

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

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# FAMILY JOURNEY (not a “pipeline”)

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



# WHAT ARE THE STEPS?

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1. Work with stakeholders to create a consensus EHDI “system map”
  - What does the “pipeline” look like in your state/region?
  - How is it supposed to work?
2. Measure and monitor key points in your state’s system
  - 1-3-6, language acquisition, other key places in the system
  - Disaggregate by historically underserved groups in your state
3. Use data to inform an annual quality improvement plan to address key issues in your state (“leaks in pipeline” – “iceberg analysis”)
  - Work with local/regional/state stakeholders
  - **Supported by federal partners**

# MCHB EHDI: IMPROVING THE SYSTEM OF CARE

## EHDI National Network

### States and Territories



59 Grants

EHDI system  
& infrastructure

### LEND Pediatric Audiology



12 Supplements

Workforce  
development for  
LEND trainees

### Implementation and Change Center (ICC)



1 Cooperative Agreement

TAT to achieve  
state/territory  
goals & objectives

### Family Leadership in Language and Learning Center (FL3)



1 Cooperative Agreement

Family support  
& engagement

### Provider Education Center (PEC)



1 Cooperative Agreement

Provider\* support  
& education

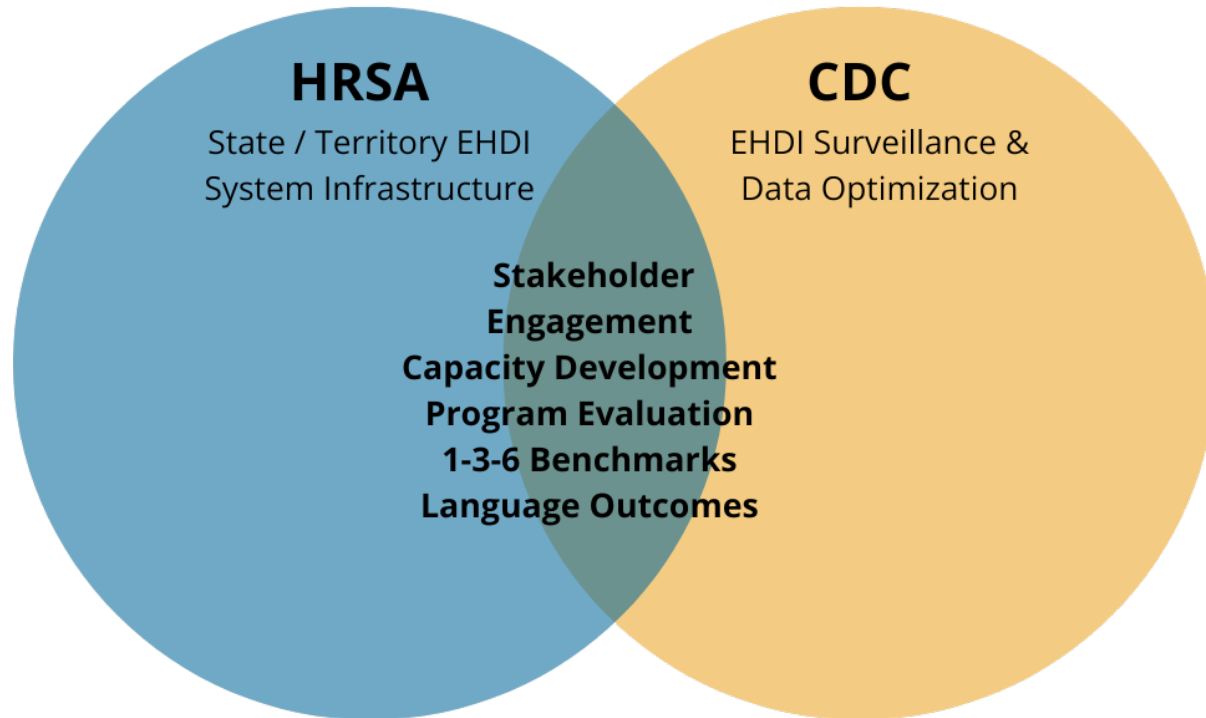
Learn more at <https://mchb.hrsa.gov>

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# WORKING TOWARDS A COMMON GOAL

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- **CDC:** Data alignment (1-3-6, family support), supplement evaluation
- **OSEP:** Partnerships, collaboration, and data sharing at state and local levels

# MCHB: IMPROVING THE SYSTEM OF CARE

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- **Family Engagement**

- Family Engagement and Leadership in Systems of Care (FELSC)
- Family Voices
- Shared definitions/metrics for family engagement
- Diverse families in systems of care

- **Research**

- CYSHCNet - University of Colorado
- QoL measures for CYSHCN and for caregivers
- Critical elements of health homes
- Epidemiology of CYSHCN

- **System of Services**

- National Center for a System of Services for CYSHCN
- “Blueprint Center”
- American Academy of Pediatrics
- Partners include Catalyst Center, Family Voices, and Got Transition
- State Title V programs; other key partners

- **CMC System of Services**

- Enhancing Systems of Care for CMC
- Academy Health
- Address social needs of CMC
- Measuring patient/family experience
- Sustainable health homes

# READ MORE ABOUT THE BLUEPRINT

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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!

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

# Contact Information

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## Blueprint for Change:

<https://mchb.hrsa.gov/programs-impact/focus-areas/children-youth-special-health-care-needs-cyshcn/blueprint-change>

**MCHB Website:** <https://mchb.hrsa.gov>



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