



# Accelerate Upstream Together: The role of EHDI in achieving the Maternal and Child Health Bureau's vision for all children and families

**Michael Warren, MD, MPH, FAAP**  
**Associate Administrator**  
**Maternal and Child Health Bureau (MCHB)**

**Vision: Healthy Communities, Healthy People**



# Department of Health and Human Services (Operating Divisions)



## Department of Health and Human Services (DHHS)

<b>Administration for Children and Families (ACF)</b>	<b>Food and Drug Administration (FDA)</b>
<b>Administration for Community Living (ACL)</b>	<b>Health Resources and Services Administration (HRSA)</b>
<b>Agency for Healthcare Research and Quality (AHRQ)</b>	<b>Indian Health Service (IHS)</b>
<b>Agency for Toxic Substances and Disease Registry (ASTDR)</b>	<b>National Institutes of Health (NIH)</b>
<b>Centers for Disease Control and Prevention (CDC)</b>	<b>Substance Abuse and Mental Health Services Administration (SAMHSA)</b>
<b>Centers for Medicare and Medicaid Services (CMS)</b>	



# Health Resources & Services Administration Bureaus



**Health Resources and Services  
Administration (HRSA)**

**Bureau of Health Workforce**

**Bureau of Primary Health Care**

**Healthcare Systems Bureau**

**HIV/AIDS Bureau**

**Federal Office of Rural Health  
Policy**

**Maternal and Child Health Bureau**



# Maternal & Child Health Bureau (MCHB)

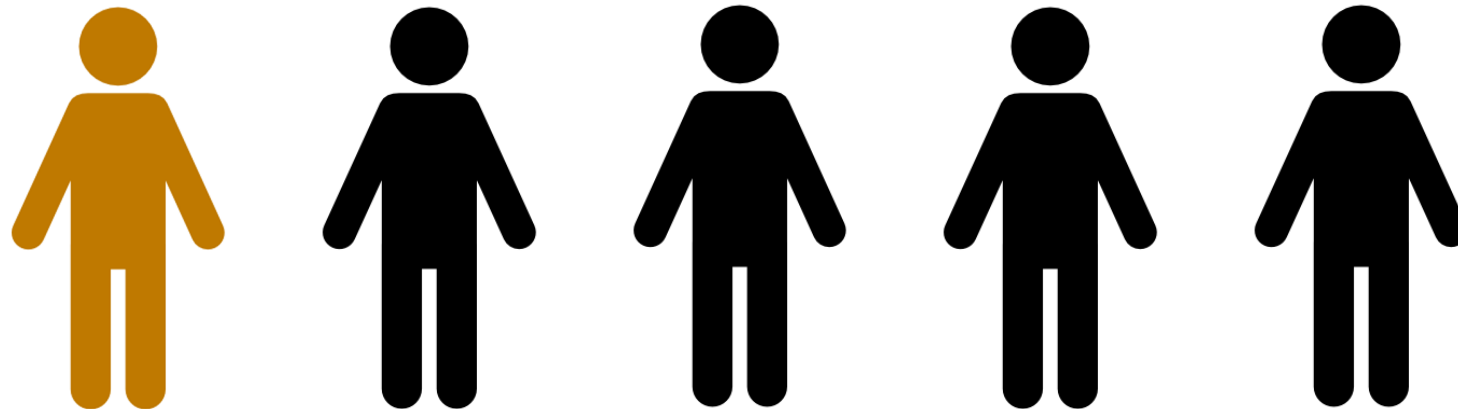
**Mission:** Improve the health of America's mothers, children, and families.



# Children and Youth with Special Health Care Needs (CYSHCN)

## Who are CYSHCN?

Children or youth *who have or are at increased risk for* a chronic physical, developmental, behavioral, or emotional conditions and who also require health and related services or a type or amount beyond that required for children generally.



# Why EHDI?

- Every year:
  - 2-3 of every 1,000 children are born deaf or hard of hearing in one or both ears.<sup>1</sup>
  - By kindergarten, the prevalence of children identified as deaf or hard of hearing increases to approximately 6 out of every 1,000 children.<sup>2</sup>
  - Over 90% of deaf and hard of hearing children are born to hearing parents.<sup>3</sup>
- 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.**



# HRSA EHDI History

- 1988 ● Demonstration grants in RI, UT, and HI to test newborn hearing screening feasibility
- 1999 ● Newborn and Infant Screening and Intervention Program Act passed
- 2000 ● James T. Walsh **Universal Newborn Hearing Screening (UNHS) Program** established
- 2002 ● First EHDI Annual Meeting
- 2006 ● All states and some territories have universal newborn hearing screening
- 2008 ● States adopt Quality Improvement methodologies to reduce LTF/D rates
- 2017 ● **Family Leadership in Language and Learning (FL3) Program** established



# EHDI Accomplishments

In 2017.....

**1** **97.1% Screened**  
by 1 month of age

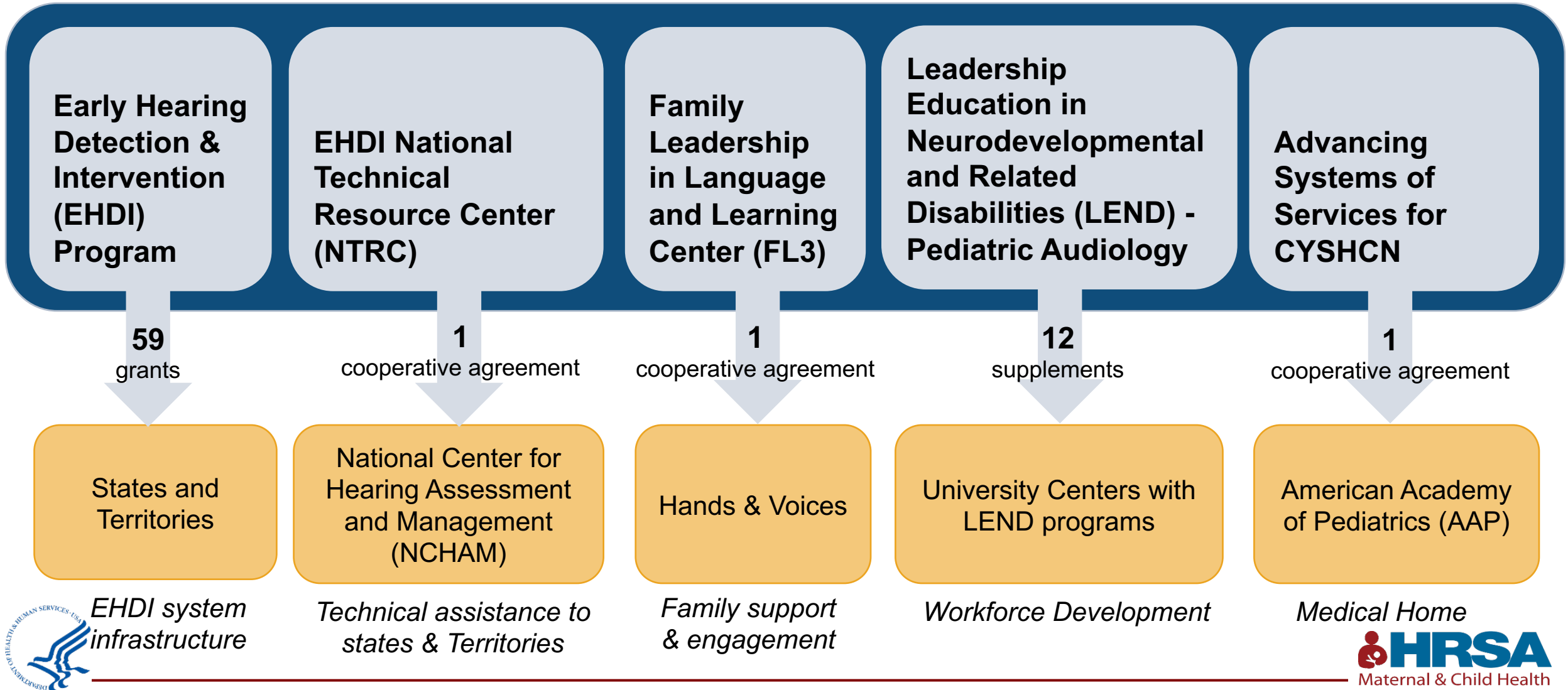
**3** **75.4% Diagnosed**  
by 3 months of age

**6** **66.7% Enrolled in Early Intervention**  
by 6 months of age





# HRSA's EHDI Programs



# New Funding Opportunities for 2020

## Address Legislative Changes

One Hundred Fifteenth Congress  
of the  
United States of America

AT THE FIRST SESSION

*Begun and held at the City of Washington on Tuesday,  
the third day of January, two thousand and seventeen*

### An Act

To amend the Public Health Service Act to reauthorize a program for early detection, diagnosis, and treatment regarding deaf and hard-of-hearing newborns, infants, and young children.

*Be it enacted by the Senate and House of Representatives of  
the United States of America in Congress assembled,*

#### SECTION 1. SHORT TITLE.

This Act may be cited as the “Early Hearing Detection and Intervention Act of 2017”.

**SEC. 2. REAUTHORIZATION OF PROGRAM FOR EARLY DETECTION,  
DIAGNOSIS, AND TREATMENT REGARDING DEAF AND HARD-  
OF-HEARING NEWBORNS, INFANTS, AND YOUNG CHILDREN.**

- Expanding hearing screening from newborn up to age 3
- Deaf and hard-of-hearing adult consumer-to-family supports
- *“Information provided to families is accurate, comprehensive, up-to-date, and evidence-based, as appropriate, to allow families to make important decisions for their children in a timely manner...”*

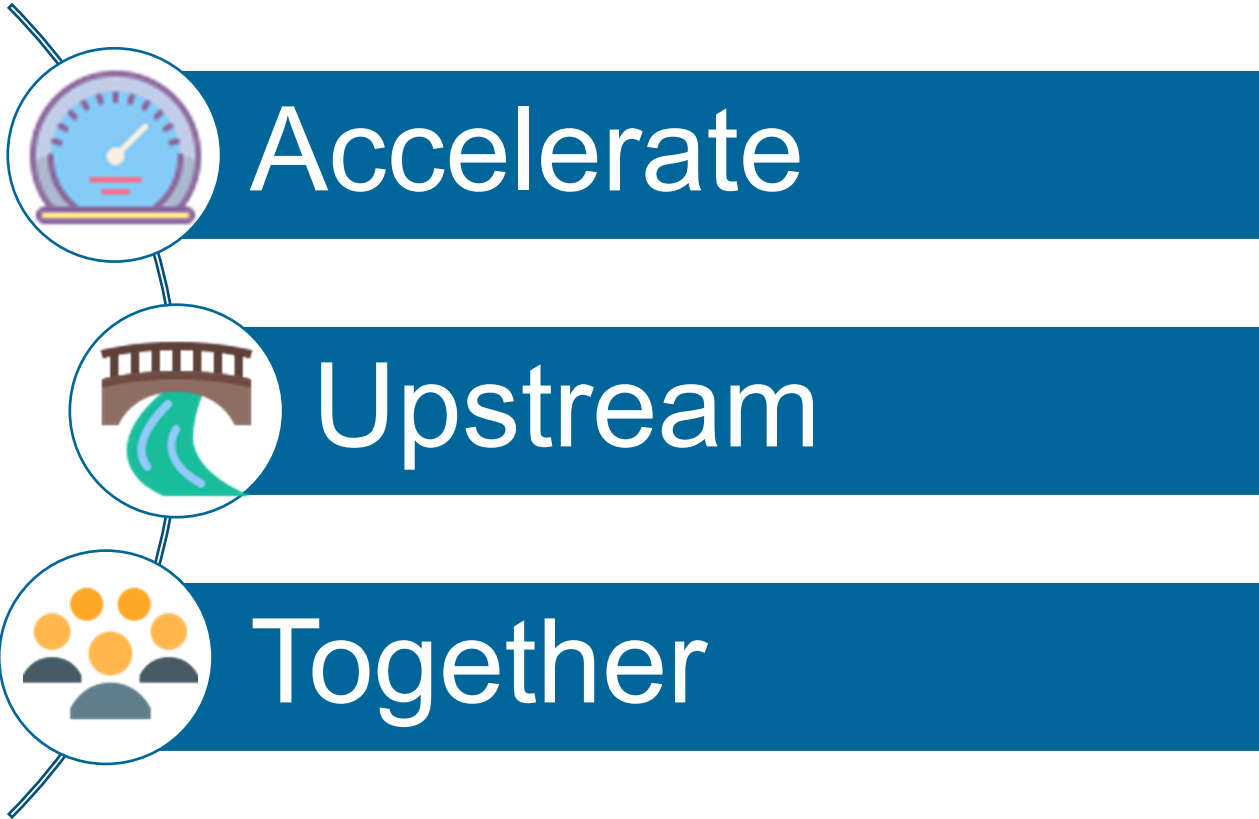


# Ongoing Challenges

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

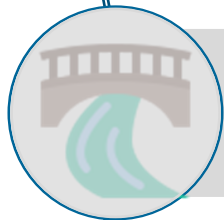


# Paradigm for Improving Maternal and Child Health

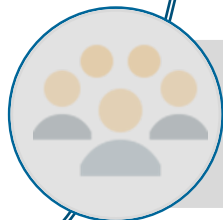




Accelerate



Upstream



Together

“...roots of problems in school-age children are in early ch

...resource brought to concerted early pres

...gaps in supervision resultant w

in the readiness of children to begin their education...”

# ATION, AND WELFARE

Children's Bureau •

1964

Government Printing Office  
ents

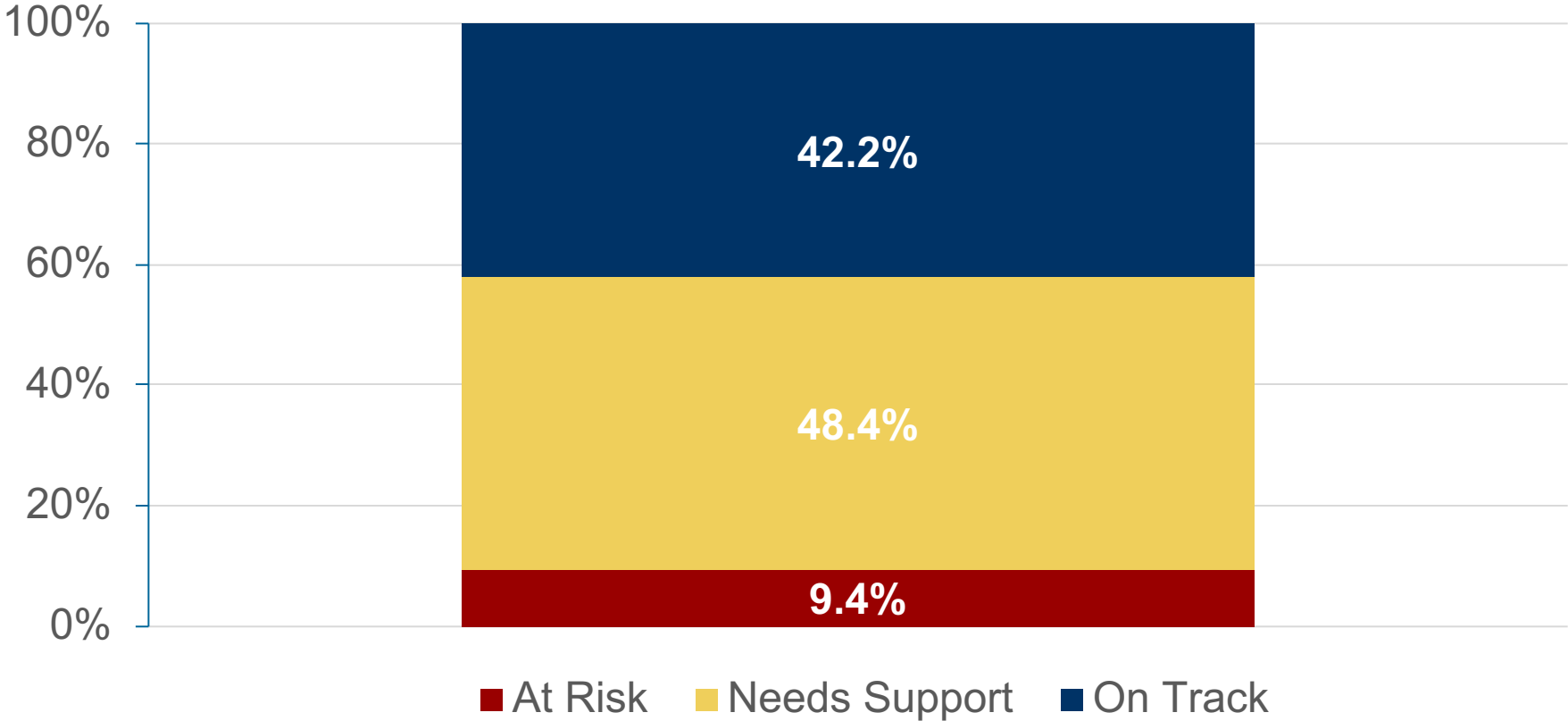
U.S. DEPARTMENT OF HEALTH, EDUCATION, AND WELFARE  
WELFARE ADMINISTRATION • Children's Bureau • 1964

For sale by the Superintendent of Documents, U.S. Government Printing Office  
Washington D.C., 20402 - Price 25 cents



# Healthy and Ready to Learn

Proportion of U.S. Children Aged 3-5 Scoring “On-Track,” “Needs Support,” or “At-Risk” for Pilot Healthy and Ready to Learn NOM, 2016 NSCH

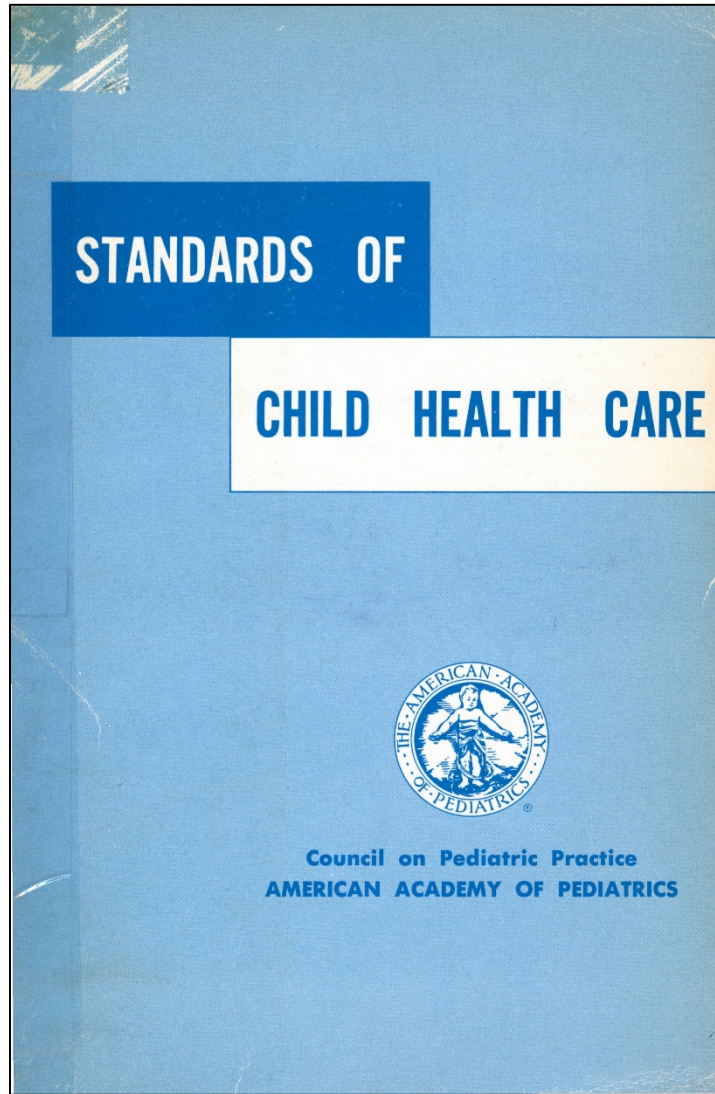


2020  
-1964

**=56 years**



# 1967



Medical home defined as “one central source of a child’s pediatric records”

“For children with chronic diseases or disabling conditions, the lack of a complete record and a ‘medical home’ is a major deterrent to adequate health supervision. Wherever the child is cared for, the question should be asked, ‘Where is the child’s medical home?’ and any pertinent information should be transmitted to that place”



# AMERICAN ACADEMY OF PEDIATRICS

## The Medical Home

### Ad Hoc Task Force on Definition of the Medical Home

The American Academy of Pediatrics believes that the medical care of infants, children, and adolescents ideally should be accessible, continuous, comprehensive, family centered, coordinated, and compassionate. It should be delivered or directed by well-trained physicians who are able to manage or facilitate essentially all aspects of pediatric care. The physician should be known to the child and family and should be able to develop a relationship of mutual responsibility and the "medical home" tradition.

office setting. In contrast, care provided through emergency departments, walk-in clinics, and other urgent-care facilities is often less effective and more costly.

We should strive to attain a "medical home" for all of our children. Although geographic barriers, personnel constraints, practice patterns, and economic and social forces make the ideal "medical home" unobtainable for many children, we believe that comprehensive health care of infants, children, and adolescents, wherever delivered, should encompass the

where these can be obtained. Provision of medical information about the patient to the consultant. Evaluation of the consultant's recommendations, implementation of recommendations that are indicated and appropriate, and interpretation of these to the family.

5. Interaction with school and community agencies to be certain that special health needs of the individual child are addressed.

zations. This record should be accessible, but confidentiality must be assured.

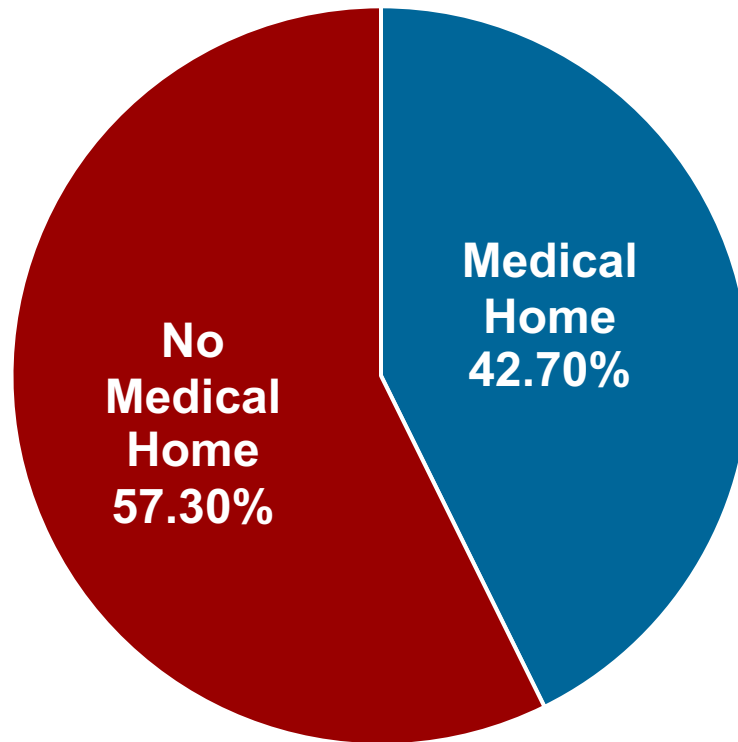
Medical care of infants, children, and adolescents must sometimes be provided in locations other than physician's offices. However, unless these locations provide all of the services listed above, they do not meet the definition of a medical home. Other venues for children's care include hospital outpatient clinics, school-based and school-linked clinics, community health centers, health department clinics, and others.

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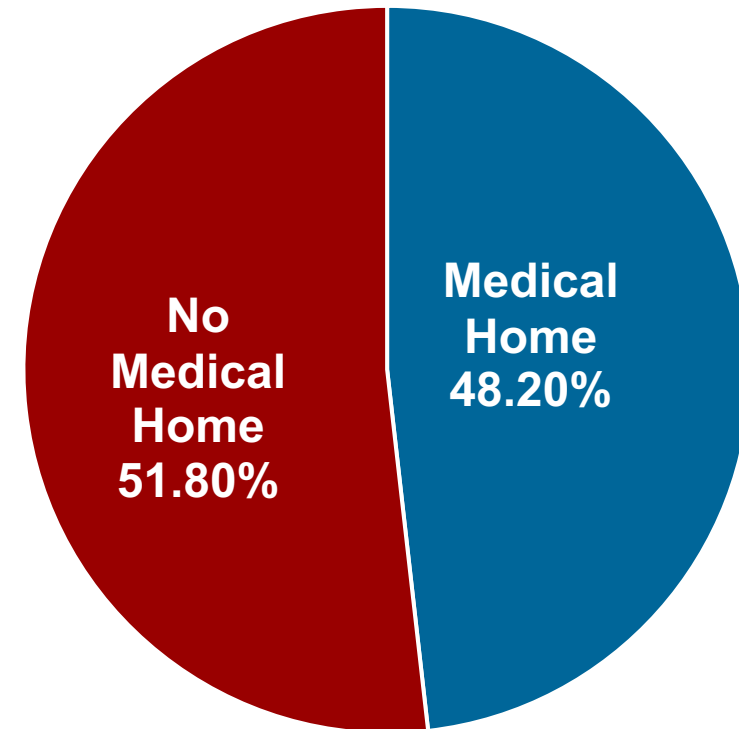


# Medical Home (National Survey of Children's Health, 2017-18)

## CSHCN



## All Children



2020  
- 1967

**=53 years**

# Position Statement

The Joint Committee on Infant Hearing endorses the goal of universal detection of infants with hearing loss as early as possible. All infants with hearing loss should be identified before 3 months of age, and receive intervention by 6 months of age.



## Joint Committee on Infant Hearing

### 1994 Position Statement

This 1994 Position Statement was developed by the Joint Committee on Infant Hearing. Joint committee member organizations that approved this statement and their respective representatives who prepared this statement include the American Speech-Language-Hearing Association (Allan O. Diefendorf, PhD, Chair; Deborah Hayes, PhD; and Evelyn Cherow, MA, ex officio); the American Academy of Otolaryngology-Head and Neck Surgery (Patrick E. Brookhouser, MD, and Stephen Epstein, MD); the American Academy of Audiology (Terese Finitzo, PhD; and Jerry Northern, PhD); the American Academy of Pediatrics (Allen Erenberg, MD, and Nancy Roizen, MD); and the Directors of Speech and Hearing Programs in State Health and Welfare Agencies (Thomas Mahoney, PhD, and Kathie J. Mense, MS).

#### Position Statement\*

The Joint Committee on Infant Hearing endorses the goal of universal detection of infants with hearing loss as early as possible. All infants with hearing loss should be identified before 3 months of age, and receive intervention by 6 months of age.

#### I. Background

In 1982, the Joint Committee on Infant Hearing recommended identification of infants at risk for hearing loss in terms of specific risk factors and suggested follow-up audiologic evaluation until an accurate assessment of hearing could be made (Joint Committee on Infant Hearing, 1982; American Academy of Pediatrics, 1982). In 1990, the Position Statement was modified to expand the list of

risk factors and recommend a specific hearing screening protocol.

In concert with the national initiative *Healthy People 2000* (U.S. Department of Health and Human Services, Public Health Service, 1990), which promotes early identification of children with hearing loss, this 1994 Position Statement addresses the need to identify all infants with hearing loss.

The prevalence of newborn and infant hearing loss is estimated to range from 1.5 to 6.0 per 1,000 live births (Watkin, Baldwin, & McEnery, 1991; Parving, 1993; White & Behrens, 1993). Risk factor screening identifies only 50% of infants with significant hearing loss (Pappas, 1983; Elisman, Matkin, & Sabo, 1987; Mauk, White, Mortensen, & Behrens, 1991). Failure to identify the remaining 50% of children with hearing loss results in diagnosis and intervention at an unacceptably late age.

This 1994 Position Statement:

1. endorses the goal of universal detection of infants with hearing loss and encourages continuing research and development to improve techniques for detection of and intervention for hearing loss as early as possible;
2. maintains a role for the high-risk factors (hereafter termed indicators) described in the 1990 Position Statement, and modifies the list of indicators associated with sensorineural and/or conductive hearing loss in newborns and infants;
3. identifies indicators associated with late-onset hearing loss and recommends procedures to monitor infants with these indicators;
4. recognizes the adverse effects of fluctuating conductive hearing loss from persistent or recurrent otitis media with effusion (OME) and recommends monitoring infants with OME for hearing loss;

6. identifies additional considerations necessary to enhance early identification of infants with hearing loss.

#### II. Considerations for Detecting Hearing Loss in Infants

A successful infant hearing program must detect hearing loss that will interfere with normal development of speech and oral language. Because normal hearing is critical for speech and oral language development as early as the first 6 months of life (Kuhl, Williams, Lacerda, Stephens, & Lindbloom, 1992), it is desirable to identify infants with hearing loss before 3 months of age.

Facilities or agencies that implement infant hearing programs must develop protocols to achieve identification of all infants with hearing loss. To gain access to most infants, the Joint Committee on Infant Hearing recommends the option of evaluating infants before discharge from the newborn nursery. For infants discharged early or delivered at an alternative birthing site, it is desirable to have their hearing assessed before 3 months of age.

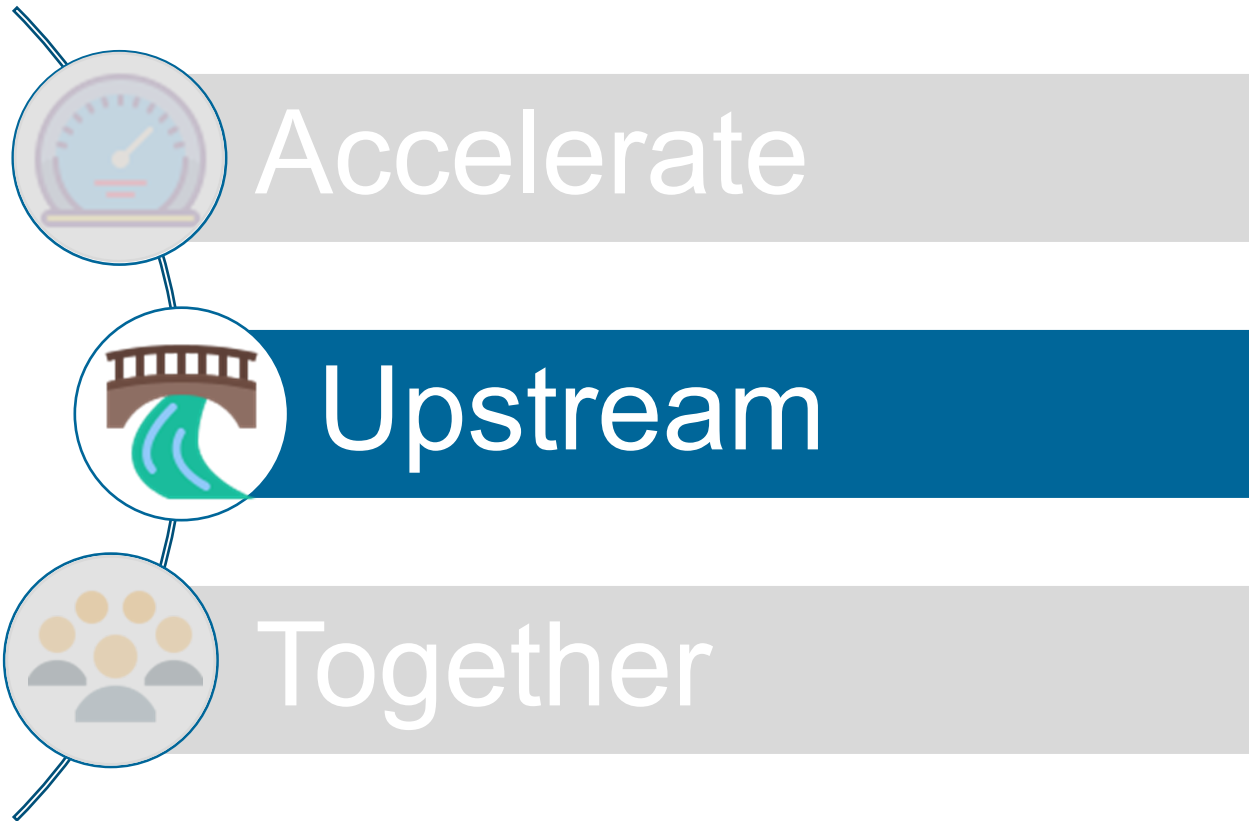
Concern for hearing should not stop at birth. Some children may develop delayed-onset hearing loss. For infants identified with indicators associated with delayed-onset hearing loss (see Sections III B and III C, below), ongoing monitoring and evaluation will be necessary (ASHA, 1991).

#### A. Technical Considerations

Hearing loss of 30 dB HL and greater in the frequency region important for speech recognition (approximately 500 through 4000 Hz) will interfere with the normal development of speech and language. Techniques used to assess hearing of infants must be capable of detecting hearing loss of this degree in

2020  
-1994

**=26 years**





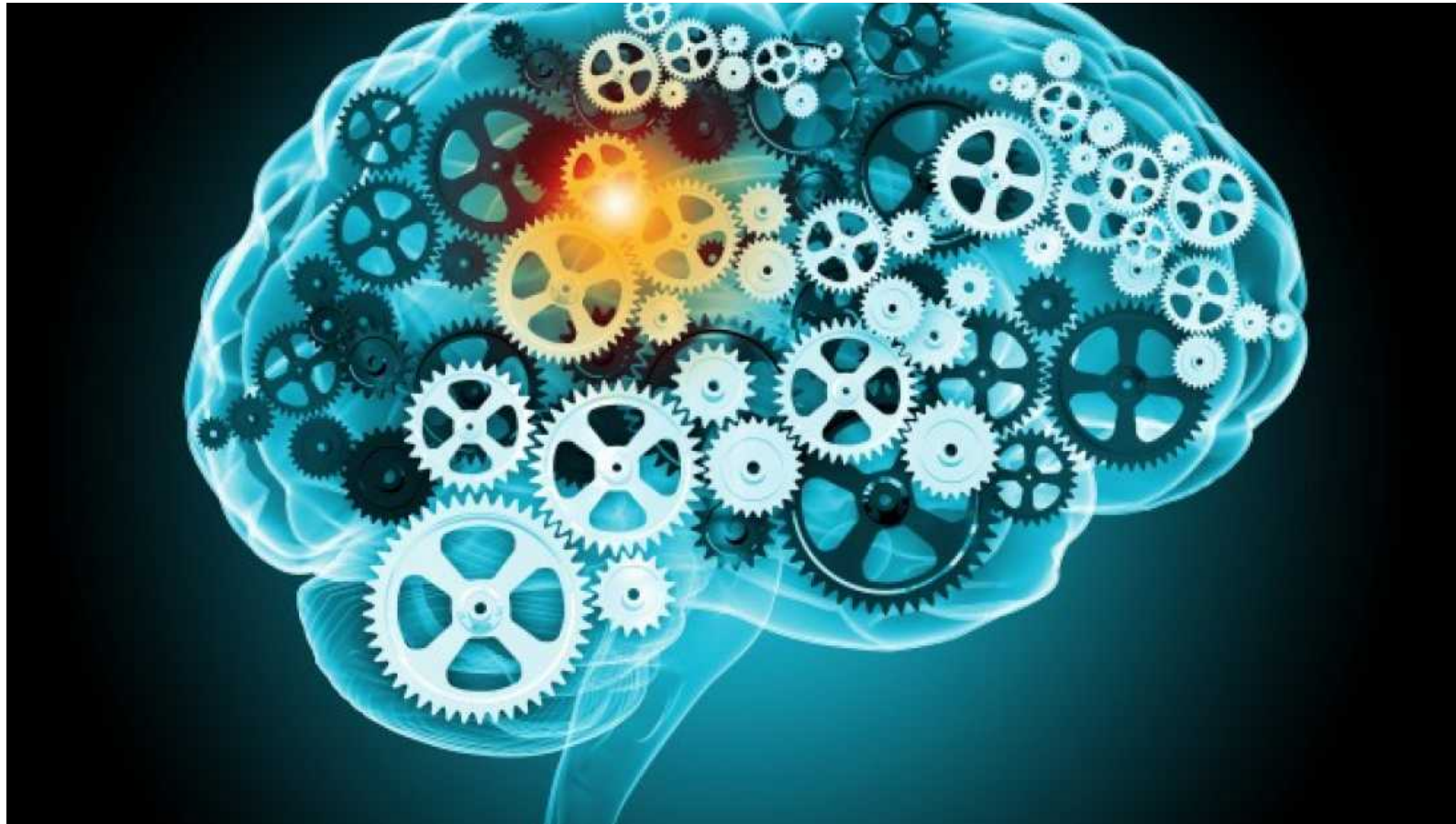


# Levels of Prevention

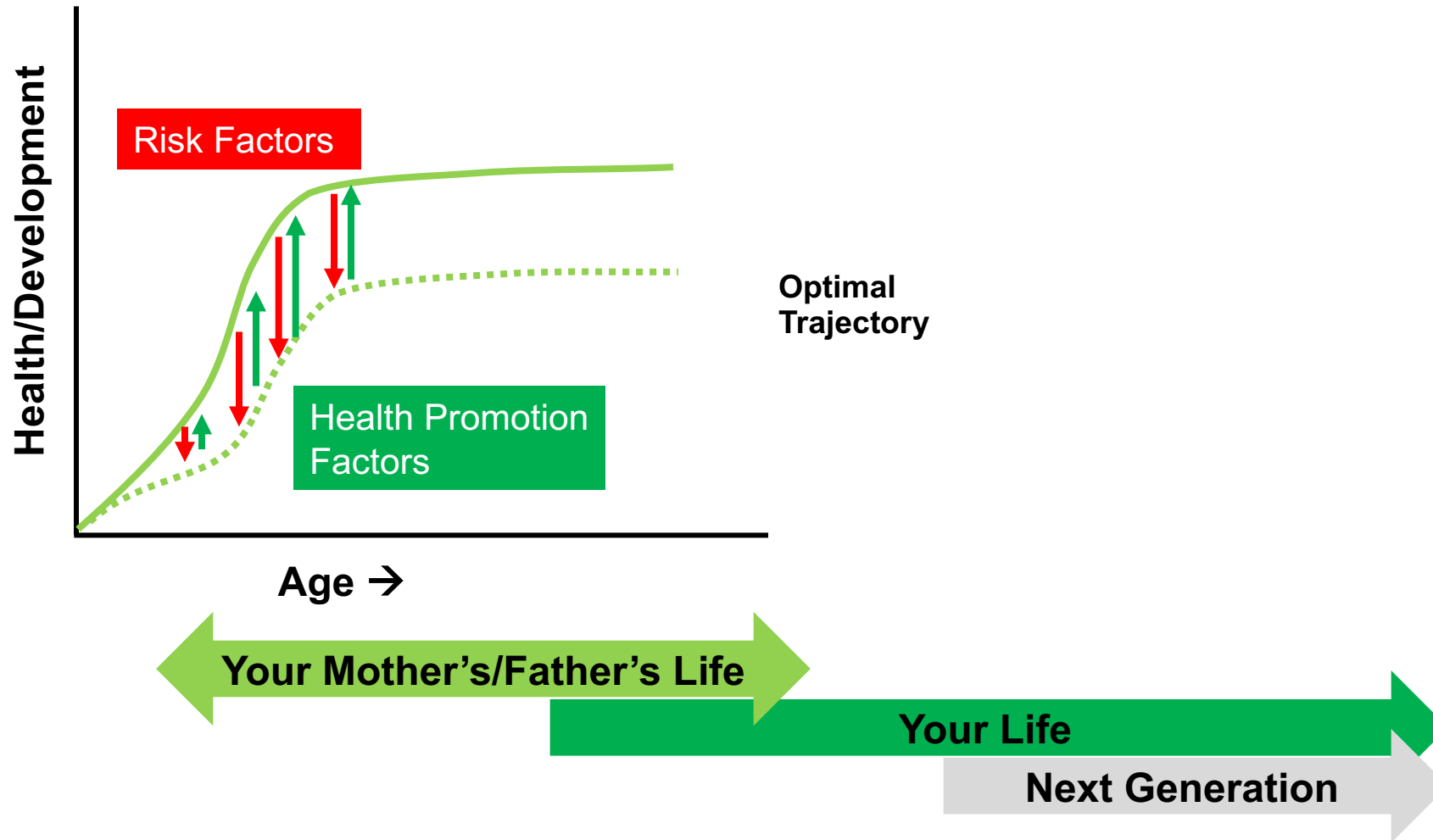
<b>PRIMARY</b> Prevention	<b>SECONDARY</b> Prevention	<b>TERTIARY</b> Prevention
An intervention implemented before there is evidence of a disease or injury	An intervention implemented after a disease has begun, but before it is symptomatic.	An intervention implemented after a disease or injury is established



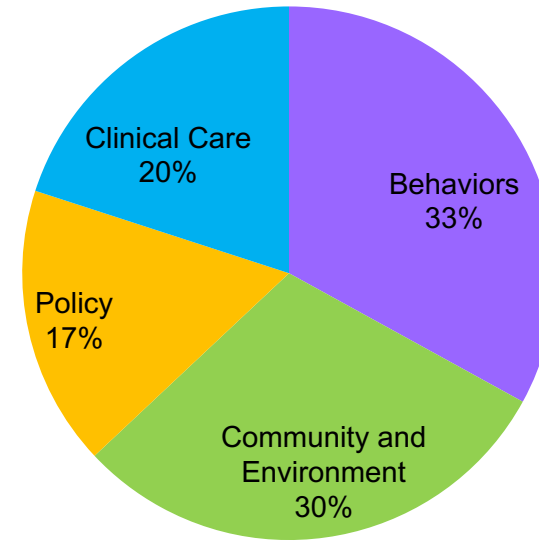
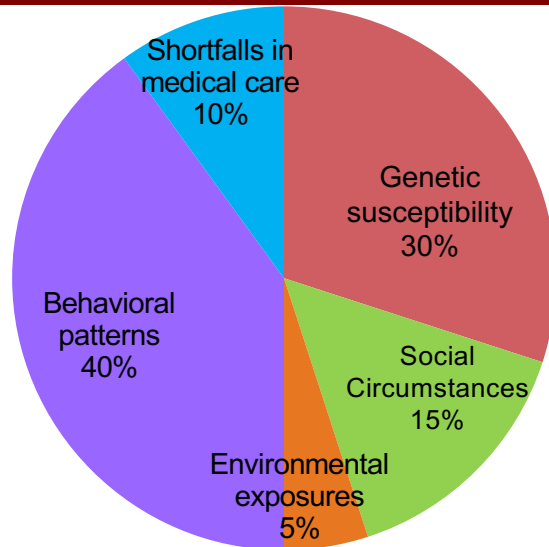
# EHDI: Upstream



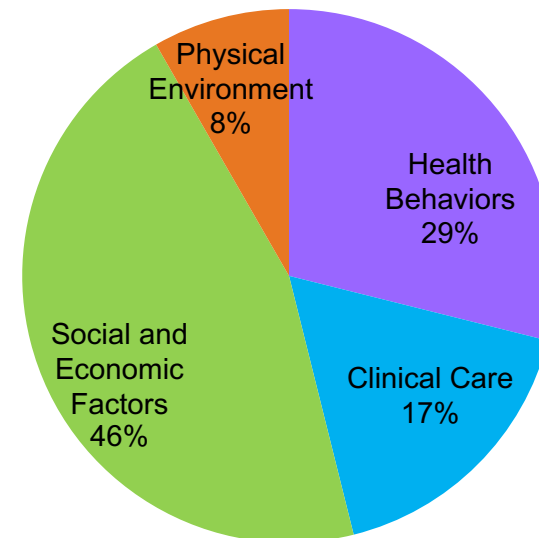
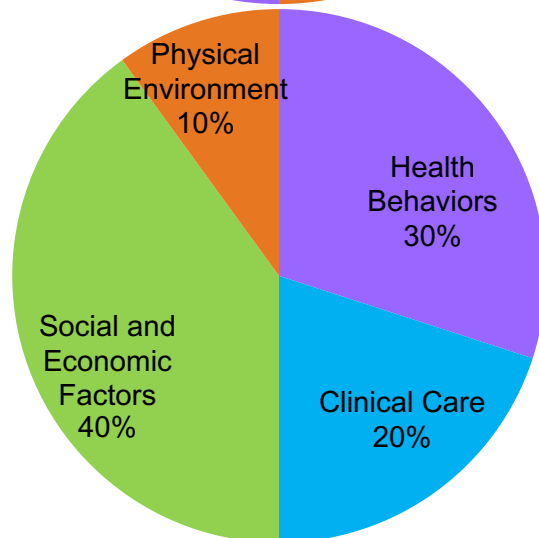
# Life Course Model

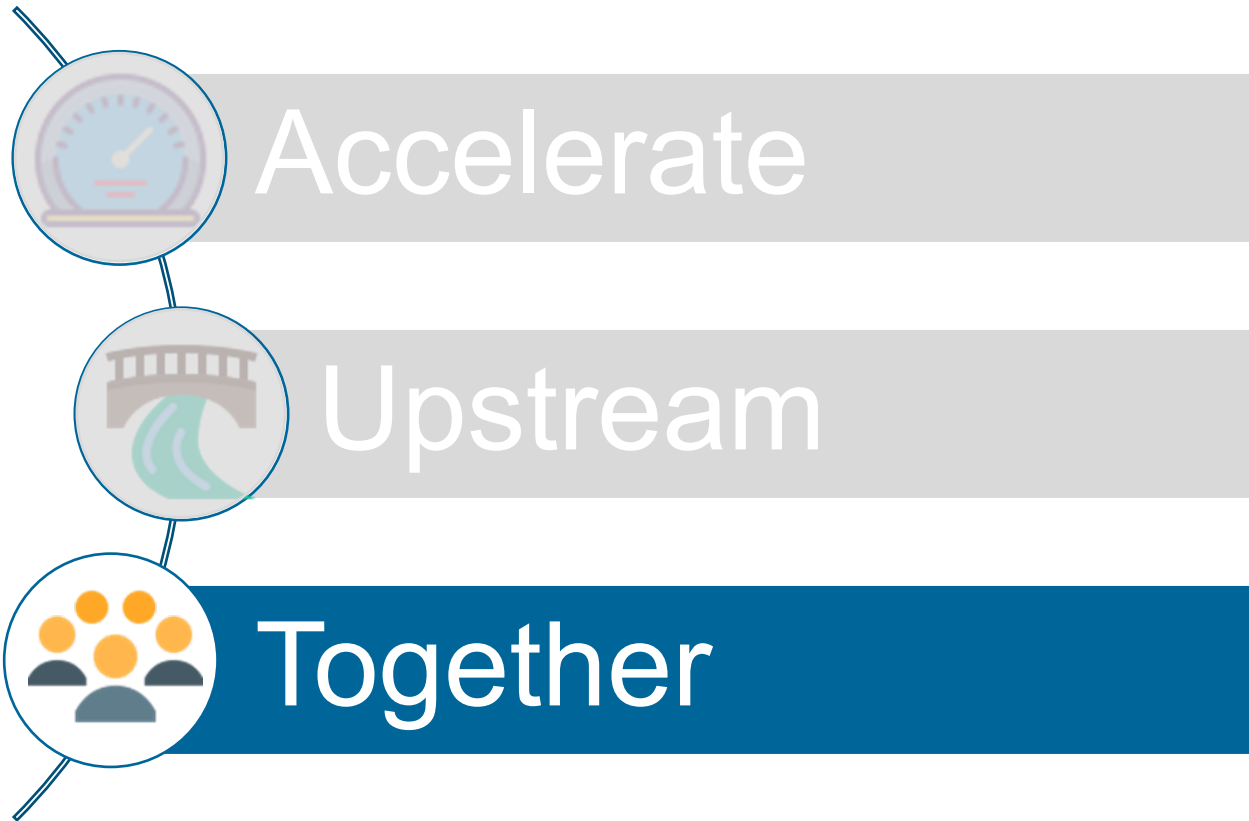


# What Determines Health?



**Health  
care  
accounts  
for only  
10-20%  
of overall  
health**







# EHDI Collaborations with other MCHB Programs



## Maternal, Infant, and Early Childhood Home Visiting Program

The Maternal, Infant, and Early Childhood Home Visiting Program (MIECHV) gives at-risk pregnant women and families necessary resources and skills to raise children who are physically, socially, and emotionally healthy and ready to succeed.

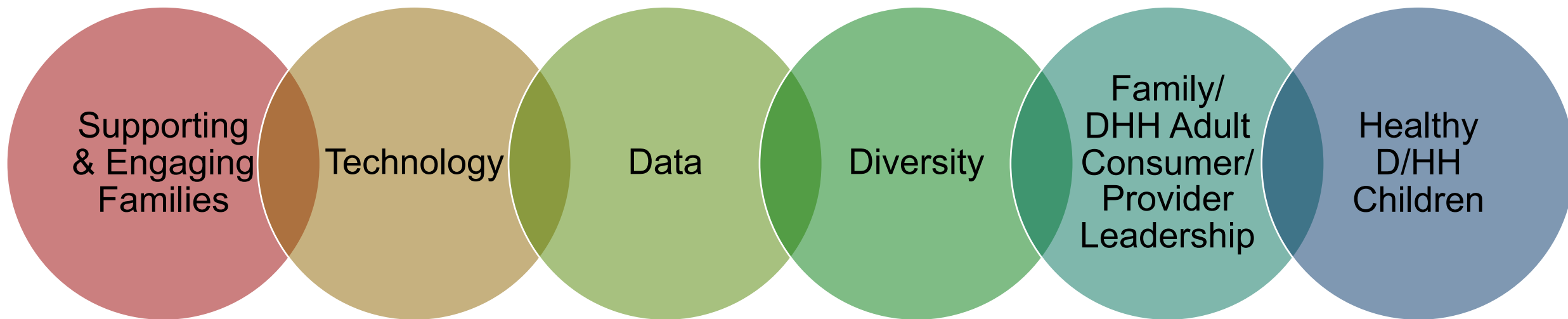
HRSA Gives Children and Families a  
**HEALTHY START**

**HRSA**  
Health Resources & Services Administration

**TITLE V MATERNAL AND  
CHILD HEALTH SERVICES  
BLOCK GRANT TO STATES  
PROGRAM**

# The Road Ahead for EHDI: Together

## *A Healthy EHDI Community*





# Thank You for Your Work in the EHDI System!



# Contact Information

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**Michael Warren, MD, MPH, FAAP**

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

**Health Resources and Services Administration (HRSA)**

**Email: [Mwarren@Hrsa.gov](mailto:Mwarren@Hrsa.gov)**

**Web: [mchb.hrsa.gov](http://mchb.hrsa.gov)**

**Twitter: [twitter.com/HRSAgov](https://twitter.com/HRSAgov)**

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