HRSA
Health Resources & Services Administration

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)

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

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Health Resources & Services Administration Bureaus

HRSA
Health Resources & Services Administration

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**

HRSA
Maternal & Child Health

Maternal & Child Health Bureau (MCHB)

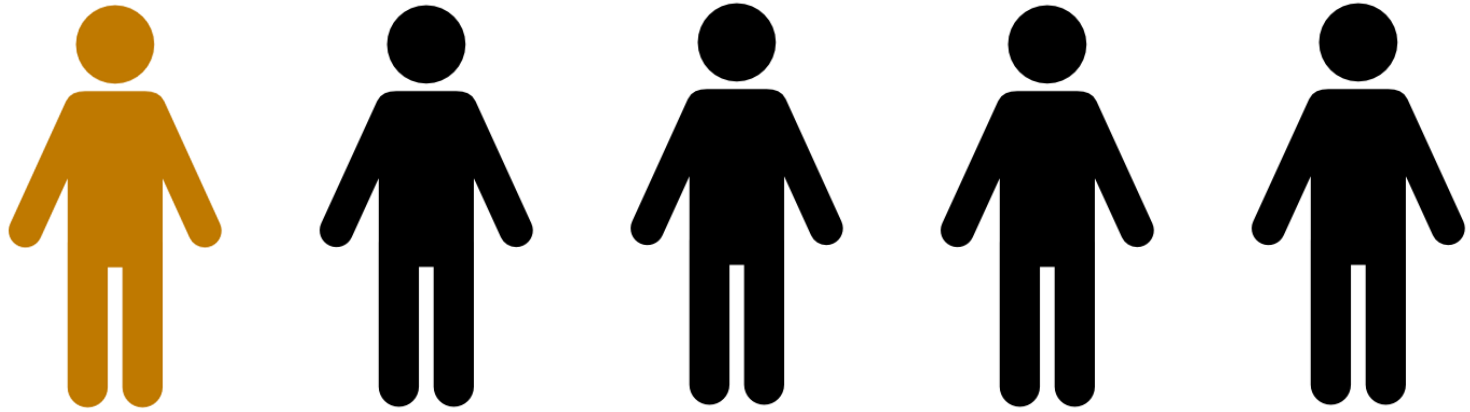
Mission: Improve the health of America's mothers, children, and families.

HRSA Maternal & Child Health

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.



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Why EHDI?

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

- 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.**

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1: Centers for Disease Control and Prevention. 2017 Hearing Screening Summary. Retrieved 2/20/2020 from: https://www.cdc.gov/ncbddd/hearingloss/2017-data/01-data-summary.html. 2: Northern JL, Downs MP. Hearing in children. 5th Ed. Chapter 1, Hearing and hearing loss in children. Baltimore: Williams and Wilkins; 2002. 3: Mitchell RE, Karchmer MA. Chasing the mythical ten percent: Parental hearing status of deaf and hard of hearing students in the United States. Sign Language Studies. 2004;4(2):138-163.

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

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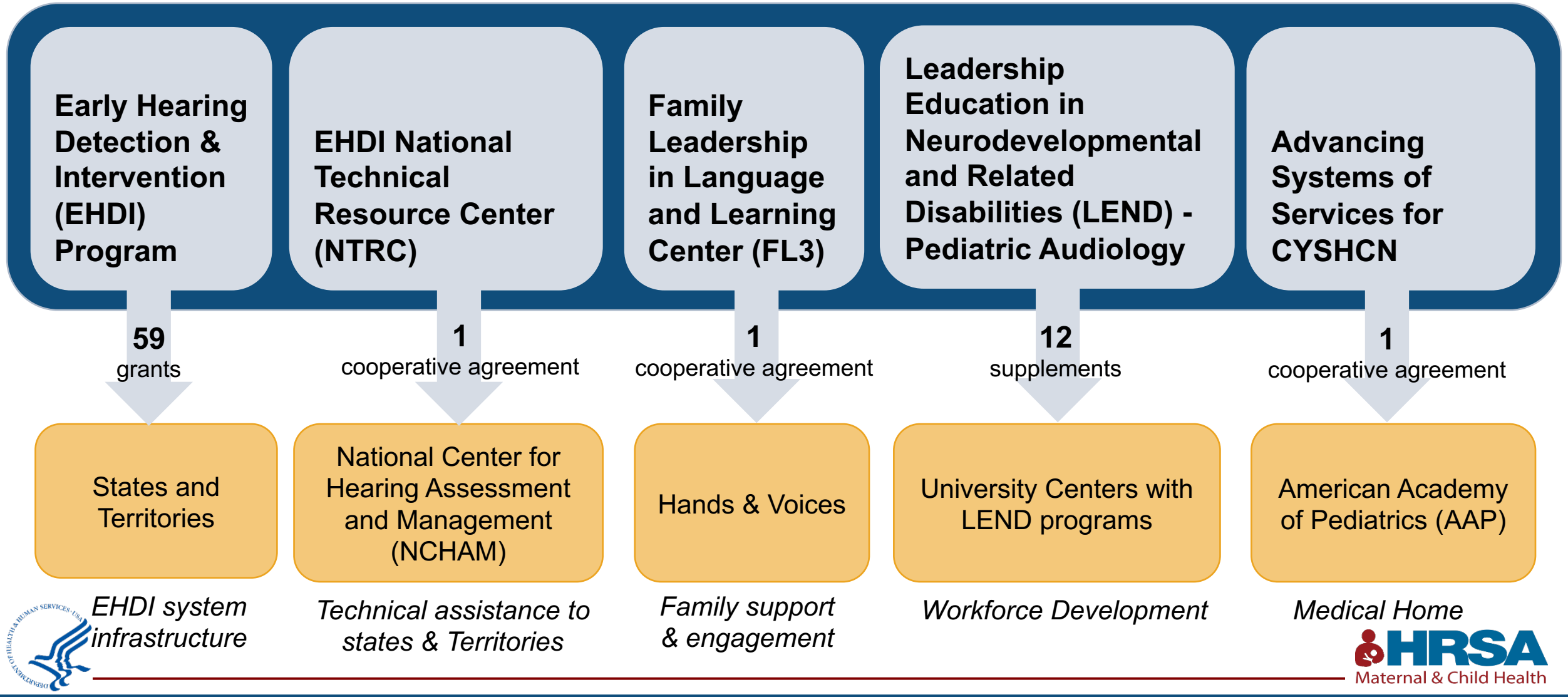
HRSA's EHDI Programs



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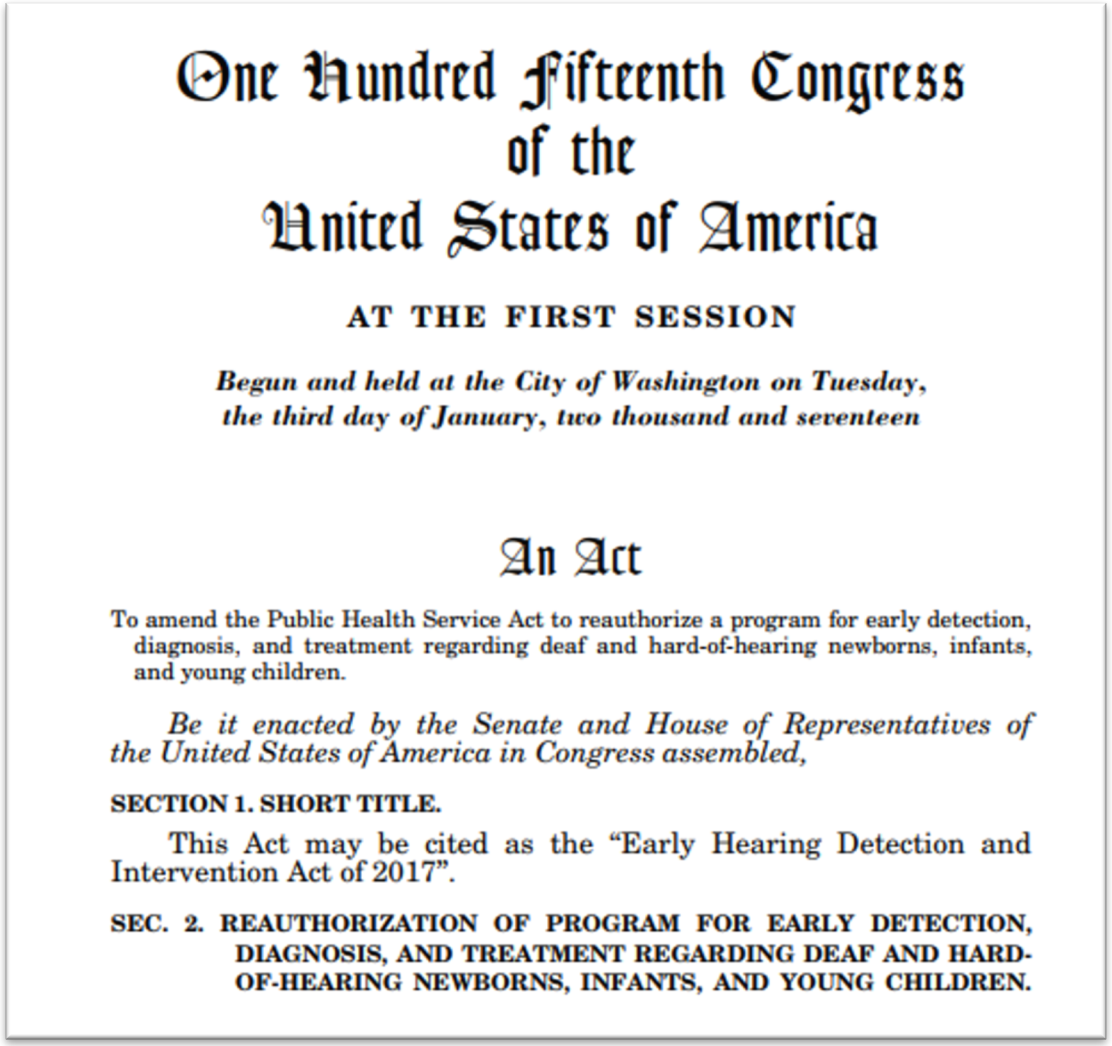
New Funding Opportunities for 2020 Address Legislative Changes



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…"*

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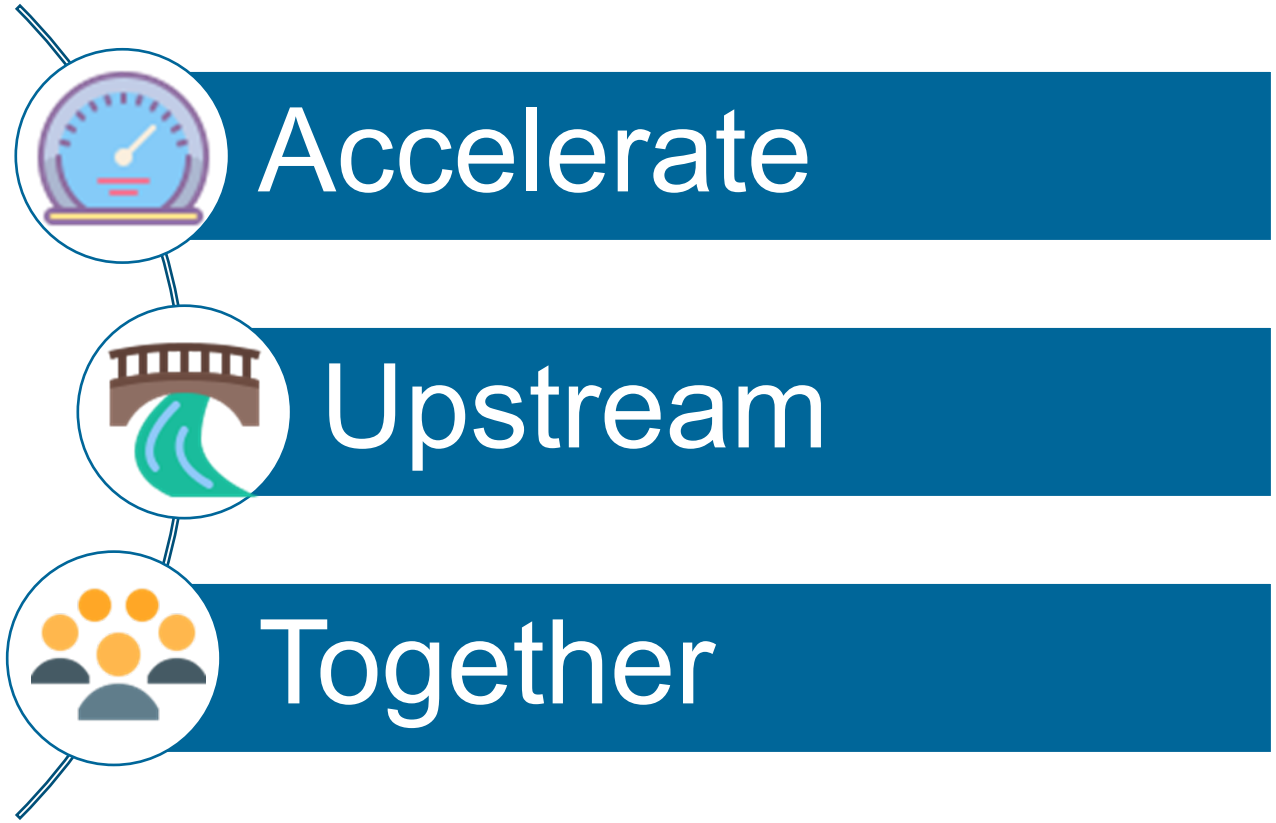
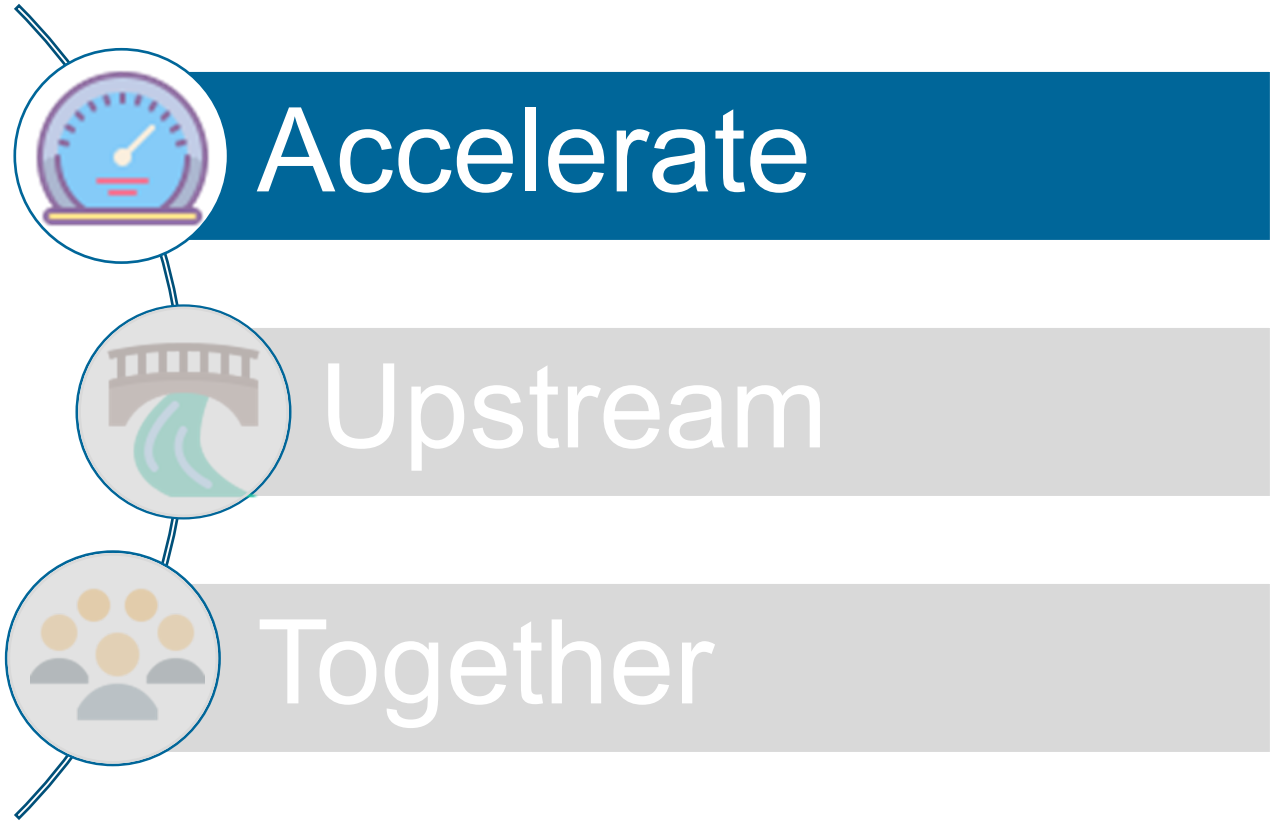
Early Hearing Detection and Intervention Act of 2017, Public Health Service Act, Title III, Section 399M (as added by P.L. 106-310, Sec. 702; as amended by P.L. 111-337 and P.L. 115-71.

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

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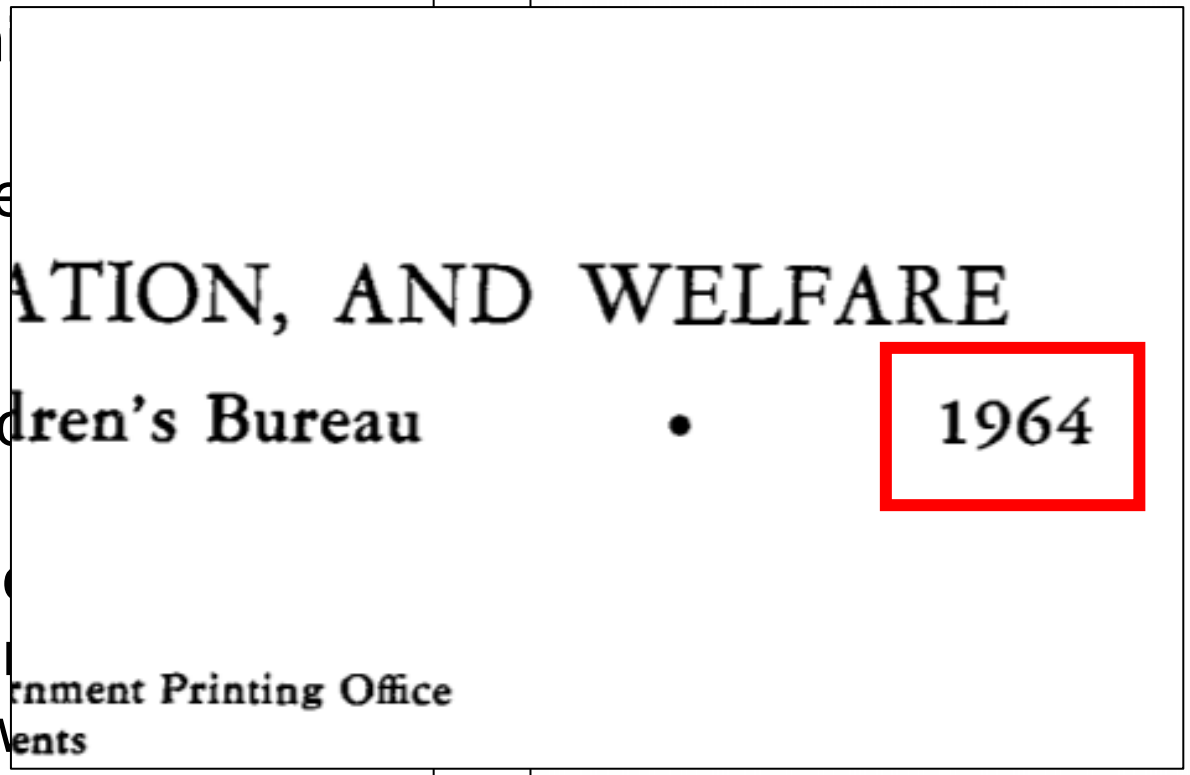
"…roots of problems in school-age children are in early ch

…resource brought to concerted early presdren's Bureau • 1964

…gaps in supervisio resultant w in the readiness of children to begin their education…"



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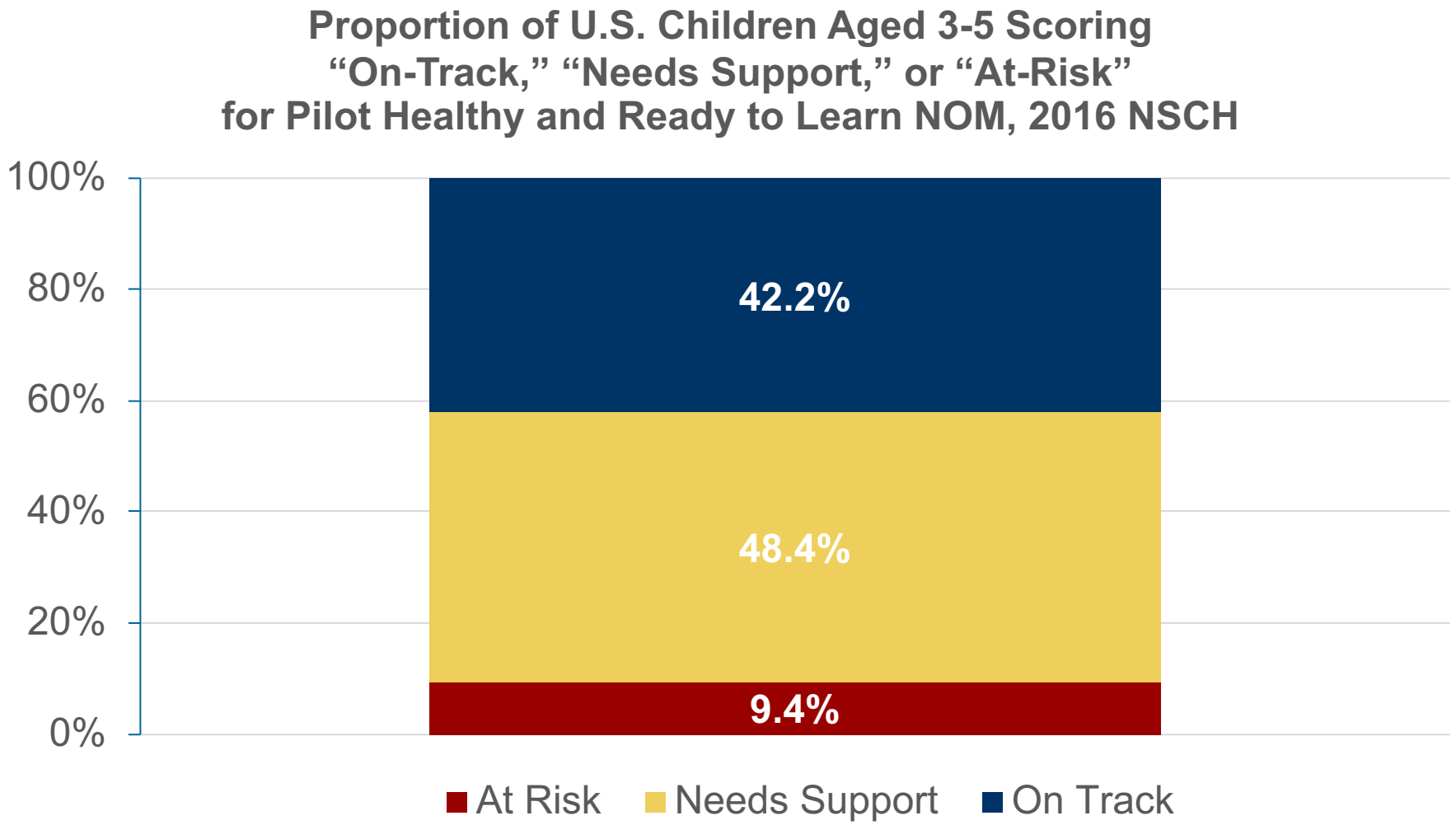
US Department of Health, Education, and Welfare. Children's Bureau. Health of Children of School Age. 1964.

Healthy and Ready to Learn



Maternal & Child Health

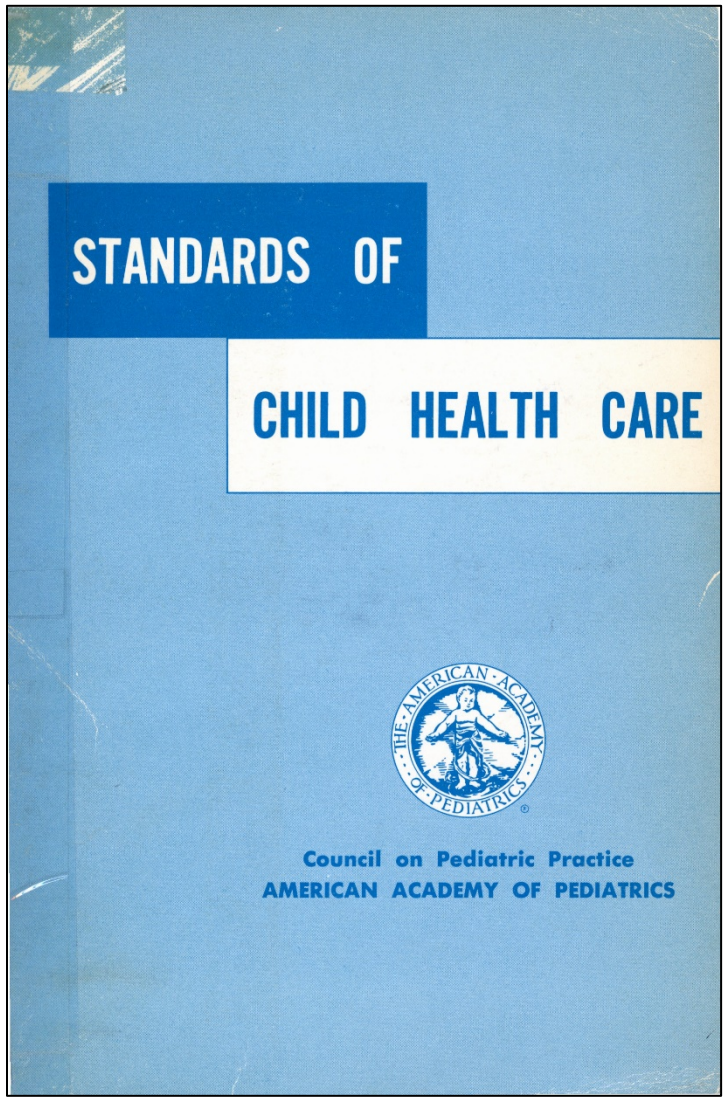
Proportion of U.S. Children Aged 3-5 Scoring "On-Track," Needs Support," or "At-Risk" for Pilot Healthy and Ready to Learn NOM. National Survey of Children's Health 2016. U.S. Department of Health and Human Services, Health Resources and Services Administration (HRSA), Maternal and Child Health Bureau (MCHB).

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”

Sia C, Tonniges TF, Osterhus E, Taba S. History of the Medical Home Concept. Pediatrics. May 2004, VOLUME 113 / ISSUE Supplement 4.
Image courtesy of American Academy of Pediatrics Library & Archival Services.

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 an
the "me
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

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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.

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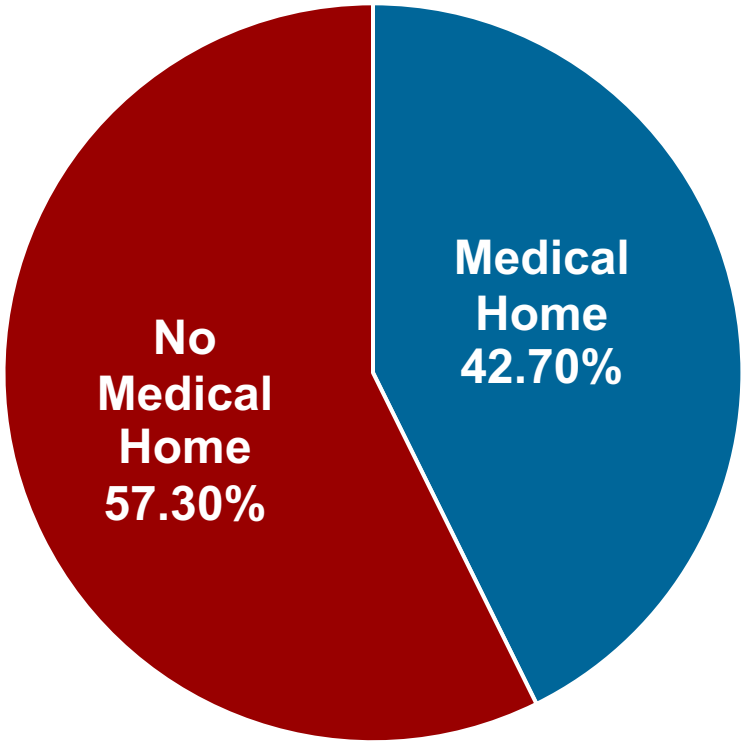
zations. This record should be accessible, but confidentiality must be assured.

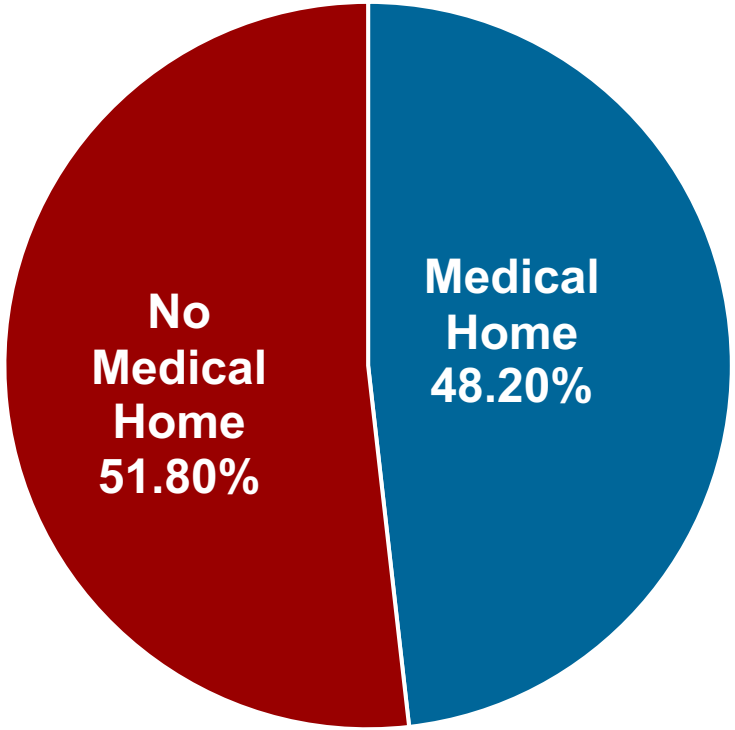
Medical care of infants, children, and adolescents must sometimes be provided in locations other than physician's offices. However, unless these locations provide all of the services listed above, they do not meet the definition of a medical home. Other venues for children's care include hospital outpatient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

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

CSHCN



All Children



Child and Adolescent Health Measurement Initiative. National Survey of Children's Health 2017-18. Data Resource Center for Child and Adolescent Health supported by the U.S. Department of Health and Human Services, Health Resources and Services Administration (HRSA), Maternal and Child Health Bureau (MCHB). Retrieved 02/19/2020 from www.childhealthdata.org.

2020

-1967

=53 years

Position S

The Joint Commi
endorses the goal c
infants with hearing
possible. All infants
be identified before
receive intervention

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; Elssman, 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).

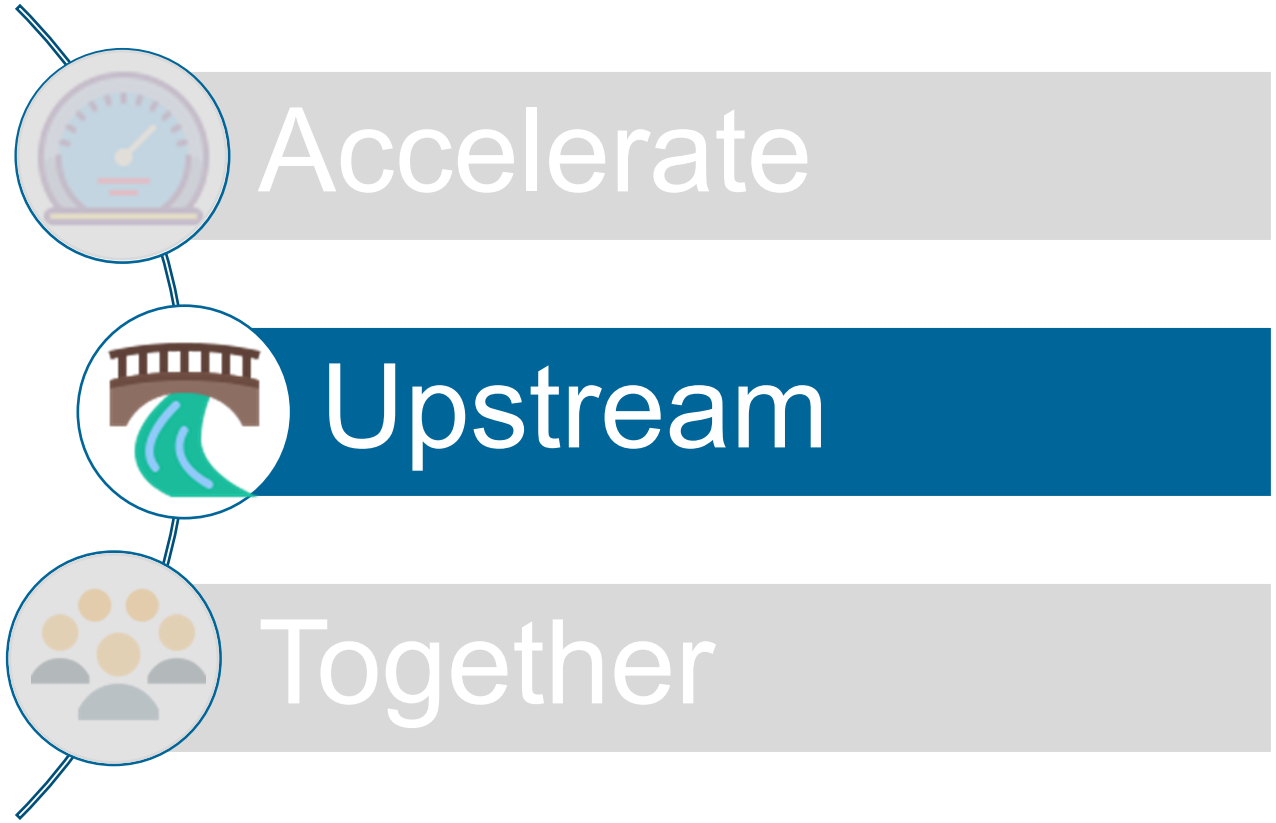
A. Technical Considerations

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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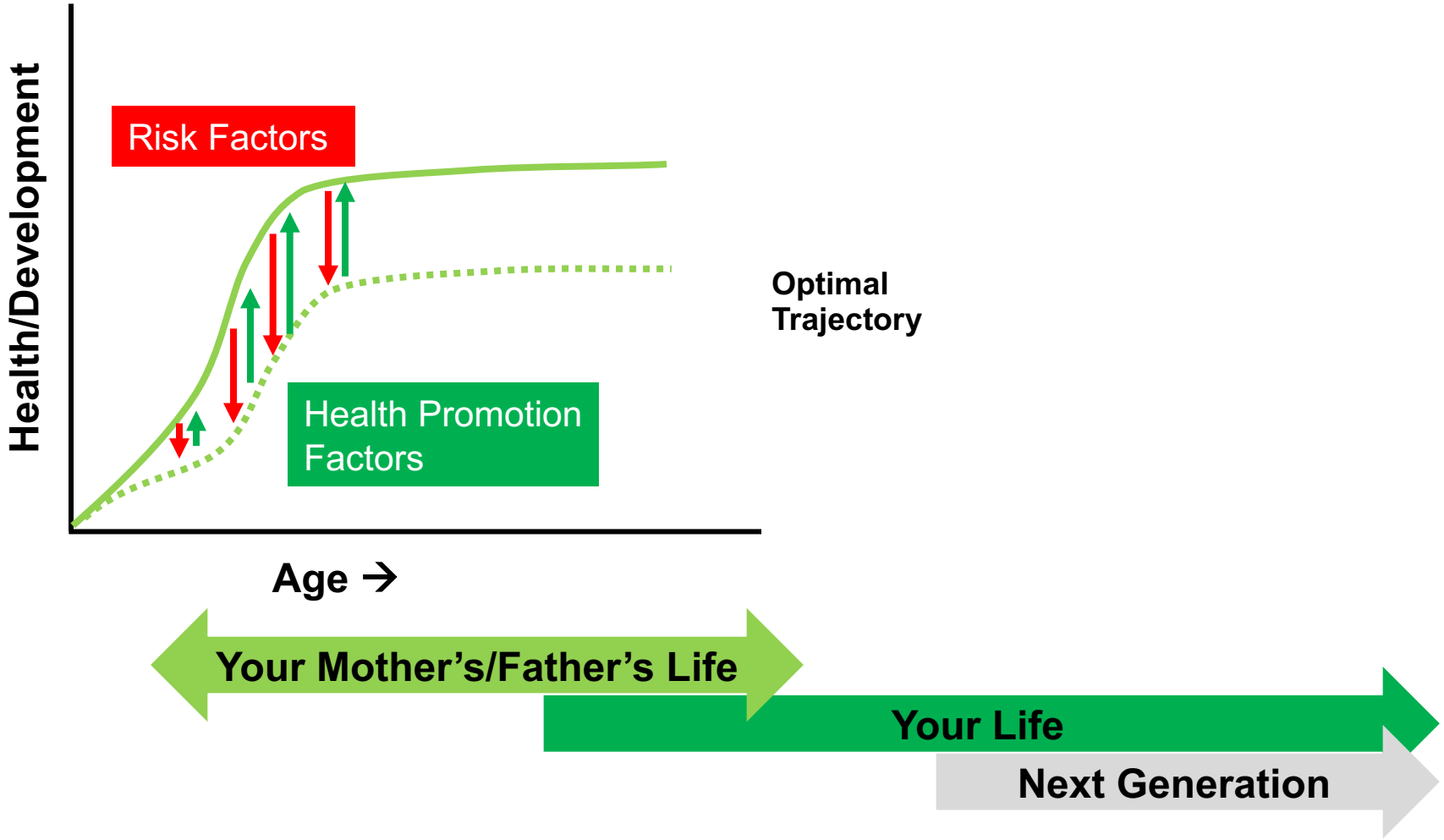
Levels of Prevention

PRIMARY Prevention	**SECONDARY** Prevention	**TERTIARY** 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

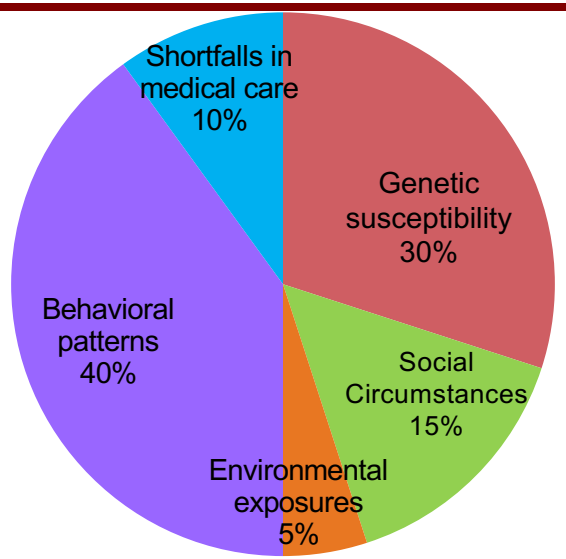
Adapted from: Centers for Disease Control and Prevention. A Framework for Assessing the Effectiveness of Disease and Injury Prevention. MMWR. 1992; 41(RR-3); 001. Available at: http://www.cdc.gov/mmwr/preview/mmwrhtml/00016403.htm

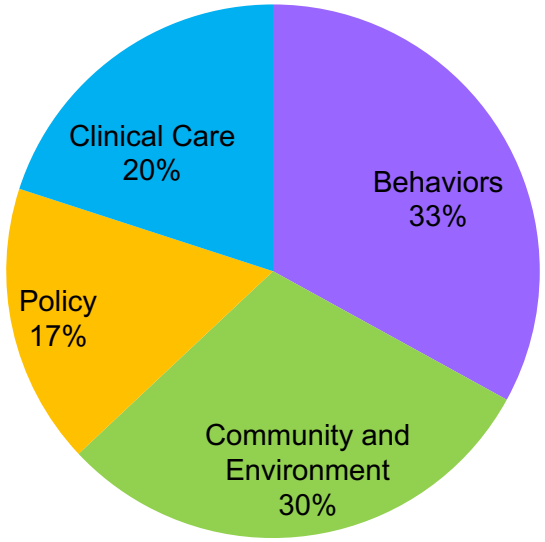
EHDI: Upstream

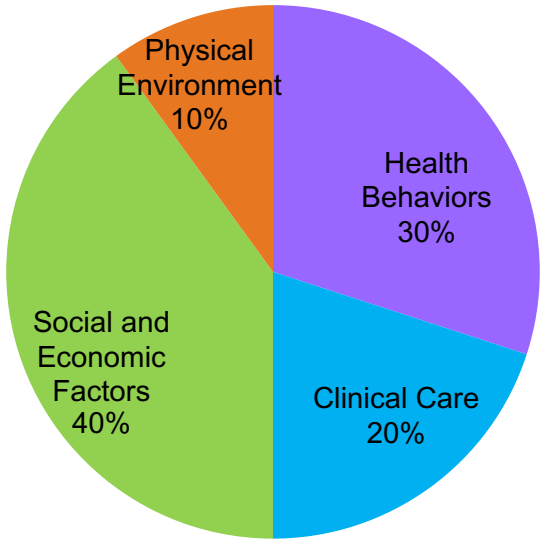
Life Course Model

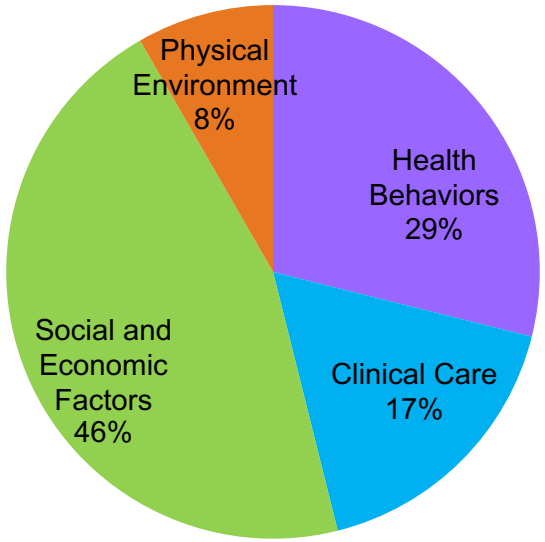


What Determines Health?

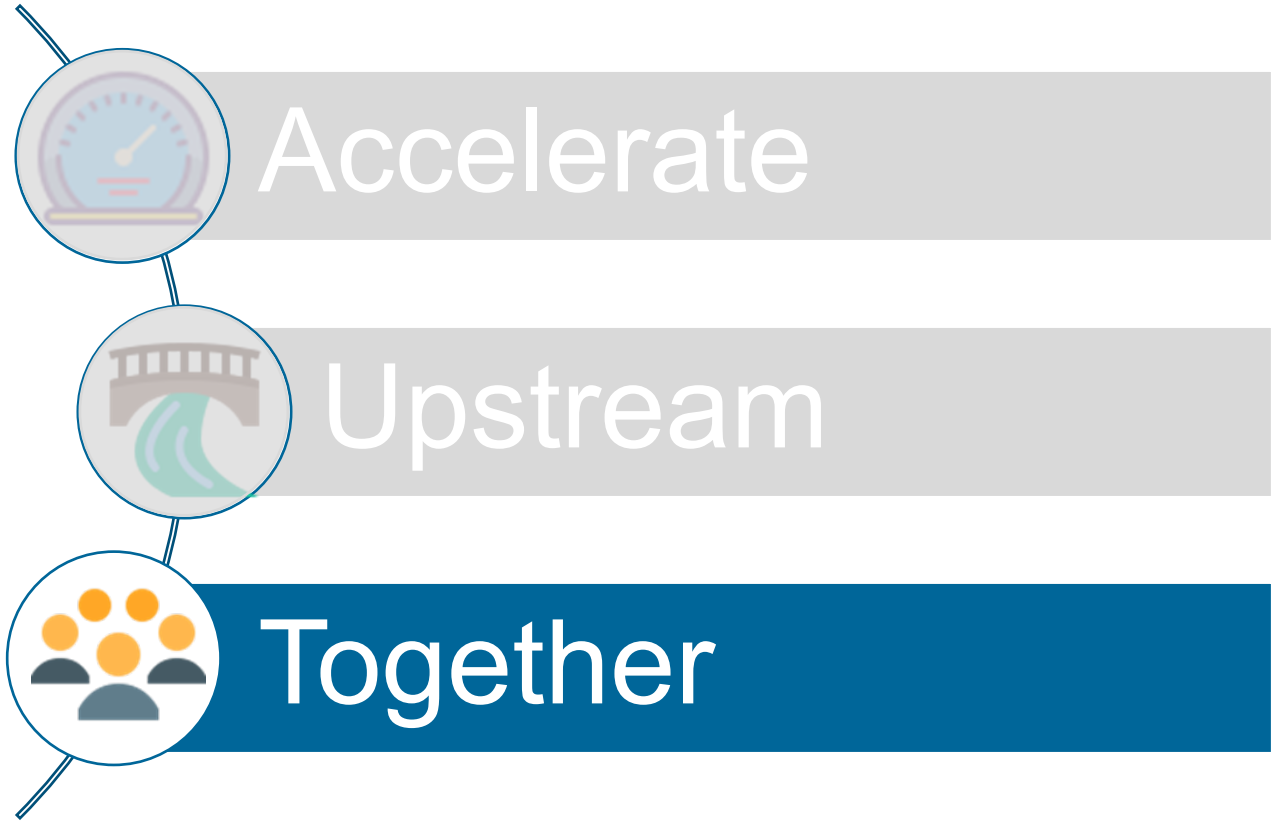








Health care accounts for only 10-20% of overall health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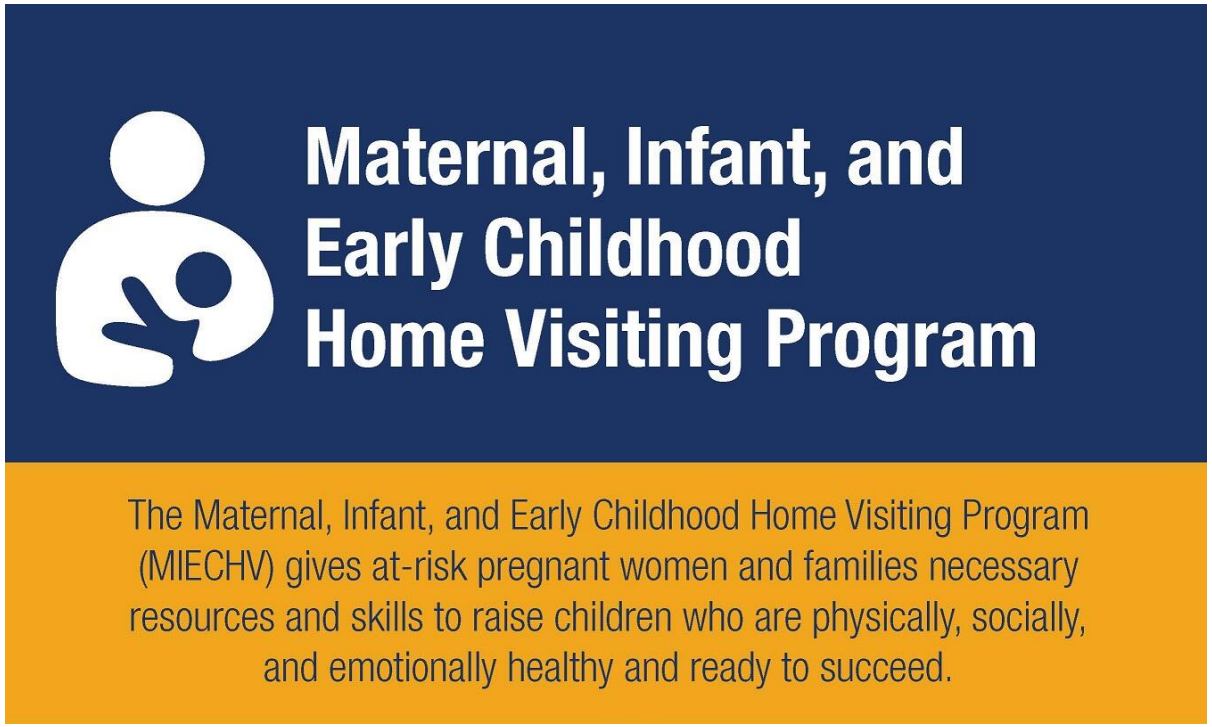
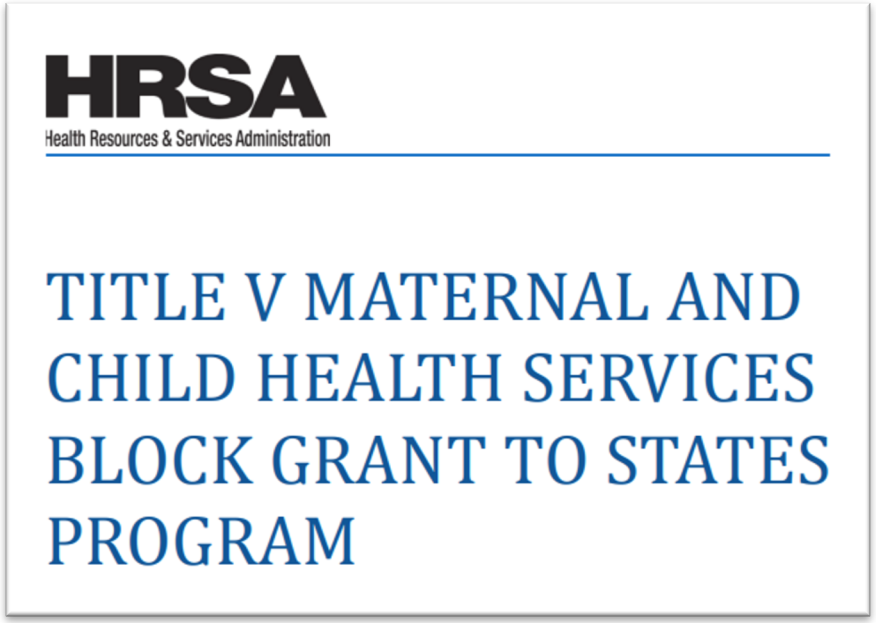
EHDI Collaborations with other MCHB Programs





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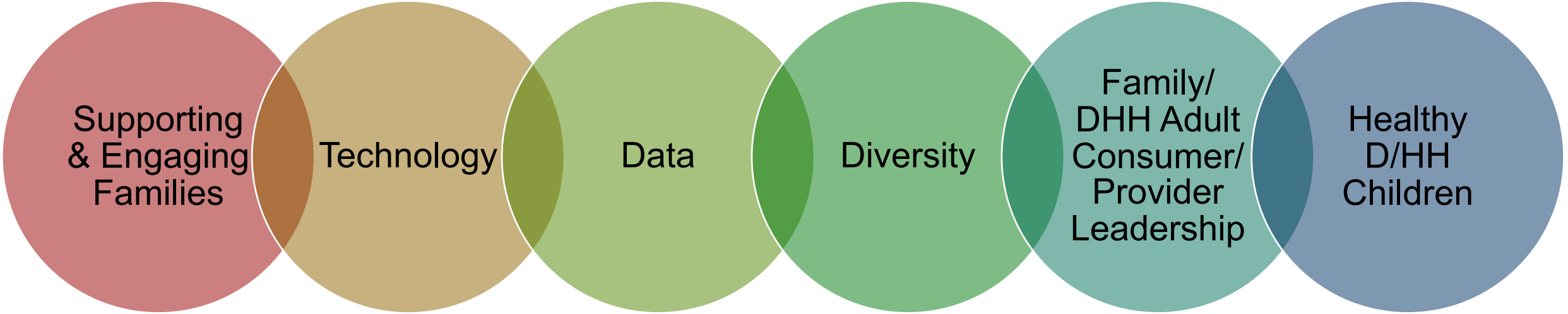
The Road Ahead for EHDI: Together

A Healthy EHDI Community



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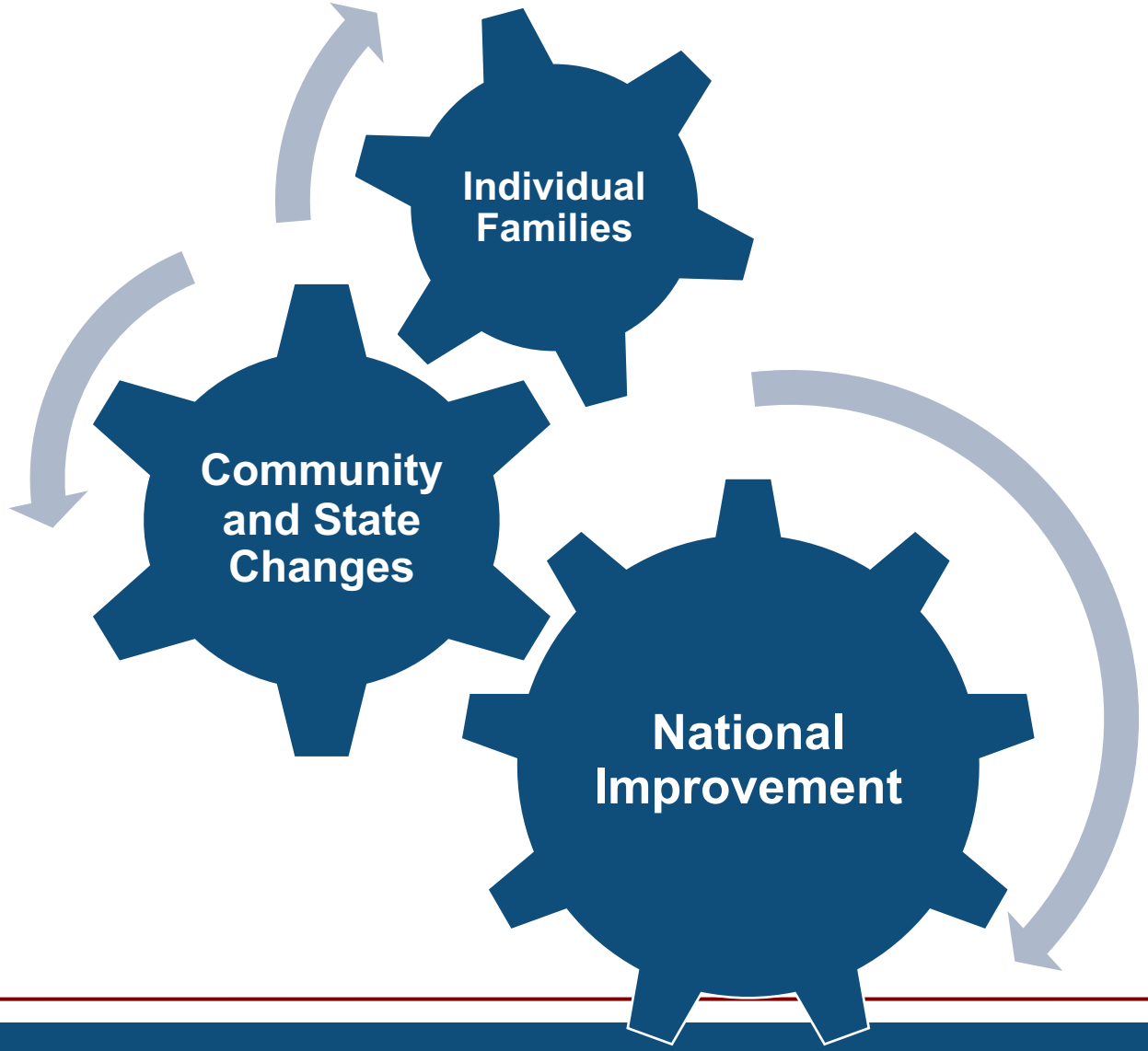
Thank You for Your Work in the EHDI System!



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Contact Information

Michael Warren, MD, MPH, FAAP
Maternal and Child Health Bureau (MCHB)
Health Resources and Services Administration (HRSA)
Email: Mwarren@Hrsa.gov
Web: mchb.hrsa.gov
Twitter: twitter.com/HRSAgov
Facebook: facebook.com/HHS.HRSA

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