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

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

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

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
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

- Early Hearing Detection & Intervention (EHDI) Program
  - States and Territories
  - 59 grants
  - EHDI system infrastructure

- EHDI National Technical Resource Center (NTRC)
  - National Center for Hearing Assessment and Management (NCHAM)
  - 1 cooperative agreement
  - Technical assistance to states & Territories

- Family Leadership in Language and Learning Center (FL3)
  - Hands & Voices
  - 1 cooperative agreement
  - Family support & engagement

- Leadership Education in Neurodevelopmental and Related Disabilities (LEND) - Pediatric Audiology
  - University Centers with LEND programs
  - 12 supplements
  - Workforce Development

- Advancing Systems of Services for CYSHCN
  - American Academy of Pediatrics (AAP)
  - 1 cooperative agreement
  - Medical Home

- Cooperative agreements and grants as indicated.
New Funding Opportunities for 2020 Address Legislative Changes

- 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

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

...resources must be brought to bear in a concerted fashion in the early preschool years...

...gaps in child health supervision with the resultant wide disparity in the readiness of children to begin their education...”
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

- 42.2% “On-Track”
- 48.4% “Needs Support”
- 9.4% “At-Risk”

2020 - 1964 = 56 years
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 trust.

In contrast, care provided through office settings, inpatient facilities, 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 children, adolescents, wherever delivered, should encompass the elements discussed above. A record of the child's personal health care, including the results of all medications, should be easily accessible to the patient and his or her family.

The 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)

<table>
<thead>
<tr>
<th>Category</th>
<th>Medical Home</th>
<th>No Medical Home</th>
</tr>
</thead>
<tbody>
<tr>
<td>CSHCN</td>
<td>42.70%</td>
<td>57.30%</td>
</tr>
<tr>
<td>All Children</td>
<td>48.20%</td>
<td>51.80%</td>
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CSHCN = Child and Adolescent Health Measurement Initiative.
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 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 below-normal audiological evaluation until an accurate assessment of hearing could be made (Joint Committee on Infant Hearing, 1982; American Academy of Pediatrics, 1989). In 1990, the Position Statement was modified to expand the list of risk factors and recommend a specific hearing screening protocol.

Joint Committee on Infant Hearing

1994 Position Statement
2020
-1994

=26 years
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## Levels of Prevention

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

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

TITLE V MATERNAL AND CHILD HEALTH SERVICES BLOCK GRANT TO STATES PROGRAM
The Road Ahead for EHDI: Together

A Healthy EHDI Community

- Supporting & Engaging Families
- Technology
- Data
- Diversity
- Family/DHH Adult Consumer/Provider Leadership
- Healthy D/HH Children
Thank You for Your Work in the EHDI System!

Individual Families

Community and State Changes

National Improvement
Contact Information

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