



It Takes a Team: Interdisciplinary Approaches to Improving Outcomes for Deaf/Hard of Hearing Children

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Disclosures

Sarah Stone and Jennifer Fleming disclosures

- No financial or nonfinancial relationships relevant to the content of the proposals exist.

Learning Objectives

- The participant will be able to describe examples of successful collaborations leading to improved family outcomes
- The participant will obtain a visual family-centered tool and informational asset to further foster collaboration with and among professionals

State of MA UNHSP

Universal Newborn Hearing Screening Program

- Law passed in 1998
- Funded by HRSA, CDC and the state
- Staff of 6, includes parents and consumers
- 48 birth hospitals, audiologist required for each program
- 40 audiological diagnostic centers, approved by UNHSP
- 60 Early Intervention programs
 - All children who are DHH are eligible for EI in MA

National Numbers

- 98 percent of U.S.-born infants are now screened for hearing loss usually before leaving the hospital
- The percent of infants receiving a hearing evaluation before the benchmark of 3 months of age has increased from 52 percent in 2005 to 76 percent in 2016.
- Between 2005 and 2014 over 45,000 deaf and hard of hearing infants born in the U.S. have been identified early.
- 25.4% lost to follow up for diagnosis
- 67.2% of children who are DHH are enrolled in EI

Data Source: 2016 CDC EHDI Hearing Screening & Follow-up Survey (HSFS)

Interdisciplinary Approach: Data supports

Early Hearing Detection and Vocabulary of Children With Hearing Loss. Christine Yoshinago-Itano et.al. Pediatrics 2017

- Across participating states, only 1/2 to 2/3 of identified children met the 1-3-6 guidelines
- Much work needs to be done...
“This requires a team approach that includes newborn screening personnel, audiologist, early interventionists, and state-based EHDI surveillance programs that monitor and facilitate timely transition from screening to diagnosis to intervention.”

MA Loss To Follow-Up Success

2016 LTF rate 3.2% -- It Takes a Team

- Birth hospitals
 - EBC, data management
- Newborn hearing screening team
 - Diagnostic appt. made prior to discharge for refers
- EHDI staff
 - LTF coordinator and epidemiologist
- Families
 - Prepared for appt. by LTF coordinator
- Pediatricians
 - Support enlisted as needed, i.e. for missed appts
- Diagnostic audiologists
 - Data management/follow-up critical

MA EHDI/Professional Collaborations



Diagnostic Center Meetings

- Face-to-face meetings biannually
- Continued education webinars

EI partnership

- Hearing specialists identified
- Deaf/HH training at EI conferences

Advisory Committee

- 14 member committee approves all policy documents

EHDI Stakeholders group

- Helps set state priorities

Learning Community

- Smaller project-based team
- executing on state-level needs

Professional/EHDI Teamwork

EXAMPLES:

You tell us!

Teamwork in action



Family Engagement Defined

AMCHP:

“The intentional practice of working with families for the ultimate goal of positive outcomes in all areas through the life course. Family Engagement reflects a belief in the value of the family leaderships at all levels for the individual, community and policy level.”

Family Engagement: Why is it Important

“High levels of family involvement correlated with positive language outcomes, and, conversely, limited family involvement was associated with significant child language delays at 5 years of age, especially when enrollment in intervention was late.”

Moeller MP. Early Intervention and Language Development in Children who are Deaf and hard of Hearing. *Pediatrics*. 2000;106(3)

“Equitable partnerships between families and EI programs and systems are critical to the success of EHDI programs and the achievement of optimal outcomes for children.”

Joint committee on Infant hearing. Year 2007 Position Statement: Principles and Guidelines for EHDI Programs. *Pediatrics* Oct 2007, 120(4)

Visual Deaf/HH Resource Guide

- How the tree came to life
- Why the tree is important
- Tree described – what is it!
- How can we use it



Roadmap (tree) Development

- Learning Community Proposal
 - LC composition: Neonatologist, EI, MCDHH, Parents, Pediatrician, Audiologist, SSP providers, EHDI
 - Project Based
- Project Goal
 - Development of visual way to describe supports and services for a deaf/HH family
- Evaluate Visual Tools in Existence
- Targeted Feedback
 - EHDI Stakeholders
 - Learning Center Members
 - Diagnostic Audiologists
 - Parents

Universal Newborn Hearing Screening Program

The UNHSP helps families get the services they need. Services include family support, outreach and education, parent-to-parent support, information and referral, technical assistance, information and resource connection.

Universal Newborn Hearing Screening Program

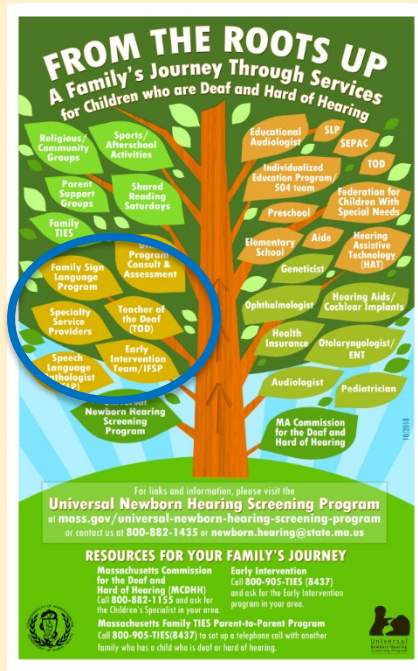
at mass.gov/universal-newborn-hearing-screening-program

or contact us at 800-882-1435 or newborn.hearing@state.ma.us

Supporting families through screening, identification of hearing loss, and Early Intervention services.

All babies are screened at birth for hearing loss. Some babies will have hearing loss; others will not. We help families of babies with hearing loss get the services they need.

Birth to Three



Early Intervention (EI) Team/IFSP

Speech Language Pathologist (SLP)

Specialty Service Providers

Teacher of the Deaf (TOD)

Family Sign Language Program

DHH Program Consult & Assessment

Early Intervention (EI) Team/IFSP

Every child who is deaf or hard of hearing is eligible to receive early intervention services. An EI Program provides services to children, birth to three, and their families including those who are deaf and hard of hearing. Team members work together to develop an Individualized Family Service Plan (IFSP), a written plan that maps out the EI services your child will receive, as well as how and when these services will be administered.

Early Intervention Call 800-905-TIES (8437)

<https://www.mass.gov/orgs/early-intervention-division>

Our services are designed to meet the needs of each eligible infant or toddler, and the needs of their family.

We aim to enhance the infant or toddler's:

- Physical development
- Cognitive development
- Communication development
- Social or emotional development
- Adaptive development

Specialty Service Providers

Once Enrolled in EI, services are available from Specialty Service Providers who have special skills and knowledge around hearing loss and are trained to work with families of children who are deaf or hard of hearing. Services may include TOD, SLP, Parent Infant Programs, playgroups featuring interactions with deaf and hard of hearing peers, and parent groups. Families can request services from more than one Specialty Service Provider.

Specialty Services for Infants/Toddlers who are Deaf or Hard of Hearing

The Universal Newborn Hearing Screening Program has created this list to help inform parents about options available to their family. The descriptions were written by the providers.

8 page document to follow.

Speech Language Pathologist (SLP)

A Speech/Language Pathologist is trained to evaluate and promote speech and language development. Some have specialized training and experience in working with children who are deaf or hard of hearing.

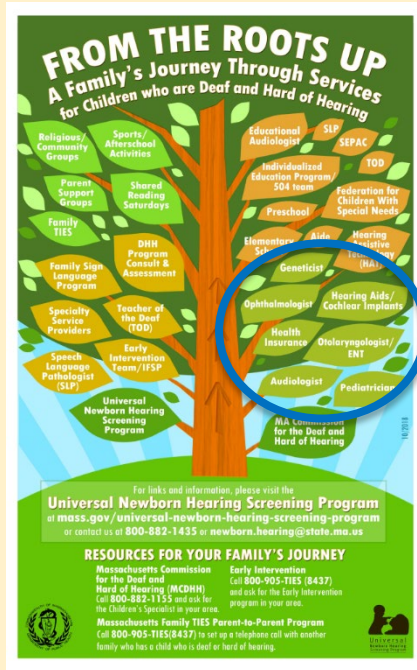
<https://www.asha.org/public/hearing/Hearing-Loss/>

Hearing Loss

Learn more about hearing loss and other problems related to hearing.

- [What is Hearing Loss?](#)
- [Types of Hearing Loss](#)
- [Causes of Hearing Loss](#)
- [Effects of Hearing Loss on Development](#)
- [Auditory Processing Disorder](#)
- [Tinnitus](#)
- [Unilateral Hearing Loss in Children](#)

Health Services



Pediatrician

Otolaryngologist/ENT

Audiologist

Hearing Aids/Cochlear Implants (CI)

Ophthalmologist

Health Insurance

Geneticist

Pediatrician

Pediatricians are doctors who manage the health of a child, including physical, behavioral, and mental health issues. They are trained to diagnose and treat childhood illnesses, from minor health problems to serious diseases.

The importance of this relationship is key. The pediatrician sees the whole child, tracks milestones, provides referrals to specialists. They are a trusted source throughout a family's journey.

Audiologist

A health care professional trained to diagnose hearing loss, evaluate hearing levels and abilities, recommend hearing aids and/or other listening devices as needed, and fit a person with a sensory aid. Pediatric specialists are available.

Your baby did not pass the hearing screening

Babies that do not pass the hearing screening will have a hearing test scheduled for them.

Testing occurs while your baby is sleeping, so bring your baby tired and hungry. You will be able to feed the baby when you arrive. You will receive the test results at this appointment. Bring another adult with you to help with the baby. The other adult can also help you remember what you are told. If you need help scheduling this appointment email newborn.hearing@state.ma.us or call (800) 882-1435.

Find a place to have your baby's hearing tested

Hearing testing centers exist throughout the state.

Ophthalmologist

An ophthalmologist is an eye specialist. Hearing and vision loss both occur in certain syndromes. A referral to the eye doctor is common. Pediatric specialists are available.

Families may not be aware of why referral was made. This can help increase compliance.

Pre-school and Beyond



- Preschool
- Elementary School
- Aide
- Teacher of the Deaf (TOD)
- Hearing Assistive Technology (HAT)
- Individualized Education Program (IEP)/504 Team
- Educational Audiologist
- SEPAC (Special Education Parent Advisory Council)
- Speech Language Pathologist (SLP)
- Geneticist
- Federation for Children with Special Needs

Individualized Education Program (IEP)/504 Team

School staff and parent work with a town/city liaison to create, support and implement the student's Individualized Education Program (IEP). The team may include advocates, professionals serving the family, and members of the school's special education program.

The IEP is an extremely important document in the educational lives of students with disabilities receiving special education under IDEA. The resources we've listed below will help you learn more about IEPs – what the law requires, what information a typical IEP contains, how IEPs are developed, and so on.

Educational Audiologist

The Educational Audiologist will focus their practice on supporting students who are deaf or hard of hearing in an educational setting by evaluating the student's hearing, listening, and auditory processing deficits that can affect their academic success, communication abilities and psychosocial well-being.

Ask Not What Your Educational Audiologist Can Do for You ...

“When audiologists and SLPs work together, children with hearing loss stand their best chance of success in school.”

[Kirsten Marconi-Hutkay, AuD, CCC-A](#)

The ASHA Leader, March 2015, Vol. 20, 30-31.

doi:10.1044/leader.SCM.20032015.30

Community

FROM THE ROOTS UP
A Family's Journey Through Services
for Children who are Deaf and Hard of Hearing

Religious/Community Groups
Sports/Afterschool Activities
Parent Support Groups
Family TIES
Family Sign Language Program
Specialty Providers
Speech Language Pathologist (SLP)
Universal Newborn Hearing Screening Program

Shared Reading Saturdays
Program Consults & Assessment
Teacher of the Deaf (TOD)
Early Intervention Team/IFSP

Educational Audiologist
SLP
SEPAC
Individualized Education Program/504 team
TOD
Prestschool
Federation for Children With Special Needs
Elementary School
Aide
Hearing Assistive Technology (HAT)
Geneticist
Ophthalmologist
Hearing Aids/Cochlear Implants
Health Insurance
Otolaryngologist/ENT
Audiologist
Pediatrician
MA Commission for the Deaf and Hard of Hearing

For links and information, please visit the
Universal Newborn Hearing Screening Program
at mass.gov/universal-newborn-hearing-screening-program
or contact us at 800-882-1435 or newborn.hearing@state.ma.us

RESOURCES FOR YOUR FAMILY'S JOURNEY

Massachusetts Commission for the Deaf and Hard of Hearing (MCDHH)
Call 800-882-1155 and ask for the Children's Specialist in your area.

Early Intervention
Call 800-905-TIES (8437) and ask for the Early Intervention program in your area.

Massachusetts Family TIES Parent-to-Parent Program
Call 800-905-TIES(8437) to set up a telephone call with another family who has a child who is deaf or hard of hearing.

Shared Reading Saturdays

Religious/Community Groups

Sports/Afterschool Activities

Parent Support Groups

Family TIES

Parent Support Groups

Parent support organizations exist that connect parents with children who are deaf or hard of hearing.

Examples include:

- Hear Together
- Family TIES
- Hear My Dreams
- AG Bell
- Universal Newborn Hearing Screening Program
- Specialty Service Providers
- Hands & Voices
- Facebook/Social media groups

The Tree In Action

- Provides an overview
- These are some available options
- Educates families and professionals alike
- Families and professionals can dig deeper together in developing the family's individual tree
- Trees grow!
 - What is needed at 6 months is different than at 2 years of age.
- Change can be good - prepares for transition

Next Steps

- Distribute to families in PIK
- Distribute to pediatricians and audiologists to facilitate family discussions
- Translate into Spanish
- Develop interactive, on-line version accessible on UNHSP website

Contact Us!

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<https://www.mass.gov/universal-newborn-hearing-screening-program>
www.facebook.com/MassNewbornHearingScreening

Thank You!