Early Hearing Detection and Intervention (EHDI): The Role of the Medical Home

A PRESENTATION FROM THE AMERICAN ACADEMY OF PEDIATRICS
Early identification and intervention of a child who is Deaf or Hard of Hearing (Deaf/HH) will support the development of good communication, language, and social skills.

Delayed Early Intervention is associated with speech and language delays and inability to reach each child’s full potential.
Comparison of Select Congenital Conditions

Incidence per 10,000 of Congenital Conditions

- Hearing loss: 30
- Cleft lip or palate: 17
- Down Syndrome: 14
- Limb defects: 5
- Sickle Cell Anemia: 5
- Spina bifida: 4
- PKU: 1
Early Hearing Detection & Intervention (EHDI) Program

1-3-6

National EHDI Goals

- All infants will receive a hearing screening before 1 month of age
- Infants not passing the screening will receive appropriate audiologic and medical evaluation before 3 months of age
- All infants identified as deaf or hard of hearing will begin receiving early intervention services before 6 months of age

Three Key Components of Early Hearing Detection & Intervention Programs
Developmental Emergency

An infant who does not pass his/her newborn hearing screening has a potential developmental emergency.

However...

Early identification of hearing loss can result in positive language outcomes for children who are Deaf or Hard of Hearing.

Language Outcomes for Early- and Later-Identified Children With Hearing Loss

<table>
<thead>
<tr>
<th>Age of Identification (months)</th>
<th>Total Language Quotient*</th>
</tr>
</thead>
<tbody>
<tr>
<td>0-6</td>
<td>80</td>
</tr>
<tr>
<td>7 to 12</td>
<td>60</td>
</tr>
<tr>
<td>13 to 18</td>
<td>60</td>
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<tr>
<td>19 to 24</td>
<td>60</td>
</tr>
<tr>
<td>25 to 34</td>
<td>50</td>
</tr>
</tbody>
</table>

*Adjusted mean: expressive and receptive language

Early Hearing Detection & Intervention

Why early diagnosis and intervention matters

Effects of Age of Identification on Language Development

Moeller, 2000
State EHDI Programs

Every state and territory in the United States has now established an Early Hearing Detection and Intervention (EHDI) program.

All 50 states and the District of Columbia have a law, regulation, or documented legislative intent about hearing screening and hearing screening guidelines.

EHDI program staff are responsible for creating, operating, and continuously improving a system of services which assures that the national EHDI goals are met.

State EHDI Laws and Regulations


NCHAM State Resource Page

http://www.infanthearing.org/states_home/
EHDI Program Components

- Universal Newborn Hearing Screening
- Medical Home
- Diagnostic Audiology
- Specialty Referrals
- Early Intervention
- Family Support
- Tracking and Data Management
National EHDI Data

Universal Newborn Hearing Screening

Percent of Infants Receiving Hearing Screening: 1999-2007

<table>
<thead>
<tr>
<th>Year</th>
<th>Percent of Infants Screened</th>
</tr>
</thead>
<tbody>
<tr>
<td>1999</td>
<td>46.5</td>
</tr>
<tr>
<td>2000</td>
<td>52.1</td>
</tr>
<tr>
<td>2001</td>
<td>65.4</td>
</tr>
<tr>
<td>2002</td>
<td>82.9</td>
</tr>
<tr>
<td>2003</td>
<td>88.1</td>
</tr>
<tr>
<td>2004</td>
<td>91.8</td>
</tr>
<tr>
<td>2005</td>
<td>94.2</td>
</tr>
<tr>
<td>2006</td>
<td>95.2</td>
</tr>
<tr>
<td>2007</td>
<td>96.9</td>
</tr>
<tr>
<td>2008</td>
<td>97.4</td>
</tr>
<tr>
<td>2009</td>
<td>97.9</td>
</tr>
<tr>
<td>2010</td>
<td>97.9</td>
</tr>
<tr>
<td>2011</td>
<td>96.6</td>
</tr>
<tr>
<td>2012</td>
<td>96.9</td>
</tr>
</tbody>
</table>

CDC, 2014
National EHDI Data

Incidence of Children who are Deaf or Hard of Hearing

Infants Identified as Permanently Deaf or Hard of Hearing, 2005 – 2012 (Total = 34,416)

Source: CDC EHDI Hearing Screening and Follow-up Survey (2014)
2012 National CDC EHDI Data

- % Screened: **96.6%** (n=3,820,624)
- Prevalence of children who are deaf/hh: **1.6 per 1,000** screened (Range 0.0-4.3 per 1,000)
- % of those identified receiving Early Intervention: **61.7%** (n=3,527)

- % Screened before 1 month of age: **86.0%** (n=3,287,614)
- % Diagnosed before 3 months of age: **69.1%** (n=20,102)
- % Receiving Intervention before 6 months of age: **67.1%** (n=2,367)

- % Loss to Follow-up or Documentation: **35.9%** (n=19,006)
Colorado Screening Rates

*Based on preliminary 2013 data

Initial Screen

Statewide (~65,000): 97.6% - Goal 98%
Hospitals: 95%
Home Births (~1,000): 30%
Largest Area Birthing Center (~300): 23%

Re-screen

Statewide: 78.9% - Goal 90%
Hospitals: 79%
Home Births: 40%
Largest Area Birthing Center: 50%
<table>
<thead>
<tr>
<th></th>
<th>Otoacoustic Emissions (OAE)</th>
<th>Automated Auditory Brain Response (AABR)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Technique</td>
<td>Probe with microphone placed in the ear canal. Acoustic stimuli presented.</td>
<td>Earphone placed in the ear canal, electrodes placed on baby's scalp. Acoustic stimuli presented.</td>
</tr>
<tr>
<td>Measurement</td>
<td>OAEs are measured in the ear canal. With outer/middle ear and/or cochlear problems, no OAEs are detected.</td>
<td>Neural activity of cochlea, auditory nerve and brainstem is measured. Problems with peripheral auditory and/or auditory nerve and/or brainstem result in abnormal or absent measurements of auditory neural activity.</td>
</tr>
<tr>
<td>Advantage</td>
<td>Is easier and quicker.</td>
<td>Can indicate auditory nerve or auditory brainstem pathway dysfunction.</td>
</tr>
<tr>
<td>Disadvantage</td>
<td>Will NOT identify auditory nerve or auditory brainstem dysfunction.</td>
<td>May require sedation after 4 months of age.</td>
</tr>
</tbody>
</table>
OAE versus AABR

- The two screening methods are reliable and can be used separately or together based on:
  - Whether the baby needs intensive (AABR) or routine newborn care (OAE and/or AABR)
  - The hospital’s choice
  - State EHDI guidelines
- Both OAE and AABR may miss very mild hearing loss and frequency-specific hearing loss
- OAE will miss auditory nerve or auditory brainstem pathway dysfunction, such as auditory neuropathy spectrum disorder
- Babies who do not pass on the first OAE screen can be given a second screen using either an OAE or the AABR
- Babies screened for hearing with an AABR in the hospital and resulted in “do not pass” should not be rescreened in the office with an OAE and “passed”
The Role of Medical Home

Early Hearing Detection and Intervention

- The medical home plays a key role in the success of EHDI programs.

- A medical home can help families understand the EHDI process.

- The medical home ensures that appropriate and timely steps are taken to identify children who are Deaf/HH and get them into an early intervention program.

- The medical home serves as the primary coordinating entity which can help significantly reduce loss to follow-up/documentation.
Early Hearing Detection and Intervention (EHDI) Guidelines for Pediatric Medical Home Providers

Colorado Infant Hearing Program – A Roadmap for Families

Child's Name: ____________________________
Child's Date of Birth: __/__/____

**Birth**
- Home or Hospital Birth
- 1st Newborn Hearing Screen: Date, Time

**Before 1 Month**
- Outpatient Hearing Screen (or Rescreen): Place, Date, Time

**Before 3 Months**
- Evaluation by a Pediatric Audiologist: Date, Time

**Before 6 Months**
- Enrollment in early intervention program
- Regular visits with Pediatric Audiologist

*Children who participate in early intervention prior to six months can have age-appropriate skills by preschool.*

If a baby has a HEARING LOSS, the next steps are:
- Refer to local Colorado Hearing Resource Coordinator (CO-HEAR) & Early Intervention Coordinator (Part C)
- Evaluation by an ENT (Ear, Nose and Throat)
- Contact Colorado families for Hands & Voices
- Learn about communication options and programs
- Discuss the use of hearing aids with a Pediatric Audiologist, including information on loaned hearing aids
- Learn about assistive listening devices (such as FM systems, cochlear implants, etc.)
The Role of Medical Home

If there is any suspicion that an infant is deaf or hard of hearing...

- Do listen to parents concerns
- Encourage prompt follow-up with rescreens and diagnostic evaluations
- Make sure diagnostic evaluations are done by an audiologist who has experience with infants
- Set up electronic medical record (EMR) system to include results of auditory screening
- Flag all patient charts for children that require follow-up for hearing screens
- Flag all patient charts for children that are at risk for late onset hearing loss
Messaging

Scripts:
What to say and how to say it.

Do not say:
• The baby failed
• The baby has a hearing loss
• Probably nothing is wrong
• A lot of babies don’t pass
• The baby doesn’t need follow-up testing
• The equipment’s not working right
• It’s just fluid or vernix (we cannot assume this)
Infants identified as deaf or hard of hearing

- Address the family’s concerns
- Ensure the family is seeing an experienced pediatric audiologist
- Refer the family to appropriate specialists
- Otolaryngology, Genetics, Ophthalmology
- Help the family obtain early intervention services
- Monitor developmental milestones and ear infections
Reducing Loss to Follow-up/Documentation (LTF/D)

- LTF/D rates: 35.9% (2012)

- Medical home providers play a key role in helping reduce the rate of LTF/D

- LTF/D resources available under the Loss to Follow-up heading at the AAP EHDI web page
Reducing Loss to Follow-up/Documentation (LTF/D) Resources

- Glossary of EHDI Terms
- Guidelines for Medical Home Providers
- Reducing LTF/D Provider Checklist

Key Highlights

- In general, medical homes should NOT conduct the initial newborn hearing screening and re-screening should be limited to OAE screening.

- It is very important that the medical home know what screening equipment is used at local birth facilities.

- If you are conducting a re-screening, you are obligated to report the results to the state EHDI program.

- Additional guidelines available at:
  
Timely and appropriate diagnostic and intervention services are associated with positive communicative outcomes.

If diagnostic audiologic assessment is indicated, complete before 3 months of age.

The diagnostic audiologic evaluation should be performed by a pediatric audiologist.

The audiologist should perform a series of screens to determine:

- If a hearing loss exists
- Type
- Degree
- Configuration of the loss
EHDI – PALS

Early Hearing Detection & Intervention – Pediatric Audiology Links to Services

- EHDI-PALS is a web-based link to information, resources, and services for children who are Deaf/HH

- A national web-based directory of facilities that offer pediatric audiology services to children less than five years of age

- The medical home can use EHDI-PALS to help refer families to the most appropriate diagnostic facility and services

http://www.ehdipals.org/
Types of Diagnostic Screens

- Case History Documentation
- Automated Auditory Brainstem Response (AABR)
- Auditory Steady State Response (ASSR)
- Otoacoustic Emission (OAE)
- Tympanometry
- Behavioral Audiometry
- Audiological Monitoring
- Hearing aids, if needed, may be prescribed at any age, and should be fit before 6 months of age.
- Routinely monitor the effectiveness of hearing aids.
- Routine assessment by audiologist after hearing aids are fit should be completed and new ear molds or hearing aids prescribed if needed.
- Hearing should be retested on a regular basis to assess levels of hearing change and to identify any issues.
Specialty Referrals

**Otolaryngology**
- Assess integrity of ear canal and middle ear
- Order appropriate diagnostic screening such as temporal bone CT, MRI, etc.
- Discuss possible surgical interventions
- Counsel family and follow for success of intervention

**Genetics**
- Evaluate for possible genetic causes of hearing change
- Counsel family and patient

**Ophthalmology**
- Assess integrity of visual system
- Evaluate for visual problems known to be associated with hearing changes
Early Intervention

- Early Intervention (EI) services are provided to children and families under the Individuals with Disability Education Act (IDEA) of 2004, Part C

- All families of infants who are Deaf/HH regardless of degree or bilaterality/unilaterality, should be considered eligible for early intervention services

- Children identified as Deaf/HH who begin services before 6 months old develop language (spoken or signed) on a par with their hearing peers (Yoshinaga et al., 1998)

- Access several early intervention tools by visiting www.infanthearing.org/earlyintervention/
Early Intervention - Part C

Audiologist Confirms Hearing Loss

Colorado Hearing Resource Coordinator (CO-HEAR) Contacted

Contacts CCBs
Community Center Board (CCB)

Initiates data management

Contacts family
What is a CO-HEAR?

• Highly trained professionals; all with M.A. and appropriate professional certification
• Employees of Colorado School for the Deaf and the Blind
• Extensive experience working with families and young children who are deaf or hard of hearing
• Work within a region to provide a statewide coordinated system of referral and intervention services
• Members of the Regional EHDI team
A Visit From the CO-HEAR

• Information
• Professional with expertise and experience in childhood hearing and communication development
• Technical support
• Emotional support
• Connections!
CHIP Outcome Data: Intervention Making a Difference

A total of 136 English-speaking children with bilateral hearing loss were assessed as part of the program in the calendar year 2012.

• 80% had a Language Quotient in the normal range when compared to their hearing peers
• Additional 9% of the children were in the borderline range on the Expressive Language Scale of the Minnesota Child Development Inventory
Physician and Family Collaboration

- The physician’s role as supporter to families to meet the 1-3-6 model is critically important.

- Families feel supported by professionals when they perceive the relationship to be a collaborative partnership built on trust.

- This process takes time and involves mutual respect, honest and clear communication, understanding, and empathy.
Organizations Supporting D/HH Individuals and Their Families

- Hands & Voices

- Alexander Graham Bell Association

- Family Voices

- American Society for Deaf Children
  [http://deafchildren.org/](http://deafchildren.org/)
The success of these programs depends on reporting, tracking, and follow-up!

According to the Joint Committee on Infant Hearing, information management is used to:

- Improve services to infants and their families
- Assess the quality and timeliness of screening, evaluation, and enrollment into intervention
- Facilitate collection of demographic data on neonatal and infant hearing status
Medical home providers confirm
1. That newborn hearing screening has been conducted
2. Which technique (A-OAE or AABR) was used
3. Screening results are reported to the state EHDI program

If conducting an in-office screen, providers **must** report the results directly to the state EHDI program

It is important that medical homes learn their unique state reporting system

AAP State EHDI Laws and Regulations Resource:
Helpful Resources from the National Center for Hearing Assessment and Management (NCHAM)

- NCHAM Interactive Web-based Newborn Hearing Screening Training Curriculum
- Educational and Training Videos
- Slideshow Presentations

*All materials can be found on the NCHAM website under the “Resources” heading: [http://www.infanthearing.org/resources_home/](http://www.infanthearing.org/resources_home/)
Useful Web sites

- American Academy of Pediatrics (AAP) EHDI page

- Joint Committee on Infant Hearing (JCIH)
  http://www.jcih.org/

- Boys Town National Research Hospital
  http://www.boystownhospital.org/
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