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

A PRESENTATION FROM THE AMERICAN ACADEMY OF PEDIATRICS
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

Newborns
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

- Birth Admission Screening
- Follow-up Screen & Diagnostic
- Early Intervention
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.

Effects of Age of Identification on Language Development

Moeller, 2000
State EHDI Programs

EHDI:
A Public Health and Clinical Medicine Partnership
State EHDI Programs

State EHDI Goals

• 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
• Diagnostic Audiology
• Specialty Referrals
• Early Intervention
• Family Support
• Care Coordination
• Tracking and Data Management
Percent of Infants Receiving Hearing Screening: 2002-2014

CDC, 2016
National EHDI Data

Incidence of Children who are Deaf or Hard of Hearing

Infants Identified as Permanently Deaf or Hard of Hearing, 2008 – 2014 (Total = 36,145)

Source: CDC EHDI Hearing Screening and Follow-up Survey (2016)
2014 National CDC EHDI Data

- Births: 3,963,042
- Screened: 3,877,851 (97.9%)
- Not Passing Screen: 63,341 (1.6%)
- Diagnosed:
  - Normal Hearing: 30,309 (47.9%)
  - DHH: 6,163. (9.7%)
- No Diagnosis: 26,869 (42.4%)
**2014 National CDC EHDI Data**

- % Screened: **97.9%** (n=3,963,042)
- Prevalence of children who are deaf/hh: **1.6 per 1,000** screened (Range 0.6-3.3 per 1,000)
- % of those identified receiving Early Intervention: **64.9%** (n=4,000)

- % Screened before 1 month of age: **96.1%** (n=3,724,684)
- % Diagnosed before 3 months of age: **71.3%** (n=26,002)
- % Receiving Intervention before 6 months of age: **67.9%** (n=2,717)

- % Loss to Follow-up or Documentation: **25.5%** (n=16,168)
- %Loss Due to Parent Unresponsiveness: **8.9%** (n=5,651)
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.

- Know your hospital’s screening policies
Why Do Kids Fall Through the Cracks?

- Inconsistent screening techniques
- Loss to follow up after screening
- Parental refusal to follow up on screening
- Lack of access to audiology follow up
- Inconsistent quality of diagnostic evaluation
- Lack of communication with state EHDI program
- False negatives for babies with mild loss
- Lack of recognition of risk for progressive hearing problems
The Role of Medical Home

Early Hearing Detection and Intervention

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

- Do listen to parents concerns
- Assure 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
The Role of Medical Home

What about risk factors?

- Any Parental Concern
- Family history of hearing loss
- NICU Graduates
- Intrauterine Infections
- Craniofacial, Anomalies
- Genetic Conditions Associated with HL
- Neurodegenerative Disorders
- Serious Head Trauma, Child Abuse
- Meningitis
- Chemotherapy
What about risk factors?

• Every family must be asked about risk factors
• Develop an individualized plan for every child with risk factors
• All children, regardless of risk factors, must have appropriate developmental surveillance as per Bright Futures and an ideologic diagnostic evaluation if concern arises
All screening results, risk factors and surveillance plans MUST be discussed with the family and documented in records!!
The Role of Medical Home

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 and coordinate care
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
The Role of the Medical Home in Tracking and Reporting

• Learn how information is sent to EHDI program in your state and what responsibilities you may have

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

• AAP State EHDI Laws and Regulations Resource:
Assuring Follow Up

Increasing Follow Up Rates After a Screen That Is Not Passed

- The primary care physician plays a key role in helping to increase the number of babies receiving follow up:
  - Emphasizing to parent the need for F/U
  - Referring to qualified audiologists
  - Creating a system to assure follow up occurs and results are received in your office

- 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:

Diagnostic Evaluations

• 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 tests, to determine:
  o If a hearing loss exists
  o Type
  o Degree
  o Configuration of the loss
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.
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/
Specialty Referrals

Otolaryngology
• Assess integrity of ear canal and middle ear
• Order appropriate diagnostic testing 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 loss
• 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)

• Communication between EI and your office is essential

• Access several early intervention tools by visiting www.infanthearing.org/earlyintervention/
Physician and Family Collaboration

• Your primary role if a diagnosis is made is to provide support and coordination!

• Importance of peer support

• Identify and celebrate progress with a family

• 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
Addressing Parental Concerns:

- Overcoming shock and denial
- Outlining next steps
- Giving hope
- Establishing a partnership
In a medical home environment, you can never:

- Tell a parent that a screen not passed is “probably nothing”
- Ignore a parent’s concern about hearing
- Never say “It can’t be his hearing. Remember he passed his screen.”
- Feel that after you’ve referred your job is done
Family Support Resources

Organizations Supporting D/HH Individuals and Their Families

• Hands & Voices
  http://www.handsandvoices.org/

• Alexander Graham Bell Association
  http://www.listeningandspokenlanguage.org/

• Family Voices
  http://www.familyvoices.org/

• American Society for Deaf Children
  http://deafchildren.org/
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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