Meeting the Needs of Physicians in Support of EHDI

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To Achieve EHDI’s 1-3-6 Goals...

- Hearing (re)screening by 1 month
- Diagnostic test by 3 months
- Intervention (including amplification, if desired) by 6 months

....a Team approach is needed.
The role of the Medical Home: Coordination, Communication, Access to EHDI

Screening confirmation

Diagnostics

Specialists

Reporting

EI Services & Family Support

Early childhood screening
Purpose of 2012 Physician Survey

✓ Understand the degree to which medical homes are engaged in EHDI systems.

✓ Update our understanding of physician attitudes & knowledge re: EHDI, assessing progress since 2005.

✓ Drive strategies to support physicians in their role in EHDI.
Methods

✓ Invitation to participate sent to state EHDI coordinators

✓ 26 states participated (n=2,172 responses; 11.5% response rate)

✓ Physicians who care for children identified by EHDI coordinators, typically w/support from state AAP, AAFP chapters

✓ All received hard copy in the mail along with URL to answer survey online

✓ Cost sharing between NCHAM (materials, analysis) and State (postage, labor)
## Demographics of Respondents

<table>
<thead>
<tr>
<th>Type of Provider</th>
<th>2005</th>
<th>2012</th>
</tr>
</thead>
<tbody>
<tr>
<td>Pediatrician</td>
<td>60.3%</td>
<td>53.8%</td>
</tr>
<tr>
<td>Family Practice Physician</td>
<td>27.8%</td>
<td>27.4%</td>
</tr>
<tr>
<td>Otolaryngologist</td>
<td>3.0%</td>
<td>7.2%</td>
</tr>
<tr>
<td>Neonatologist</td>
<td>2.8%</td>
<td>3.1%</td>
</tr>
<tr>
<td>OB/GYN</td>
<td>0.5%</td>
<td>0.6%</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Practice Location</th>
<th>2005</th>
<th>2012</th>
</tr>
</thead>
<tbody>
<tr>
<td>Metro area</td>
<td>62.5%</td>
<td>56.5%</td>
</tr>
<tr>
<td>Small Town</td>
<td>24.1%</td>
<td>25.5%</td>
</tr>
<tr>
<td>Rural Area</td>
<td>13.3%</td>
<td>18.0%</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Type of Practice</th>
<th>2005</th>
<th>2012</th>
</tr>
</thead>
<tbody>
<tr>
<td>Private Practice or Community Clinic</td>
<td>78.2%</td>
<td>81.8%</td>
</tr>
<tr>
<td>Hospital</td>
<td>10.8%</td>
<td>10.0%</td>
</tr>
<tr>
<td>Medical School or University</td>
<td>6.1%</td>
<td>3.8%</td>
</tr>
<tr>
<td>Other</td>
<td>4.0%</td>
<td>4.9%</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Gender</th>
<th>2005</th>
<th>2012</th>
</tr>
</thead>
<tbody>
<tr>
<td>Male</td>
<td>53.2%</td>
<td>51.8%</td>
</tr>
</tbody>
</table>
For newborns in your practice during the past year, estimate the percentage for which you received initial newborn hearing screening results?

**2005**
- N=1968
  - Mean 82.47%
  - Median 99.0%

**2012**
- N=2172
  - Mean 79.6%
  - Median 99.0%
How Much Trust Do You Have in Newborn Hearing Screening Results?

- **Complete**
  - 0 CPHL in last 3 yrs: 27.2%
  - >25 CPHL in last 3 yrs: 35.7%
  - All Data: 33.0%

- **Fair Amount**
  - 0 CPHL in last 3 yrs: 60.6%
  - >25 CPHL in last 3 yrs: 64.0%
  - All Data: 72.8%

- **None/Minimal**
  - 0.0%
  - 3.6%
  - All Data: 3.0%

Note: This question was not asked in 2005
How often do you connect with your state EHDI program?

- 45.5% Never
- 44.3% Occasionally
- 10.2% Frequently

Note: This question was not asked in 2005
What is your best estimate of the earliest age at which:

<table>
<thead>
<tr>
<th>Age Range</th>
<th>0-1 mo</th>
<th>1-3 mos</th>
<th>4-6 mos</th>
<th>7-9 mos</th>
<th>10-12 mos</th>
<th>&gt;12 mos</th>
</tr>
</thead>
<tbody>
<tr>
<td>&lt;1 mo</td>
<td>75.7%</td>
<td>11.7%</td>
<td>7.1%</td>
<td>4.2%</td>
<td>0.1%</td>
<td>1.2%</td>
</tr>
<tr>
<td></td>
<td>41.0%</td>
<td>51.9%</td>
<td>6.1%</td>
<td>0.3%</td>
<td>0.7%</td>
<td>0.8%</td>
</tr>
<tr>
<td></td>
<td>51.9%</td>
<td>10.8%</td>
<td>12.4%</td>
<td>15.3%</td>
<td>0.3%</td>
<td>9.3%</td>
</tr>
<tr>
<td></td>
<td>20.9%</td>
<td>37.0%</td>
<td>24.8%</td>
<td>2.3%</td>
<td>10.2%</td>
<td>5.3%</td>
</tr>
<tr>
<td></td>
<td>38.3%</td>
<td>9.0%</td>
<td>11.2%</td>
<td>0%</td>
<td>0%</td>
<td>18.1%</td>
</tr>
<tr>
<td></td>
<td>12.2%</td>
<td>26.9%</td>
<td>31.9%</td>
<td>3.7%</td>
<td>16.6%</td>
<td>9.1%</td>
</tr>
<tr>
<td></td>
<td>61.6%</td>
<td>8.0%</td>
<td>0%</td>
<td>0.4%</td>
<td>7.0%</td>
<td></td>
</tr>
<tr>
<td></td>
<td>26.9%</td>
<td>33.3%</td>
<td>8.1%</td>
<td>4.2%</td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

- a. A newborn not passing the hearing screening should receive additional testing
- b. A child can be definitively diagnosed as having a permanent hearing loss
- c. A child can begin wearing hearing aids
- d. A child with permanent hearing loss should be referred to early intervention services

2005/2012 Comparison
American Academy of Pediatrics

Universal Newborn Hearing Screening, Diagnosis, and Intervention Guidelines for Pediatric Home Medical Providers

Birth
- Hospital-based Infant Screen (OAE/AABR)
- Results sent to Medical Home

Before 1 Month
- Pediatric Audiologic Evaluation
  - Otoscopic inspection
  - Child & family history
  - Middle ear function
  - OAE

Before 3 Months
- Report to State EMDI Program
- Every child with a permanent hearing loss
- Refer to IDEA Part C
- Coordinating agency for early intervention

Before 6 Months
- Continued enrollment in IDEA Part C
- (transition to Part B at 3 years of age)

Medical Evaluations
- To determine etiology and identify related conditions
  - Ophthalmologic (annually)
  - Genetic
  - Developmental pediatrics, neurology, cardiology, and nephrology (as needed)

Pediatric Audiologic Services
- Behavioral response audiometry
- Ongoing monitoring

Medical & Otolologic Evaluations
- To recommend treatment and provide clearance for hearing aid fitting
- Pediatric Audiologic Hearing aid fitting and monitoring
- Assess family about assistive listening devices (hearing aids, cochlear implants, etc.) and communication options

Notes:
(a) Infant screening programs that do not provide Outpatient Screening, Infants will be referred directly from Infant Screening to Pediatric Audiologic Evaluation.
(b) Part C of IDEA may provide diagnostic audiologic evaluation services as part of Child Find activities.
(c) Infants who fail the screening in one or both ears should be referred for further screening or Pediatric Audiologic Evaluation.
(d) Includes infants whose parents refused initial or follow-up hearing screening.

List any specialists to whom you would routinely refer the family of a child with confirmed permanent hearing loss (open-ended question)

<table>
<thead>
<tr>
<th>Specialist</th>
<th>2005</th>
<th>2012</th>
</tr>
</thead>
<tbody>
<tr>
<td>ENT/Otolaryngology*</td>
<td>75.6%</td>
<td>73.4%</td>
</tr>
<tr>
<td>Geneticist*</td>
<td>8.8%</td>
<td>9.3%</td>
</tr>
<tr>
<td>Ophthalmologist*</td>
<td>0.9%</td>
<td>2.2%</td>
</tr>
<tr>
<td>Audiologist</td>
<td>41.2%</td>
<td>53.0%</td>
</tr>
<tr>
<td>Speech Language Pathologist</td>
<td>22.9%</td>
<td>27.0%</td>
</tr>
<tr>
<td>Early Intervention</td>
<td>11.4%</td>
<td>12.0%</td>
</tr>
<tr>
<td>Neurologist</td>
<td>7.0%</td>
<td>5.6%</td>
</tr>
</tbody>
</table>
Which of the following conditions puts a child at risk for permanent late onset hearing loss? (Check all that apply)

- Meningitis: 94.5% in 2005, 94.1% in 2012
- NICU: 49.2% in 2005, 55.3% in 2012
- Congenital Heart Disease: 21.3% in 2005, 26.1% in 2012
- Family History of Childhood HL: 88.5% in 2005, 89% in 2012
- Frequent Colds: 88% in 2005, 89% in 2012
- Cleft Palate: 88% in 2005, 80.9% in 2012
- History of Cytomegalovirus: 80.8% in 2005, 80.8% in 2012
- Hypoponia: 63.8% in 2005, 60.8% in 2012
- Mother Age 40+: 64.0% in 2005, 63.2% in 2012
- Congenital Syphilis: 0% in 2005, 2005
Did your training prepare you adequately to meet the needs of infants with permanent hearing loss?

- Yes: 18.0% (2005), 18.6% (2012)
- No: 67.8% (2005), 51.3% (2012)
- Unsure: 14.2% (2005), 30.0% (2012)
Children with which of the following hearing losses may be candidates for cochlear implants? (Check all that apply)

- Bilateral mild-moderate: 15.5% in 2005, 26.2% in 2012
- Profound bilateral: 74.3% in 2005, 89.5% in 2012
- Unilateral mild-moderate: 5.9% in 2005, 12.2% in 2012
- Unilateral profound: 26.2% in 2005, 32.9% in 2012
### How confident are you in talking to parents of a child with permanent hearing loss about...?

<table>
<thead>
<tr>
<th></th>
<th>Very Confident</th>
<th>Somewhat Confident</th>
<th>Unsure</th>
<th>Not Confident</th>
</tr>
</thead>
<tbody>
<tr>
<td>2005</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Not included in 2005 survey</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>2012</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>NBHS Process</td>
<td>54.0%</td>
<td>37.2%</td>
<td>0.0%</td>
<td>8.8%</td>
</tr>
<tr>
<td>Causes of HL</td>
<td>28.5%</td>
<td>56.9%</td>
<td>0.0%</td>
<td>12.7%</td>
</tr>
<tr>
<td>Communication Options (e.g., ASL, LSL, Cued Speech)</td>
<td>12.8%</td>
<td>37.8%</td>
<td>0.0%</td>
<td>49.3%</td>
</tr>
<tr>
<td>Unilateral or Mild Hearing Loss Consequences</td>
<td>28.0%</td>
<td>54.7%</td>
<td>0.0%</td>
<td>17.3%</td>
</tr>
<tr>
<td>Bilateral moderate to profound HL Consequences</td>
<td>21.7%</td>
<td>48.3%</td>
<td>0.0%</td>
<td>30.0%</td>
</tr>
<tr>
<td>Cochlear implant candidacy</td>
<td>9.8%</td>
<td>33.9%</td>
<td>0.0%</td>
<td>56.3%</td>
</tr>
<tr>
<td>What to do next when a child diagnosed</td>
<td>37.0%</td>
<td>49.7%</td>
<td>0.0%</td>
<td>13.3%</td>
</tr>
</tbody>
</table>

Not included in 2005 survey
Which of the following can have an impact on speech and language development? (Check all that apply):

- 72.1%
- 88.6%
- 96.1%
- 96.3%
- 0%
- 20%
- 40%
- 60%
- 80%
- 100%

Unilateral HL
Mild Bilateral HL
Moderate Bilateral HL
Severe/Profound Bilateral HL

Note: This question was not asked in 2005
Do you do hearing screening for infants and young children in your office?

Yes – 28.6%

No – 71.4%

Note: This question was not asked in 2005
<table>
<thead>
<tr>
<th>Category</th>
<th>Percentage</th>
</tr>
</thead>
<tbody>
<tr>
<td>Newborns who do not pass NBHS in hospital</td>
<td>50.2%</td>
</tr>
<tr>
<td>Newborns for whom you cannot obtain NBHS results</td>
<td>43.3%</td>
</tr>
<tr>
<td>All newborns regardless of previous tests</td>
<td>15.4%</td>
</tr>
<tr>
<td>Children ages 1-3 years as part of their annual check-ups</td>
<td>50.9%</td>
</tr>
<tr>
<td>Children of parents who voice concerns about their child’s hearing</td>
<td>81.4%</td>
</tr>
</tbody>
</table>

Note: This question was not asked in 2005
How often do you use each of the following to screen hearing in your office?

<table>
<thead>
<tr>
<th></th>
<th>Never</th>
<th>Occasionally</th>
<th>Frequently</th>
<th>Always</th>
</tr>
</thead>
<tbody>
<tr>
<td>a. AABR</td>
<td>71.6%</td>
<td>14.4%</td>
<td>10.3%</td>
<td>3.7%</td>
</tr>
<tr>
<td>b. Response to sounds/noisemakers</td>
<td>17.1%</td>
<td>25.3%</td>
<td>36.4%</td>
<td>21.2%</td>
</tr>
<tr>
<td>c. Caregiver interview or questionnaire</td>
<td>9.7%</td>
<td>12.5%</td>
<td>35.4%</td>
<td>42.4%</td>
</tr>
<tr>
<td>d. OAE</td>
<td>34.2%</td>
<td>13.4%</td>
<td>29.2%</td>
<td>23.2%</td>
</tr>
<tr>
<td>e. Tuning Fork</td>
<td>53.5%</td>
<td>33.7%</td>
<td>9.7%</td>
<td>3.1%</td>
</tr>
<tr>
<td>f. Tympanometry</td>
<td>21.1%</td>
<td>28.2%</td>
<td>32.5%</td>
<td>18.3%</td>
</tr>
</tbody>
</table>

Note: This question was not asked in 2005
Who does most of the hearing screening in your office? (Choose one)

- Nurse: 45.0%
- Audiologist: 24.6%
- Self: 18.7%
- Medical Assistant: 9.9%
- Other: 1.8%

Note: This question was not asked in 2005
Number of children seen with permanent hearing Loss in your practice during last 3 years

<table>
<thead>
<tr>
<th></th>
<th>0  (n=672)</th>
<th>1-3  (n=858)</th>
<th>4-9  (n=310)</th>
<th>10-24  (n=141)</th>
<th>25-49  (n=29)</th>
<th>50+  (n=30)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Routinely refer the family of a child with permanent hearing loss to a geneticist.</td>
<td>4.8%</td>
<td>7.9%</td>
<td>16.1%</td>
<td>17.7%</td>
<td>13.8%</td>
<td>50.0%</td>
</tr>
<tr>
<td>Believe hearing aids can be fit for children 0 to 3 months of age.</td>
<td>34.4%</td>
<td>38.9%</td>
<td>42.3%</td>
<td>39.6%</td>
<td>46.4%</td>
<td>66.7%</td>
</tr>
<tr>
<td>Believe infants with bilateral mild-moderate hearing loss are candidates for cochlear implants.</td>
<td>25.6%</td>
<td>28.6%</td>
<td>30.3%</td>
<td>18.4%</td>
<td>17.2%</td>
<td>13.3%</td>
</tr>
<tr>
<td>Believe unilateral hearing loss affects speech and language development</td>
<td>71.0%</td>
<td>73.2%</td>
<td>75.5%</td>
<td>75.2%</td>
<td>75.9%</td>
<td>90.0%</td>
</tr>
</tbody>
</table>
What correlates with knowledge about hearing loss and treatment?

- Number of children seen w/hearing loss? (substantial effect)
- Perceived adequacy of training? (some effect)
- Years of experience in pediatrics? (little effect)
- Percent of practice comprised of 0-5 year olds? (small positive effect)
Survey Take-Home Messages

• Physicians are getting NBHS results, but little other communication with state EHDI program
• Some skepticism re: trust in NBHS results
• No better knowledge re: 1-3-6 rule
• No better knowledge re: risk factors
• Feel less prepared in terms of training
• Apx. ¼ perform hearing screening, often via noisemakers and parent interview

There’s a lot more work to do!
How can this information be used by EHDI?

Reported coordinator activities:

- **Raise awareness**
  - Share results with state EHDI Advisory Board
  - Present at grand rounds
  - Present at physician conferences, audiology task forces

- **Educate & provide resources for physicians**
  - Engage Chapter Champions in training
  - Target high LTF hospitals, support medical homes in area
  - Conduct follow up surveys to “drill down”

- **Guide EHDI policies and practices**
  - Target physician behaviors in QI efforts
  - Interdisciplinary training
What are the biggest problems facing EHDI programs?
Lost to Follow-Up (3 Months)

FIGURE. Status of infants who did not pass initial hearing screening — United States, 2005–2007

- 2005
- 2007

Nonresident/moved
Died/refused*
In process
Hearing loss
Normal hearing
LFU/LTD†

Percentage

0 20 40 60 80

Characteristic

MMWR March 10, 2010, 59:8, M. Gaffney, J Eichwald et al

39% - 2010
Lost to Treatment (Hearing Aids by 6 Months)

In spite of 91% retest rate

Only 39% fit with aids on time

Late diagnosis

Medicaid - more lost to follow-up

NICU babies harder to treat because of compounding factors

Distance from specialized centers

“Newborn Hearing Screening Follow-Up: Factors Affecting Hearing Aid Fitting by 6 Months of Age”, Spivak et al. American J. Audiology, June 2009
Early Intervention

Only 60-70% of infants with hearing loss are enrolled by 6 months (CDC)
Barriers – M. Gaffney CDC

| Hospital screening | • Technique and/or low numbers = high false positives  
|                    | • Presentation of results |
| Documentation      | • Data reporting systems and ease  
|                    | • Importance |
| Audiology          | • Lack of experienced “pediatric” audiologists  
|                    | • Communication |
| Family             | • Cost and transportation  
|                    | • Language access  
|                    | • Mobility  
|                    | • Urgency |
# Challenges to medical home

<table>
<thead>
<tr>
<th>Challenge</th>
<th>Details</th>
</tr>
</thead>
<tbody>
<tr>
<td>Relatively low incidence of severe hearing loss</td>
<td>• One of the most common congenital disorder</td>
</tr>
<tr>
<td>Lack of physician knowledge and education*</td>
<td>• Different terminology</td>
</tr>
<tr>
<td></td>
<td>• Misconceptions – success of UNHS*</td>
</tr>
<tr>
<td>Getting newborn results</td>
<td>• Difficulty with hospital</td>
</tr>
<tr>
<td></td>
<td>• Integrating with electronic medical records</td>
</tr>
<tr>
<td>Retesting in office</td>
<td>• Reporting results*</td>
</tr>
</tbody>
</table>
Challenges to medical home

- Family support
- Working with EI
  - Working with community agencies
- Time constraints and financial constraints
Before one month

Outpatient Rescreening
- Hospital
- Audiologist
- Retesting in Primary Care facility
- OAE
- ABR

LTF/D
- Communication with family, hospital, audiologist
- Office protocol?
- Office staff can help
- Don’t pass – DO TEST!!
Office Rescreening*

- How common?
  - 25% of pediatricians rescreen
  - NYS survey/Regional meetings
  - Many have OAEs in office

- Helpful to parents? Easier? Better?

- Who does it and are they trained?
  - Techs

- OAE? ABR? Both?

- Initial screen?
  - NY - 23%

- Need to report to State EHDI programs
  - Only 12% in NY
“Do not pass” - Parental support

Explain and discuss results
  • Importance of hearing loss

Use language that encourages follow-up

Avoid negative and meaningless words

Be sensitive to cultural meanings of words

ALWAYS RETEST!!

Assist in arranging retest and FOLLOW-UP
Before 3 months

“Pediatric” audiological evaluation

Report to state EHDI

Early Intervention

Family support, education and information

Medical and ENT evaluation* – Genetics, Eye

Hearing aids – if desired
Remember!

- At least 90% of children who are either born deaf or lose their hearing are born to hearing parents.

- Conversely, 90% of the children of deaf parents are hearing.
Most important predictor of success is meaningful and effective family involvement.

Support reduces parental stress.

Direct **parent-to-parent support** ranks as one of the strongest measures of family support – Hands & Voices.

**Less than 50% received support that they needed**.

Parents were more likely to get support when encouraged.

Face-to-face interaction with professionals – major importance.

Means and SDs of PPVT scores for subjects as a function of age of enrollment in intervention.

Moeller M P Pediatrics 2000;106:e43
Mean vocabulary scores plotted as a function of the two key variables, age of enrollment and family involvement ratings.
Before 6 months

Early Intervention services

Etiology and associated problems

- ENT
- Eye
- Genetics
- Neurology, Developmental Pediatrics and others if needed

Audiological follow-up
1/3 of children with hearing loss have another major disability!
Genetics

Genetic counseling

• Future children - recessive
• Other family members may be effected
• Etiology/diagnosis – why?

Syndromes

• Trisomy 21
• Usher Syndrome - Retinitis pigmentosa
• Treacher-Collins – cranio-facial abnormalities
• Jervell and Lange-Nielsen syndrome
  • Prolonged QT, sudden death
EYE examination

Optimize vision – coexisting vision issues

• Common in both syndromic and non-syndromic causes

Assess findings of syndromes and etiology

Retinal findings of CMV and toxoplasmosis
Status of cochlea, cochlear nerve and middle ear?

Imaging of the temporal bones – may help in etiology

Abnormal in about 30% of patients
- More likely with asymmetric hearing impairments
- Abnormal architecture of the inner ear

Most commonly large vestibular aqueduct
- Often progressive
- Trauma can make worse – sports?
- MRI/CT scan - age – 8-9 months
JCIH Risk Factors* - 40% of Hearing Loss Occurs after Newborn Period

- Family history of hearing loss
- NICU graduates
- Intrauterine infections like CMV
- Craniofacial, genetic and neurological conditions
- Serious head trauma – child abuse
- Meningitis
- Chemotherapy
Ongoing Care – “Bright Futures”

- Provide information about hearing, speech and developmental issues
- Aggressively treat middle ear disease (tympanometry)
- Routine hearing and vision screening (OAE, Sweep) – Referral to audiologist if not passed
- Developmental/autism screening – only 20% screen
- Referral if parental or PCP concern
- Refer if risk factor by 24 to 30 months - CMV
- Audiological evaluation of developmentally delayed or uncooperative children
### Glossary of Terms for Newborn Hearing Screening

The American Academy of Pediatrics (AAP) Early Hearing Detection and Intervention (EHDI) Lost to Follow-Up (LTF/D) Workgroup has compiled a glossary of terms important to newborn hearing screening and resources related to LTF/D.

<table>
<thead>
<tr>
<th>Term</th>
<th>Definition</th>
</tr>
</thead>
<tbody>
<tr>
<td>Newborn hearing screening (NHS)</td>
<td>This occurs shortly after birth, typically performed in hospitals to identify hearing loss in newborns.</td>
</tr>
<tr>
<td>Otoacoustic Emissions (OAE)</td>
<td>This test measures a response produced by the cochlea (inner ear) when a sound is presented.</td>
</tr>
<tr>
<td>Automated Auditory Brainstem Response (AABR)</td>
<td>This screening test measures the integrity of the auditory nerve and cochlea.</td>
</tr>
<tr>
<td>Outpatient screening</td>
<td>An outpatient screening can take place any of the following: 1. Hospital: Screening protocols vary and often include an outpatient screening stage. The specific testing used to conduct the outpatient screening should be based on the knowledge of how the infant’s hearing was obtained. 2. Provider Office: Initially the newborn hearing screening and rescreening (if needed) will take place at the birthing hospital. However, in some cases where the infant is discharged from the hospital, a provider may conduct a rescreen in the office as needed. 3. Audiologist: Similar to the provider office, a rescreen may also take place at the audiologist’s office.</td>
</tr>
<tr>
<td>Lost to follow up</td>
<td>For infants who did not pass newborn hearing screening, “lost to follow-up” refers to a failure to receive the next step of treatment. If the screen or comprehensive audiological evaluation.</td>
</tr>
<tr>
<td>Lost to documentation</td>
<td>Failure to report the results from hearing screening, rescreening, diagnostic services, and/or treatment services which are needed for comprehensive surveillance and monitoring by EHDI and the medical home.</td>
</tr>
<tr>
<td>Lost to treatment</td>
<td>Failure for a child with an identified hearing loss to receive needed, therapeutic services and failure for families to receive necessary information to support decisions regarding treatment options.</td>
</tr>
<tr>
<td>Medical home</td>
<td>A model for providing high-quality primary care that addresses and integrates health promotion, acute care and chronic condition management in a planned, coordinated, and family-centered manner.</td>
</tr>
<tr>
<td>Late onset hearing loss</td>
<td>A hearing loss that has not been present at birth and the newborn hearing screening would result in “lost to follow-up.”</td>
</tr>
<tr>
<td>Auditory Neurapathy</td>
<td>This term describes a rare condition of the auditory system where the auditory nerve and/or its brainstem representation is not present. Functional hearing can often be quite impaired and diagnosis and treatment can be confusing and complicated.</td>
</tr>
</tbody>
</table>

### Newborn Hearing Screening: Lost to Documented Follow Up Considerations for the Medical Home

Since 2000, the percentage of newborns screened for hearing loss dramatically increased from 52 to 95 percent. However, almost half of the children who do not pass** hearing screening tests lack a documented diagnosis. The infant’s primary care medical home provides an important role in ensuring that timely follow up and the appropriate documentation of that follow up occur. Without the active assistance of the medical home, the infant may be considered “lost” in the early hearing detection and intervention (EHDI) system, which undeniates the potential benefits of newborn hearing screening. A “wait and see” approach is never appropriate.

An infant who does not pass his/her newborn hearing screen has a potential developmental emergency. **Do not pass includes babies that have “failed” or missed the hearing screening or for those who had an invalid, uninterpretable result.

**WHAT CAN A NEWBORN IDENTIFIED WITH POSSIBLE HEARING LOSS BE “LOST” TO?**

Lost to follow up: For infants who did not pass newborn hearing screening. “Lost to follow-up” refers to a failure to receive the next step of treatment. Be it rescreen or comprehensive audiological evaluation.

Lost to documentation: Failure to report the results from hearing screening, rescreening, diagnostic services, and/or treatment services to the state EHDI program and the medical home. This data is needed for comprehensive surveillance and monitoring to ensure infants receive recommended services. Lost to documentation can mean:

- Hospital does not record and/or report results of first screen
- Hospital does not record and/or report results of second screen
- Audiologist does not report results

Medical home provider does not record and/or report the results of the rescreen

Lost to treatment: Failure for a child with an identified hearing loss to receive needed, therapeutic services and failure for families to receive necessary information to support decisions regarding treatment options.

**WHAT IS THE MEDICAL HOME’S ROLE IN REDUCING THE PERCENTAGE OF INFANTS THAT DO NOT PASS THE NEWBORN HEARING SCREEN AND WHO ARE THEN CONSIDERED “LOST TO DOCUMENTED FOLLOW UP”?**

The following information outlines specific actions the medical home can take to reduce the percentage of infants who do not pass a newborn hearing screen who either do not receive follow up care or whom follow up is not reported back to the state EHDI programs. It is important to note that the actions outlined below are specific to reducing lost to documented follow up. There are many more recommendations for providers for the overall EHDI process that are not listed here. For additional information, please see the AAP/APHAA Committee on Infant Hearing Position Statement and EHDI Guidelines for Pediatric Medical Home Providers.

**Practice Considerations**

Medical homes should obtain, document, and discuss all screening test results and risk factors** which includes:

- Birth asyle symptoms
- Congenital anomalies
- Delayed developmental milestones
- Family history of hearing loss
- Anomalies
- Newborn illness
- Otorrhea
- Other risk factors

**AAP EHDI LTF/D Background Resources**
AAP EHDI LTF/D Guidelines & Checklist

Reducing Loss to Follow-Up/Documentation in Newborn Hearing Screening: Guidelines for Medical Home Providers

1-3-6 NEWBORN HEARING SCREENING CHECKLIST

Patient Name: 
Patient DOB: 
Date of Visit:

1 INITIAL SCREENING (by no later than 1 month of age)

- Has the child had a newborn hearing screening?
  Yes No
- Did you obtain the test results from the screening hospital or state EHDI program?
  Yes No
- Are the results recorded in the patient's chart?
  Yes No
- Did the child pass the newborn hearing screening?
  Yes No
- How were the results reported to the state EHDI program?
  Yes No
- How were results discussed with family?
  Yes No
- Has a rescreening occurred if the initial screen resulted in “minor pass” or “otherwise necessary”?
  Yes No

RESCREENING (by no later than 1 month of age)

- Where will the rescreening be performed?
  Yes No
- If hospital/outpatient center, when is the rescreening appointment?
  Yes No
- If conducted in offices:
  - Determine what screening equipment was used in the past;
  - Follow the AAP office rescreening guidelines.

2 DIAGNOSTIC EVALUATION (by no later than 3 months of age)

- If the child did not pass the rescreening, was there referral to an audiologist with expertise in pediatrics?
  Yes No
- Did the child pass the rescreening?
  Yes No
- Discuss EI and need for comprehensive plan.
  Yes No
- Has the result been reported?
  Yes No

3 EARLY INTERVENTION (by no later than 3 months of age)

- If the child was diagnosed with a hearing loss, was the child referred for early intervention and multidisciplinary services?
  Yes No
- Date of visit:
  Yes No
- Provide early intervention referral and audiophony, and EHDI, after genetics.

ONGOING SURVEILLANCE AND SCREENING

Continue to perform ongoing surveillance and screening for late-onset hearing loss, particularly those children with risk factors.

*JCIH Risk Factors

* 2/3 Risk Factor
** AAH* guidelines on rescreening in office

Early Hearing Detection & Intervention Program
Revised September 2012
Medical Home and LTF/D
AAP  EHDI Tools

Obtain, document, and discuss all screening test results and risk factors by one month

- Whenever possible information should be received from the hospital rather than the parent
- Work with local birthing facilities to establish best method for obtaining test results

Coordinate care of a child that has a ‘do not pass’ screening result or for whom you cannot obtain the documented screening results

- Either screen, rescreen or arrange screen or rescreen by one month
- Medical Home takes lead in scheduling - Assist parents with rescreen appointment
Medical Home and LTF/D
AAP EHDI Tools

Confirm results with state EHDI program within 48 hours

• Need to learn state reporting program

IF ‘do not pass’ the second screen, refer to audiologist that has experience with infants and ensure follow-up appointment is scheduled

• Confirm appointments and notify state EHDI program
• refer to CDC EHDI Directory – EHDI PALS

Ensure family is referred to local EI program

• Medical home should get parent/family to release medical information/records to PCP so they can obtain the results

Ensure family is referred to local EI program
# Medical Home and LTF/D AAP EHDI Tools

<table>
<thead>
<tr>
<th>Dedicated staff person in the practice</th>
<th>Provide education and support to families</th>
<th>Culturally competent and health literate appropriate information</th>
</tr>
</thead>
<tbody>
<tr>
<td>• Obtain all screening results</td>
<td>• Hearing, speech, and language milestones</td>
<td>• Hands and Voices, Guide-By-Your-Side, NCHAM, etc.</td>
</tr>
<tr>
<td>• Coordinate the education/support of families</td>
<td>• Discuss and explain all test results, next steps, and importance of follow-up</td>
<td>• Educational options</td>
</tr>
<tr>
<td>• Relationship with State EHDI program</td>
<td>• Confirm with family that follow-up appointments have been made and kept</td>
<td></td>
</tr>
<tr>
<td></td>
<td>• Help to arrange transportation and social service support</td>
<td></td>
</tr>
</tbody>
</table>
AAP EHDI LTF/D Rescreening Guidelines

AAP HEARING SCREENING GUIDELINES FOR MEDICAL HOMES

GUIDELINES AT A GLANCE:
✓ Except in rare circumstances, medical homes should NOT conduct the initial newborn hearing screening.
✓ Proper equipment (e.g., AABR) is required for screening in order NOT to miss auditory neuropathy. For this reason, it is very important that the medical homes know what screening equipment is used at their local birthing facilities.
✓ If you are conducting a hearing screening, you are obligated to report the results to the state EHDI program.

REPORTING
• Rescreening in the medical office comes with an important **obligation to report all normal and abnormal screening results** to the state EHDI system (and in some states it is required by law).
• To find your EHDI state coordinator: [http://www.infanthearing.org/status/cnhs.html](http://www.infanthearing.org/status/cnhs.html).

EQUIPMENT
• Re-screening of infants must be performed by a **physiologic measurement**, not by assessing behavioral responses to environmental sounds or noises. Currently, the technology that is most commonly available and affordable for such office-based re-screening is *otoacoustic emission* or *OAE* technology.
• The equipment used for re-screening must be calibrated by the manufacturer, with a declaration that the device is capable of separating “pass” from “not pass” at a level that can detect a hearing loss of at least 30 db.
• The equipment must be maintained and recalibrated on a regular basis (at least annually) or more frequently if recommended by the manufacturer.
• Babies with auditory neuropathy will pass an OAE (normal middle and inner ear function) but not pass an AABR (nerve defect). If an infant does not pass an automated AABR screening (AABR) in the hospital and then passes on OAE, IT DOES **NOT** assure normal hearing. This child must be rescreened with an AABR. If however, the infant does not pass the OAE than a hearing loss is likely and the infant must be referred immediately for further evaluation.
• Infants who were hospitalized in the newborn intensive care unit (NICU) are at much higher risk for hearing loss, particularly auditory neuropathy which can only be determined with an AABR or ABR. These babies should only be screened with an AABR, and if they do not pass, they should be referred for an audiologist with experience with infants to perform a rescreen with an AABR.

PROPER SCREENING TECHNIQUE
• It is best to have a quiet environment for office-based testing to minimize the risk of ambient noise interfering with the screening results.
• Office personnel who perform the re-screening should be trained and experienced in screening infants and children.
• It is important that the infant is only re-screened at a single visit in the office so that there is no delay in identification of infants with hearing loss. They should be referred to a qualified infant audiologist.
• During the re-screening visit, there should be no more than three tests of each ear with the OAE probe. After three probe tests, each ear or ear conduction test, the baby should be re-screened with a qualified infant audiologist.
• At the time of re-screening, both ears should always be tested, even if only one ear did not pass the hospital-based hearing screening test.

COMMUNICATION OF RESULTS TO FAMILY
• Screening results should be conveyed to families in a culturally competent, sensitive manner to ensure understanding.
• The results of hearing screening should be explained to families in a way that conveys the screen and not a definitive diagnosis so as not to cause undue anxiety. But strongly encourages the family to take the next appropriate step in adhering with a diagnostic testing.

DELAYED-ONSET HEARING LOSS
• A passing screen at birth does not assure that delayed-onset hearing loss will not later be diagnosed.
• Referral for pediatric audiology evaluation should be made when there is caregiver concern about hearing, a delay in the child’s language development, or there are identified JCH risk factors for childhood hearing loss.

NICU graduates

Guidelines at a glance:
✓ Except in rare circumstances, medical homes should NOT conduct the initial newborn hearing screening.
✓ In some circumstances an AABR may be warranted to rule out auditory neuropathy.
✓ If you are conducting a hearing screening, you are obligated to report the results to the state EHDI program.
TOP Trusted Sources

- (1) Pediatricians (58%)
- (2) Friends and family (55%)
- (3) Evening news (39%)
- (4) Internet searches (38%)
- (5) Physician office (37%)
- (6) Web sites (33%)
- (7) Parenting books (32%)
- (8) Morning TV talk shows (31%)
- (9) Newspaper articles (28%)
- (10) Magazine articles (25%)

CDC data
How to Reach PCPs?

Decide who you want to reach? Who is reachable?

**Face to face visits**
- Physician champion - enthusiastic
- Office managers – make appointment
- Brief and focused
- Bring gifts 😊

**Web site with online/printable materials**
- Handouts – patient education
- “Just-in-time” – desktop
- Journals?

**Mobile applications**
- Younger
- Must be easy to use

**Less Effective**
- Conference/phone calls
- Grand rounds?
- Clinical guidelines

Stevenson and Biernath 2010, Lieser and Levine 2012, Texas EHDI Pilot Program 2011
Can the Medical Home Reduce LTF/D?

It's tough to make predictions, especially about the future.

Yogi Berra
Find these resources at:

http://www.infanthearing.org/
medicalhome/index.html

PEHDIC/Pages/Early-Hearing-Detection-and-Intervention.aspx
Please type questions or comments in the chat box.

This session will be posted on our EHDI website for future viewing.

Thank you for your participation!
## Are Confident People More Accurate?

<table>
<thead>
<tr>
<th>How confident are you in talking to parents of a child with permanent hearing loss about who is a candidate for CI's?</th>
<th>Are children with bilateral mild-moderate hearing loss candidates for a cochlear Implant?</th>
</tr>
</thead>
<tbody>
<tr>
<td>Very Confident</td>
<td>Yes</td>
</tr>
<tr>
<td>Somewhat Confident</td>
<td>Yes</td>
</tr>
<tr>
<td>Not Confident</td>
<td>Yes</td>
</tr>
</tbody>
</table>

**Note:** Data only from 2012 survey
<table>
<thead>
<tr>
<th>Did your training prepare you adequately to meet the needs of infants with permanent hearing loss?</th>
<th>Yes (n=383)</th>
<th>Unsure (n=618)</th>
<th>No (n=1056)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Routinely refer the family of a child with permanent hearing loss to a geneticist.</td>
<td>17.0%</td>
<td>9.7%</td>
<td>6.4%</td>
</tr>
<tr>
<td>Believe hearing aids can be fit for children 0 to 3 months of age.</td>
<td>46.9%</td>
<td>38.8%</td>
<td>36.3%</td>
</tr>
<tr>
<td>Believe infants with bilateral mild-moderate hearing loss are candidates for cochlear implants.</td>
<td>18.3%</td>
<td>30.6%</td>
<td>27.8%</td>
</tr>
<tr>
<td>Believe unilateral hearing loss affects speech and language development</td>
<td>73.1%</td>
<td>73.0%</td>
<td>73.9%</td>
</tr>
</tbody>
</table>
### Years of practice with pediatric population

<table>
<thead>
<tr>
<th></th>
<th>0-10 Years (n=564)</th>
<th>10-20 Years (n=651)</th>
<th>20-30 Years (n=531)</th>
<th>30+ Years (n=300)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Routinely refer the family of a child with permanent hearing loss to a geneticist.</td>
<td>9.0%</td>
<td>10.9%</td>
<td>7.7%</td>
<td>9.3%</td>
</tr>
<tr>
<td>Believe hearing aids can be fit for children 0 to 3 months of age.</td>
<td>32.7%</td>
<td>38.6%</td>
<td>43.7%</td>
<td>41.6%</td>
</tr>
<tr>
<td>Believe infants with bilateral mild-moderate hearing loss are candidates for cochlear implants.</td>
<td>31.9%</td>
<td>29.2%</td>
<td>20.9%</td>
<td>20.3%</td>
</tr>
<tr>
<td>Believe unilateral hearing loss affects speech and language development</td>
<td>78.4%</td>
<td>75.3%</td>
<td>71.4%</td>
<td>63.3%</td>
</tr>
</tbody>
</table>
### What percentage of your practice is comprised of infants or children 0-5 years of age?

<table>
<thead>
<tr>
<th>Response Description</th>
<th>≤ 33% (n=1096)</th>
<th>34-65% (n=637)</th>
<th>≥ 66% (n=357)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Routinely refer the family of a child with permanent hearing loss to a geneticist.</td>
<td>6.8%</td>
<td>11.6%</td>
<td>13.7%</td>
</tr>
<tr>
<td>Believe hearing aids can be fit for children 0 to 3 months of age.</td>
<td>33.6%</td>
<td>43.9%</td>
<td>45.0%</td>
</tr>
<tr>
<td>Believe infants with bilateral mild-moderate hearing loss are candidates for cochlear implants.</td>
<td>23.4%</td>
<td>28.7%</td>
<td>30.8%</td>
</tr>
<tr>
<td>Believe unilateral hearing loss affects speech and language development</td>
<td>70.7%</td>
<td>74.4%</td>
<td>73.9%</td>
</tr>
<tr>
<td>Type of Provider</td>
<td>Pediatric (n=115)</td>
<td>Family Practice Physician (n=587)</td>
<td>Otolaryngologist (n=155)</td>
</tr>
<tr>
<td>-------------------------</td>
<td>-------------------</td>
<td>-----------------------------------</td>
<td>--------------------------</td>
</tr>
<tr>
<td>FREQUENTLY receive information from your state EHDI program?</td>
<td>13.3%</td>
<td>7.3%</td>
<td>7.3%</td>
</tr>
<tr>
<td>COMPLETE trust in newborn hearing screening results?</td>
<td>34.5%</td>
<td>33.5%</td>
<td>21.2%</td>
</tr>
<tr>
<td>Believes that &quot;Mother's age &gt; 40 years&quot; puts a child at increased risk for permanent hearing loss</td>
<td>14.5%</td>
<td>23.3%</td>
<td>6.5%</td>
</tr>
<tr>
<td>Conducts in-office screening</td>
<td>26.7%</td>
<td>22.2%</td>
<td>77.8%</td>
</tr>
<tr>
<td>Type of Provider</td>
<td>Pediatric (n=1152)</td>
<td>Family Practice Physician (n=587)</td>
<td>Otolaryngologist (n=155)</td>
</tr>
<tr>
<td>---------------------------------------------------------------------------------</td>
<td>--------------------</td>
<td>---------------------------------</td>
<td>--------------------------</td>
</tr>
<tr>
<td>Routinely refer the family of a child with permanent hearing loss to a geneticist</td>
<td>10.9%</td>
<td>2.7%</td>
<td>27.1%</td>
</tr>
<tr>
<td>Believe hearing aids can be fit for children 0 to 3 months of age</td>
<td>43.1%</td>
<td>29.1%</td>
<td>47.9%</td>
</tr>
<tr>
<td>Believe infants with bilateral mild-moderate hearing loss are candidates for cochlear implants.</td>
<td>30.0%</td>
<td>23.3%</td>
<td>6.5%</td>
</tr>
<tr>
<td>Believe unilateral hearing loss affects speech and language development.</td>
<td>75.2%</td>
<td>71.7%</td>
<td>66.5%</td>
</tr>
</tbody>
</table>
## Type of Provider and Setting

<table>
<thead>
<tr>
<th></th>
<th>Pediatric (n=995)</th>
<th>Family Practice Physician (n=505)</th>
<th>Otolaryngologist (n=116)</th>
<th>Nurse Practitioner (n=37)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Conducts in-office hearing screening</td>
<td>27.1</td>
<td>23.1</td>
<td>78.9</td>
<td>30.6</td>
</tr>
<tr>
<td></td>
<td>17.2</td>
<td>27.8</td>
<td>84.2</td>
<td></td>
</tr>
<tr>
<td>Routinely refers the family of a</td>
<td>9.9</td>
<td>3.0</td>
<td>23.3</td>
<td>8.1</td>
</tr>
<tr>
<td>child with permanent hearing loss to</td>
<td>13.8</td>
<td>5.6</td>
<td>57.9</td>
<td></td>
</tr>
<tr>
<td>a geneticist</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Believes hearing aids can be fit</td>
<td>42.7</td>
<td>29.8</td>
<td>45.6</td>
<td>41.9</td>
</tr>
<tr>
<td>for children 0-3 months of age</td>
<td>46.2</td>
<td>20.0</td>
<td>50.0</td>
<td></td>
</tr>
<tr>
<td>Believe infants with bilateral</td>
<td>30.5</td>
<td>24.0</td>
<td>7.8</td>
<td>24.3</td>
</tr>
<tr>
<td>mild-moderate hearing loss are</td>
<td>10.3</td>
<td>16.7</td>
<td>0.0</td>
<td></td>
</tr>
<tr>
<td>candidates for cochlear implants</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Believe that &quot;Mothers age &gt; 40</td>
<td>15.0</td>
<td>23.0</td>
<td>32.8</td>
<td>21.6</td>
</tr>
<tr>
<td>years&quot; puts a child at increased</td>
<td>13.8</td>
<td>16.7</td>
<td>26.3</td>
<td></td>
</tr>
<tr>
<td>risk for permanent hearing loss</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

Private practice or community clinic (n=1,747)

Medical School (n=81)
<table>
<thead>
<tr>
<th>Type of Provider</th>
<th>Pediatric (n=1152)</th>
<th>Family Practice Physician (n=587)</th>
<th>Otolaryngologist (n=155)</th>
<th>Neonatologist (n=67)</th>
<th>OB/GYN (n=12)</th>
<th>Nurse Practitioner (n=37)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Routinely refer the family of a child with permanent hearing loss to a geneticist</td>
<td>10.9%</td>
<td>2.7%</td>
<td>27.1%</td>
<td>9.0%</td>
<td>0.0%</td>
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<td>40.5%</td>
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<td>Believe infants with bilateral mild-moderate hearing loss are candidates for cochlear implants.</td>
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<td>23.3%</td>
<td>6.5%</td>
<td>29.9%</td>
<td>25.0%</td>
<td>26.1%</td>
</tr>
<tr>
<td>Believe unilateral hearing loss affects speech and language development.</td>
<td>75.2%</td>
<td>71.7%</td>
<td>66.5%</td>
<td>58.2%</td>
<td>66.7%</td>
<td>82.6%</td>
</tr>
</tbody>
</table>