Newborn Hearing Screening: Success and Challenges

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AAP EHDI Chapter Champion Webinar
March 2013

Hearing Screening in the U.S.

• No federal law requiring hearing screening & follow-up

• All states have an Early Hearing Detection and Intervention (EHDI) program
  – Most states have passed laws related to hearing screening but the requirements vary

• Ensuring infants are documented to receive recommended follow-up remains a key challenge
CDC EHDI Program

- Support the development & implementation of state-based EHDI Information Systems
  - Ensure infants receive recommended follow-up
  - Collect & report unduplicated, individual level data on all births
  - Promote integration w. other data systems

- Awarded 52 Cooperative Agreements
  - Provide technical assistance

Documented Hearing Screening Among Infants (U.S. 2010*)

- Screened for Hearing Loss, 97.9%
- No Documented Screen, 2.1%
Infants Identified with Hearing Loss, 2005 – 2010 (*Total = 23,498*)

Challenges

- Lost to follow-up (*LFU*)/Lost to documentation (*LTD*)
  - LFU: Did not receive recommended services
  - LTD: Received services but the results are not reported

- Without recommended follow-up the benefits of hearing screening can be severely diminished

- LFU/LTD occurs between:
  - Screening – Rescreening
  - Screening – Diagnosis
  - Diagnosis – Intervention
Barriers: Screening

- Lack of standardized screening protocols
- High false positives rates
- Lack of protocols for presenting screening results
  - Families do not think follow-up is important
- Low patient volume can decrease quality of services
Barriers: Audiology

- Lack of audiologists who work with infants, especially in rural areas.
- Lack of communication and coordination between audiologists, medical home, families and EHDI program
  - Need for multiple diagnostic tests

Barriers: Family Issues

- Costs
- Lack of transportation
- Language (Non-English speaking)
- Transient nature of some families
- Confusion and/or lack of understanding
**Barriers: Data Reporting**

- **Documentation**
  - Lack of reporting requirements
  - Burden
    - Time
    - Duplicate data entry
    - Usability of systems

- **Limited awareness about the importance of reporting and sharing data**
  - Only report confirmed cases of hearing loss

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**CDC EHDI Survey: Background**

- **Hearing Screening and Follow-up Survey (HSFS)**
  - Collects only aggregate data
  - Voluntary response
  - Data collected for years 2005 – 2011

- **Developed in collaboration with state and national partners**
  - Approved by the Office of Management and Budget

- **Required to account for the status of all births**
Survey: Goals & Uses

• **Goal**
  – Provide detailed and accurate data that reflects what is occurring across the U.S

• **Uses**
  – Provide data for states, the general public, and other interested persons
  – Help determine progress related to National EHDI Goals
  – Provide data for Healthy People (HP) 2020

Survey: Overview

• **3 Components**
  – Part 1: Screening, Diagnostics, and Intervention
  – Part 2: Type & Severity of Hearing Losses
  – Part 3: Demographics

• **Web-based survey**
  – Includes error checks
  – Administered in January of each year
2010 Documented Screening
\( (n = 54) \)

<table>
<thead>
<tr>
<th>Occurrent Births</th>
<th>3,965,744</th>
</tr>
</thead>
<tbody>
<tr>
<td>Percent Screened</td>
<td>97.9% ((n = 3,881,048))</td>
</tr>
<tr>
<td>Percent Not Passing final / most recent screening</td>
<td>1.7% ((n = 65,036))</td>
</tr>
<tr>
<td>o Percent Not Passing Inpatient Screen &amp; Not Receiving an Outpatient Screen*</td>
<td>13.7% ((n = 8,935))</td>
</tr>
</tbody>
</table>

*In states with an inpatient / outpatient screening protocol

2010 Documented Diagnosis
\( (n = 52) \)

- 59,719 infants not passing final / most recent screen

| Percent No Diagnosed Hearing Loss | 44.1% \((n = 26,324)\) |
| Percent Hearing Loss | 8.7% \((n = 5,046)\) |
| Prevalence of Hearing Loss | 1.4 per 1,000 screened |
| Percent w. No Documented Diagnosis (of those Not Passing): | 47.5% \((n = 28,349)\) |
2010 LFU / LTD for Diagnosis

- 59,719 infants not passing final / most recent screen

<table>
<thead>
<tr>
<th>Percent w. No Documented Diagnosis</th>
<th>47.5%</th>
</tr>
</thead>
<tbody>
<tr>
<td>o Percent LFU / LTD for Diagnosis</td>
<td>39.3%</td>
</tr>
<tr>
<td>(n = 23,474) (Range: 0 – 95%)</td>
<td></td>
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</table>
**CDC Diagnostic LFU / LTD Formula**

\[
\frac{# \text{ Unable to Contact} + \text{Unresponsive} + \text{Unknown}}{\# \text{ Total Not Pass Final Hearing Screening}} \times 100 = 39.3\%
\]

**LFU / LTD by Reason (2010)**

- Unable to Contact: 18%
- LFU/LTD: 23,474
- Parents / Family
- Unresponsive: 31%
- Unknown: 51%
Early Intervention Status of Infants with Hearing Loss
(U.S., 2010) Total w. Hearing Loss = 5,035

- Receiving EI, 66.5%
- LFU/LTD, 25.1%
- Died/Declined, 5.1%
- Not Eligible Part C, 1.4%
- Non-resident / Moved, 1.4%

Comparison of LFU / LTD for Diagnosis (2010)

<table>
<thead>
<tr>
<th>LFU / LTD &lt; 25%</th>
<th>LFU / LTD &gt; 60%</th>
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</thead>
<tbody>
<tr>
<td><strong>State</strong></td>
<td># LFU / LTD</td>
</tr>
<tr>
<td>Massachusetts</td>
<td>35</td>
</tr>
<tr>
<td>Wyoming</td>
<td>5</td>
</tr>
<tr>
<td>Indiana</td>
<td>372</td>
</tr>
<tr>
<td>Rhode Island</td>
<td>17</td>
</tr>
<tr>
<td>Kentucky</td>
<td>471</td>
</tr>
<tr>
<td>Colorado</td>
<td>497</td>
</tr>
<tr>
<td>Oklahoma</td>
<td>581</td>
</tr>
<tr>
<td>Tennessee</td>
<td>799</td>
</tr>
<tr>
<td>Wisconsin</td>
<td>185</td>
</tr>
<tr>
<td>South Carolina</td>
<td>400</td>
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</table>
Variation in LFU / LTD

• **State Factors**
  – Births & geography (e.g., rural areas)
  – Variation in follow-up protocols
  – Legal requirements

• **Data Quality**
  – Incomplete reporting
  – Availability of individual vs. aggregate data
  – Limitations with data systems
  – Misunderstanding of CDC reporting guidelines

**EHDI Data Online**

[www.cdc.gov/ncbddd/hearingloss/ehdi-data.html](http://www.cdc.gov/ncbddd/hearingloss/ehdi-data.html)

• Annual national & jurisdictional summaries
  – By screening, diagnosis, and intervention

• **Type & Severity**

• **Demographic data**

• **Data comparisons & articles**
Thank you & Questions

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CHALLENGES TO MEDICAL HOME

<table>
<thead>
<tr>
<th>CHALLENGE</th>
<th>ISSUES</th>
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<tbody>
<tr>
<td>Relatively low incidence of severe hearing loss</td>
<td>• One of the most common congenital disorders</td>
</tr>
<tr>
<td>Lack of physician knowledge and education</td>
<td>• Different terminology</td>
</tr>
<tr>
<td>• Misconceptions – success of UNHS</td>
<td></td>
</tr>
<tr>
<td>Getting newborn results</td>
<td>• Difficulty with hospital</td>
</tr>
<tr>
<td>• Integrating with electronic medical records</td>
<td></td>
</tr>
<tr>
<td>Retesting in office</td>
<td>• Reporting results</td>
</tr>
<tr>
<td>Family support</td>
<td>• Less than 50% received needed support (H&amp;V)</td>
</tr>
<tr>
<td>Working with EI</td>
<td>• Working with community agencies</td>
</tr>
<tr>
<td>Time constraints and financial constraints</td>
<td>• 60-70% enrolled by 6 months (CDC)</td>
</tr>
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LEARNING FROM PARENT EXPERIENCES

Know when and where to refer

• Don’t idly reassure
• Timely access to service is critical
• Excessive screening delays process
  • Need to define nature of problem when screening failed
• Connect parents to audiologist for hearing assessment
  • Many parents will not be persistent or know how to move forward on their own

Have written information / resources for parents

Know risk indicators for late-onset hearing loss and when to refer for hearing testing


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!!
BEFORE 3 MONTHS

- Pediatric audiological evaluation
- Report to state EHDI
- Early Intervention
- Family support, education and information
- Medical and ENT evaluation
- Hearing aids

BEFORE 6 MONTHS

- Early Intervention services
- Etiology and associated problems
  - ENT
  - Eye
  - Genetics
  - Neurology, Developmental Pediatrics and others if needed
- Audiological follow-up
WORKGROUP ON MEDICAL HOME AND LTF

- Parent
  - Ada Determan, MPH

- Pediatrician
  - Jack Levine, MD
  - Albert L. Mehl, MD
  - Rachel St. John, MD
  - Debra B. Waldron, MD, MPH
  - Susan Wiley, MD
  - Alan Zuckerman, MD
WORKGROUP ON MEDICAL HOME AND LTF

- CDC
  - John Eichwald, MA, FAAA
  - Marcus Gaffney, MPH
- HRSA
  - Irene Forsman, RN, MS
- NCHAM
  - Diane Behl, M Ed
  - Karl White, PhD
- AAP STAFF
  - Faiza Khan, MPH
  - Corrie Pierce

MEDICAL HOME AND LTF/D
AAP EHDI TASK FORCE

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

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 TASK FORCE**

- **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

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**MEDICAL HOME AND LTF/D**

**AAP EHDI TASK FORCE**

- **Dedicated staff person in the practice**
  - Obtain all screening results
  - Coordinate the education/support of families
  - Relationship with State EHDI program
- **Provide education and support to families**
  - Hearing, speech, and language milestones
  - Discuss and explain all test results, next steps, and importance of follow-up
  - Confirm with family that follow-up appointments have been made and kept
  - Help to arrange transportation and social service support
- **Culturally competent and health literate appropriate information**
  - Hands and Voices, Guide-By-Your-Side, NCHAM, etc.
  - Educational options
RESCREENING IN THE MEDICAL HOME – AAP EHDI TASK FORCE

Report results

Oto-acoustic Emission (OAE)
- NICU babies
- Failed ABR
- Auditory neuropathy/dyssynchrony
- Need to know screening protocol!

Technical recommendations

RESCREENING IN THE MEDICAL HOME

Calibration

Technique

3 times maximum attempts

NCHAM support – ECHO initiative
- www.infanthearing.org/earlychildhood/healthcare.html
CAN THE MEDICAL HOME REDUCE LTF/D?

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

~Yogi Berra