The National Early Hearing Detection and Intervention (EHDI) Landscape:

May 8, 2013
CT EHDI Roadmap Conference
GPS: Navigating the Deaf and Hard of Hearing Experience

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National Center for Hearing Assessment and Management
www.infanthearing.org
Disclosure Information

• I do not have a significant financial interest or other relationship with the manufacturers of products or providers of services that will be discussed in my presentation.

• This presentation will not include discussion of pharmaceuticals or devices that have not been approved by the FDA nor will I be discussing unapproved or “off-label” uses of pharmaceuticals or devices.
Which of the following "birth defects" has the highest incidence?

a. Down Syndrome
b. Permanent hearing loss
c. Spina bifida
d. Cleft lip or palate
e. Sickle cell anemia
Frequency of Congenital Hearing Loss?

- 1 per 1,000
- 2 per 1,000
- 3 per 1,000
- 6 per 1000
## Rate Per 1,000 of Permanent Childhood Hearing Loss in EHDI Programs

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## Population-based Ascertainment of Hearing Loss

<table>
<thead>
<tr>
<th></th>
<th>NHANES II</th>
<th></th>
<th>NHANES III</th>
<th></th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>Point</td>
<td>Cumulative</td>
<td>Point</td>
<td>Cumulative</td>
</tr>
<tr>
<td>Profound Bilateral (PTA₄ &gt; 75 dB HL)</td>
<td>0.75</td>
<td>0.75</td>
<td>0.57</td>
<td>0.57</td>
</tr>
<tr>
<td>Severe Bilateral (45 dB HL &lt; PTA₄ ≤ 75 dB HL)</td>
<td>0.51</td>
<td>1.26</td>
<td>0.28</td>
<td>0.85</td>
</tr>
<tr>
<td>Moderate Bilateral (30 dB HL &lt; PTA₄ ≤ 45 dB HL)</td>
<td>2.37</td>
<td>3.63</td>
<td>1.66</td>
<td>2.51</td>
</tr>
<tr>
<td>Mild Bilateral (15 dB HL &lt; PTA₄ ≤ 30 dB HL)</td>
<td>13.7</td>
<td>17.33</td>
<td>13.8</td>
<td>16.31</td>
</tr>
<tr>
<td>Unilateral (mild, moderate, severe)</td>
<td>49.0</td>
<td>66.33</td>
<td>57.0</td>
<td>73.31</td>
</tr>
</tbody>
</table>

Target population is the civilian, non-institutionalized U.S. population.
Sample size for audiometry in children, 6 to 19 years old, was 7,119 in NHANES II and 6,166 in NHANES III.
PTA₄ is the pure-tone average of air-conduction thresholds at 0.5, 1, 2, & 4 kHz; Normal hearing — PTA₄ ≤ 15 dB HL, both ears
Permanent hearing loss occurs more frequently than any other condition for which we can screen at birth.
Blindness separates people from things. Deafness separates people from people.

--- Helen Keller
What do these people have in common?

- Thomas Edison: Inventor
- Jonathan Swift: Author & Clergyman
- Ludwig Van Beethoven: Composer
- Vinton Cerf: Father of the Internet
- Marlee Matlin: Academy Award Winning Actress
What percentage of children who are DHH are born to hearing parents?

a. <25%
b. 50%
c. 70%
d. 85%
e. >90%
Key Points

1. Most parents with a newly identified deaf child are completely surprised.
2. Many of the professionals from whom parents seek help are not up-to-date.
3. The most important thing to parents is to be able to COMMUNICATE with their child.
Spring is my favorite season. The sun shines bright. The flowers begin to grow. I like spring.
What enabled us to move from ....

Availability of Better Hearing Technology

Earlier Identification of Hearing Loss

High quality, comprehensive Early Intervention programs that focus on teaching LANGUAGE

There to Here?
From 1988–1993, the Rhode Island Hearing Assessment Project conducted a large-scale clinical trial of universal newborn hearing screening.
In March, 1993 an NIH Consensus Panel concluded that:

- The average age of diagnosis of hearing loss remains constant at about 2 ½ years of age.
- All infants should be screened for hearing loss…this will be accomplished most efficiently by screening prior to discharge from the well-baby nursery.
- Identification of hearing loss must be seen as imperative for all infants.
What percentage of newborns in the United States are screened for hearing loss?

a. 50%
b. 70%
c. 80%
d. 90%
e. 98%
Percentage of Newborns Screened for Hearing in the United States

- Jan-80
- Jan-82
- Jan-84
- Jan-86
- Jan-88
- Jan-90
- Jan-92
- Jan-94
- Jan-96
- Jan-98
- Jan-00
- Jan-02
- Jan-04
- Jan-06
- Jan-08
- Jan-10
- Jan-12

0% - 100%

- 0%
- 10%
- 20%
- 30%
- 40%
- 50%
- 60%
- 70%
- 80%
- 90%
- 100%
Age in Months at Which Permanent Hearing Loss Was Diagnosed

- Coplan (1987): 35
- Elssman et al. (1987): 19
- Gustason (1987): 30
- Meadow-Orlans (1987): 30
- Stein et al. (1990): 25
- Mace et al. (1991): 31
- Johnson et al. (1997): 3
- Vohr et al. (1998): 3
- Harrison and Roush (2003): 4
- Massachusetts (2004): 2

Newborn Hearing Screening Around the World

Poland
United States
India
Malaysia
Costa Rica
Botswana
# Newborn Hearing Screening Around the World

<table>
<thead>
<tr>
<th>Screening &gt; 90% (n=9)</th>
<th>Screening 30-80% (n=8)</th>
<th>Published Reports of Pilot programs (n=41)</th>
</tr>
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<tbody>
<tr>
<td>Austria</td>
<td>Argentina</td>
<td>Portugal</td>
</tr>
<tr>
<td>Croatia</td>
<td>Brazil</td>
<td>Qatar</td>
</tr>
<tr>
<td>Luxembourg</td>
<td>China</td>
<td>Romania</td>
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<td>Germany</td>
<td>Columbia</td>
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<td>Singapore</td>
<td>Finland</td>
<td>Slovenia</td>
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<td>United Kingdom</td>
<td>France</td>
<td>South Africa</td>
</tr>
<tr>
<td>USA</td>
<td>Greece</td>
<td>South Korea</td>
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<td></td>
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<td>Turkey</td>
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**Note:** The table lists countries and regions where newborn hearing screening programs have been implemented. The categories indicate the percentage of newborns screened. The last column lists countries for which published reports of pilot programs are available.
Proportion of Births Outside of Hospital Facilities


Data Source: UNICEF 2005 [50]
Good work, but I think we might need a little more detail right here.
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I always wondered why somebody
didn't do something about that.
Then I realized I was somebody.

--Lily Tomlin
What Contributes to “Loss to Follow-up”?  

- **Referral rates in the hospital are too high** (because of poorly trained screeners, poorly maintained equipment, lack of commitment, etc)  
- **Ineffective information for parents** (about initial results, need for follow-up, what to do next, etc)  
- **Accurate data isn’t shared quickly with the right stakeholders** (hospitals, state EHDI program, medical home, audiologists, early interventionists, etc)  
- **Shortage of pediatric audiologists** (because of not enough training programs, poor reimbursement rates, rural/remote residences, etc)  
- **Lack of knowledge about current “effective practices”** (among program managers, health care providers, early interventionists, etc).  
- **Not enough public awareness about importance of issue** (taxpayers, administrators, extended family, etc)  
- **Lack of resources** (for screening, follow-up diagnosis, early intervention, case management, etc)
The Hearing Head Start Project

- Feasibility study from 2001-2004
- 69 programs in 3 states with 3,000+ children screened
- Identified 2 per 1,000 with permanent hearing loss and 20 per 1,000 with unidentified transient losses
- Currently in 42 of 50 states—expanding to others by 2015

Does a 2-stage (OAE/AABR) newborn hearing screening protocol miss babies with mild hearing loss?

Study Sample
Comprehensive Audiological Assessment at 8-12 months of age

Comparison Group
Comprehensive Hearing Evaluation Before 6 Months of Age
## How Many Additional Babies with Permanent Hearing Loss were Identified?

<table>
<thead>
<tr>
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<th>Comparison Group (Fail OAE/ Fail AABR)</th>
<th>Study Group (Fail OAE/ Pass AABR)</th>
<th>Total</th>
</tr>
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<tbody>
<tr>
<td>Number of Babies</td>
<td>158</td>
<td>21</td>
<td>179</td>
</tr>
<tr>
<td>Prevalence per 1,000</td>
<td>1.82</td>
<td>.55*</td>
<td>2.37</td>
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*Adjusted for proportion of OAE fails that enrolled

*Represents 23% of all babies with PHL in birth cohort

To which of the following specialists should a newborn with permanent hearing loss be referred?

a. Ophthalmologist
b. Otolaryngologist
c. Geneticist
d. All of the above
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
Assume a newborn for whom you are caring is diagnosed with a moderate to profound bilateral hearing loss. If no other indications are present, to which specialists would you refer the baby?:

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<th>Specialist Evaluation</th>
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<tr>
<td>Ophthalmological evaluation</td>
<td>0.6%</td>
</tr>
<tr>
<td>Genetic evaluation</td>
<td>8.9%</td>
</tr>
<tr>
<td>Otolaryngological evaluation</td>
<td>75.6%</td>
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Responses of 1975 physicians in 21 states

How old must a baby be to be appropriately fit with a hearing aid?

a. 1 month
b. 3 months
c. 6 months
d. 12 months
When can an infant be fit with hearing aids?
Protests at 2012 National EHDI Meeting

It is time to raise our fists and demand solidarity!

Don't get mad! Get EVEN! Show them! STAND UP for your rights!

The same goes for all oral programs around the country. It is an act of terrorism. We are experiencing domestic terrorism from those audists.
Take Home Messages

Ah, but a man's reach should exceed his grasp. Or what's a heaven for?

---- Robert Browning

1. Reducing Loss to Follow-up

2. Hearing screening in early childhood programs

3. More efficient screening

4. More and better trained providers

5. Better access to services

6. Respectful collaboration
I am only one, but still I am one. I cannot do everything, but still I can do something; and because I cannot do everything, I will not refuse to do something that I can do....The world is moved along, not only by the mighty shoves of its heroes, but also by the aggregate of tiny pushes of each honest worker.

-----Helen Keller
www.infanthearing.org

NCHAM serves as the National Resource Center for the implementation and improvement of comprehensive and effective Early Hearing Detection and Intervention (EHDI) systems. As a multidisciplinary Center, our goal is to ensure that all infants and toddlers with hearing loss are identified as early as possible and provided with timely and appropriate audiological, educational, and medical intervention.

EHDI Components
- Newborn Hearing Screening
- Early Childhood Hearing Screening
- Diagnostic Audiology
- Early Intervention
- Family Support
- Medical Home
- Data Management
- Financing & Reimbursements
- Program Evaluation

EHDI/UNHS Resources
- UNHS Implementation Guide
- Addressing Privacy Regulations
- Position Statements
- EHDI/UNHS FAQ
- Slideshow Presentations
- Educational and Training Videos
- Fact Sheet [PDF]
- NCHAM Materials
- EHDI Implementation in Latin America
- EHDI E-Book
- More EHDI/UNHS Resources...

State EHDI Information
- Status of the United States
- State Profiles
- Web Sites & Guidelines
- EHDI Contacts
- 2004 State EHDI Survey
- State Coordinator Toolbox

EHDI Legislation
- State Legislation
- Rules & Regulations
- Legislative Summaries
  - By State: Table | Text
  - By Provisions