Lessons Learned: From a Decade of Implementing EHDI Programs

Partnering For Progress
EHDI Southeastern Regional Conference
Jackson, Mississippi

by
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National Center for Hearing Assessment and Management
www.infanthearing.org
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Newborn hearing screening has become the “standard of care”

- 38 states with legislative mandates
- 93%+ of all newborns now screened for hearing before discharge
Why is Early Identification of Hearing Loss so Important?

- Hearing loss occurs more frequently than any other newborn condition that may cause significant developmental delays.

- Undetected hearing loss has serious negative consequences.

- Early identification has dramatic benefits for affected children and families.

- Medical-legal issues
The consensus panel concluded that all infants should be screened for hearing impairment...this will be accomplished most efficiently by screening prior to discharge from the well-baby nursery. Infants who fail ... should have a comprehensive hearing evaluation no later than 6 months of age.
Implementing Effective Newborn Hearing Screening Programs

Universal Newborn Hearing Screening

Diagnosis
Early Intervention
Medical Home
Data Management
Program Evaluation
Family Support

Start

Good work, but I think we might need a little more detail right here
Universal newborn hearing screening is not a new idea.
1973 compared to 2005

• What Remains the Same?
  - Babies may not talk much for a year, but they are learning
  - For babies to have a good start on learning language, they must be found at birth
  - Whatever the cause of hearing loss, each day counts
  - Expense of doing it keeps us from finding babies early
  - Technological advances accelerated the progress
  - Individual initiative and creativity is the key

• What Has Changed?
  - Keenan’s hearing loss was discovered early --- 18 months
  - For the most part, it is up to the mother
  - Very few babies are identified at birth
  - No laws requiring states to screen babies
  - Technology for screening, diagnosis and amplification
Montreal School
For the Deaf
Group 4     1977-78
Spring is my favorite season. The sun shines bright. The flowers begin to grow. I like spring.
What enabled us to move from …. 

Earlier Identification of Hearing Loss

Availability of Better Assistive Listening Devices

High Quality Early Intervention Programs that focus on teaching LANGUAGE

Advocacy and Public Policy Initiatives

There to Here?
Confirmation of Permanent Hearing Loss

Average Age in Months

- Coplan (1987): 35
- Eissman et al. (1987): 19
- Gustason (1987): 30
- Meadow-Orlans (1987): 30
- Stein et al. (1990): 25
- Mace et al. (1991): 31
- O'Neil (1996): 56
- Johnson et al. (1997): 3
- Vohr et al. (1998): 3

Average Age in Months
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
- Programs now being replicated in 12 additional states
What enabled us to move from ....

- Earlier Identification of Hearing Loss
- Availability of Better Assistive Listening Devices
- Advocacy and Public Policy Initiatives
- High Quality Early Intervention Programs that focus on teaching LANGUAGE
Earlier Identification of Hearing Loss

High Quality Early Intervention Programs that focus on teaching LANGUAGE

Availability of Better Assistive Listening Devices

Advocacy and Public Policy Initiatives

What enabled us to move from ....
Boys Town National Research Hospital Study of Earlier vs. Later

129 deaf and hard-of-hearing children assessed 2x each year.

Assessments done by trained diagnostian as normal part of early intervention program.

Moeller, M.P. (1997). Personal communication moeller@boystown.org
Earlier Identification of Hearing Loss

High Quality Early Intervention Programs that focus on teaching LANGUAGE

Availability of Better Assistive Listening Devices

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What enabled us to move from ….?
Many people are surprised to learn that 12,000 babies a year in the U.S. are born with a permanent hearing loss. That makes hearing loss the most common birth defect. It also means that about 1 out of every 300 babies will need special help to hear and speak. This is why hospitals now screen (test) the hearing of most newborns. When a hearing loss is found early, parents and professionals can work together to help a child develop normally. If you have questions or concerns about your child's hearing, don't wait and see--help your child.

- What do I do if my baby failed a hearing screening test?
- Was my baby's hearing screened?
- I am worried my child doesn't hear well.
- Why is hearing so important for children?
American Academy of Pediatrics

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

Birth
- Hospital-based Inpatient Screening (OAE/ABR®)
  - Results sent to Medical Home

Before 1 Month
- Pediatric Audiologic Evaluation
  - Otoscopic Inspection
  - Child & family history
  - Middle ear function
  - OAE
  - ABR
  - Frequency-specific tone bursts
  - Air & bone conduction
  - Sedation capability (only needed for some infants)

Before 3 Months
- Report to State EHDI Program
  - Every child with a permanent hearing loss
- Refer to IDEA® Part C
  - Coordinating agency for early intervention
- Medical & Otologic Evaluations
  - To recommend treatment and provide clearance for hearing aid fitting
- Pediatric Audiologic Hearing aid fitting and monitoring
- Advise family
  - About assistive listening devices (hearing aids, cochlear implants, etc.) and communication options

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

Ongoing Care of All Infants® From the Medical Home Provider
- Provide parents with information about hearing, speech, and language milestones
- Identify and aggressively treat middle ear disease
- Provide vision screening and referral as needed
- Provide ongoing developmental surveillance and referral to appropriate resources
- Identify and refer for audiologic monitoring infants who have the following risk indicators for late-onset hearing loss:
  - Parental or caregiver concern regarding hearing, speech, language, and/or developmental delay
  - Stigmata or other findings associated with a syndrome known to include a sensorineural or conductive hearing loss or persistent tube dysfunction
  - Postnatal infections associated with sensorineural hearing loss including bacterial meningitis
  - In utero infections such as cytomegalovirus, herpes, rubella, syphilis, and toxoplasmosis
  - Neonatal indicators—specifically hyperbilirubinemia at a serum level requiring exchange transfusion, persistent pulmonary hypertension of the newborn associated with mechanical ventilation, and conditions requiring the use of extracorporeal membrane oxygenation
  - Syndromes associated with progressive hearing loss such as neurofibromatosis, osteopetrosis, and Usher syndrome
  - Neurodegenerative disorders, such as Hunter syndrome, or sensory motor neuropathies, such as Friedreich ataxia and Charcot-Marie-Tooth disease
  - Head trauma
  - Recurrent or persistent otitis media with effusion for at least 3 months

Notes:
(a) In screening programs that do not provide Outpatient Screening, infants will be referred directly from Inpatient Screening to Pediatric Audiologic Evaluation. Likewise, infants at higher risk for hearing loss, or those to follow-up, also may be referred directly 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.

*OAE = Otoacoustic Emissions, ABR = Automated Auditory Brainstem Response, IDEa = Individuals with Disabilities Education Act

January 2003
Policy and Legislative Initiatives with Local, State and Federal Partners
Examples of Current Challenges

• Only 21 states are attempting to screen home births

• Only 56% of babies who fail screening are known to receive follow-up

• Only 36 states collect data about the age at which diagnostic evaluation was completed for referred babies
  – Only 55% of those diagnosed babies completed evaluation before 3 months of age

• Only 34 states collect data about age at which early intervention began for babies with hearing loss
  – Only 49% of those babies with hearing loss began early intervention before 6 months of age

• 62% of physicians think babies must be 4+ months of age before they can be fit with hearing aids

• Only 18 states report that children enrolled in Part C programs are screened for hearing loss

• Only 7 states have a written report of a systematic evaluation of their EHDI program done in the last 4 years.

• Only 17% of resources for the state EHDI program administration come from state appropriations
Lessons Learned

---- H. L. Mencken

There is always an easy solution to every human problem — neat, plausible, and WRONG.
Lessons Learned

1. Be wary of simple answers to complex problems
Lessons Learned

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2. Technological Advances have been critical to past success….and will continue to be important

   ✓ Faster and more effective screening equipment
   ✓ Linking physiological screening to genetic analysis based on the dried blood spot
   ✓ Screening for cytomegalovirus (CMV)
   ✓ Regeneration of hair cells
Lessons Learned

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3. The greatest enemy of good is excellent
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4. Partnership is the key to success
Partnership is the Key to Successful EDHI Programs

- Health Insurance
- Birthing Hospital
- Audiology
- Medical Specialists
- Advocacy & Support Groups
- Public Health Program
- Speech Therapy
- Early Intervention Programs
- Policy makers

Child & Family Medical Home
Part C of the Individuals with Disabilities Act (IDEA, 1997)

It is therefore the policy of the United States to provide financial assistance to States –

1) to develop and implement a statewide, comprehensive, coordinated, multidisciplinary, interagency system that provides early intervention services for infants and toddlers with disabilities and their families
Part C of the Individuals with Disabilities Act (IDEA, 1997)

a) A statewide system...shall include, at minimum, the following components

1. Definition of eligibility criteria
2. Statewide policy to ensure services to all infants and toddlers
3. Timely, comprehensive multidisciplinary evaluation
4. An individualized family service plan (IFSP) for all identified children
5. Comprehensive child find system
6. Public awareness program
7. Central information directory of services
8. Comprehensive system of personnel development
9. A lead agency
10. Procedural safeguards
11. State interagency coordinating council
Federal regulations for IDEA require all states to provide Part C services to any child who:

(i) is experiencing developmental delays, as measured by appropriate diagnostic instruments and procedures in one or more of the areas of cognitive development, physical development, communication development, social or emotional development, and adaptive development; or

(ii) has a diagnosed physical or mental condition which has a high probability of resulting in developmental delay.
Are Children with Hearing Loss Eligible for Part C Service?

• **55 of 55 (100%)** indicated that services would be provided to a child who had a diagnosed physical or mental condition with a high probability of resulting in developmental delay.

• **37 of 55 (67%)** listed hearing loss, auditory impairment, deafness, or something similar as one of the specific conditions.

• **Only 7 of 55 (13%)** of the State Plans provided any kind of operational definition that could be used to determine if a specific child with hearing loss would be eligible.

• **Twelve other states (22%)** provided some type of operational definition for hearing loss in other documents.
# Part C Early Intervention Eligibility for Infants and Toddlers with Hearing Loss

**DRAFT: NOT FOR DISTRIBUTION**

<table>
<thead>
<tr>
<th>Part C State Coordinator</th>
<th>As Defined by the State Plan, are infants and toddlers with established risk conditions eligible for Part C-funded services?</th>
<th>Are Specific Conditions Listed?</th>
<th>Is Hearing Loss Noted as a Specific Condition?</th>
<th>Is Hearing Loss Operationally Defined in the State Plan or in other official documents? If yes, what is the definition?</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Alabama</strong></td>
<td><strong>Yes</strong>...criteria applied to conditions with known etiologies...includes but is not limited to: Comorbid abnormalities, Genetic or congenital disorders, Severe sensory impairments (including hearing and vision), Inborn errors of metabolism, Disorders reflecting disturbances of the nervous system, Congenital infections, Disorders secondary to exposure to toxic substances (including fetal Alcohol Syndrome), Severe speech disorders</td>
<td><strong>Yes</strong></td>
<td><strong>Yes</strong> (Severe sensory impairments (including hearing and vision))</td>
<td><strong>State Plan: No</strong></td>
</tr>
<tr>
<td><strong>Alaska</strong></td>
<td><strong>Yes</strong> Disability encompasses physical, mental, sensory or physical condition which has a high probability of resulting in a 50% developmental delay...even though IHC may not be exhibited at the time. The team’s decision shall be supported by a physician’s report documenting the condition.</td>
<td><strong>No</strong></td>
<td><strong>No</strong></td>
<td><strong>State Plan: No</strong></td>
</tr>
</tbody>
</table>

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*Notes:*  
1. “As infants and toddlers with established risk conditions eligible for Part C-funded services?” Based on State Plan, answer ‘Yes’ or ‘No’ as well as summarizing the relevant criteria and conditions under which children are defined as having an established risk condition.
Part C of the Individuals with Disabilities Act (IDEA, 1997)

1. Definition of eligibility criteria
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Demographic Considerations Regarding Provision of Early Intervention Programs for Children with Hearing Loss

- 95% of all newborns with hearing loss have parents with normal hearing.

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• When parents in North Carolina were given a choice

  In 1995: 60% chose sign-language options; 40% chose auditory-oral
  In 2005: 15% chose sign-language options; 85% chose auditory-oral


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• The number of cochlear implants for children under age 5 has quadrupled in the last 4 years (to 2000+ implants per year)


Primary Emphasis of University-based Personnel Preparation Programs for Teachers of Deaf and Hard of Hearing

LEGEND

Graduates per Year:

Primary Emphasis 1-5 6-15 16+

Sign Language-based ○ ● ●

Spoken Language-based ○ ○ ○

Note: Although many programs describe themselves as providing “comprehensive” services, most have a primary emphasis on a specific approach as indicated by the curriculum offerings, the placement of graduates, the type of practicum available, etc. Classification of programs on this map considered those factors in conjunction with annual self-report survey data from the 2004 and 2005 issues of the American Annals of the Deaf.
Partnership is the Key to Successful EDHI Programs

Child & Family Medical Home

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☐ Ophthalmologic (annually)
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☐ Behavioral response audiometry
☐ Ongoing monitoring

American Academy of Pediatrics
Educating Primary Health Care Providers About Progress in Early Identification of Hearing Loss

Assume a newborn for whom you are caring is diagnosed with a moderate to profound bilateral hearing loss. If no other indications are present, would you refer the baby for a(n):

<table>
<thead>
<tr>
<th>Evaluation</th>
<th>Always or Often</th>
</tr>
</thead>
<tbody>
<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>
</tr>
</tbody>
</table>

Responses of 1975 physicians in 21 states
When can an infant be fit with hearing aids?

![Bar chart showing the percentage of physicians at different ages for fitting hearing aids.

- Birth: 10%
- 1 month: 15%
- 2 months: 10%
- 3 months: 5%
- 4-5 months: 25%
- 6 months: 20%
- 7 to 11 months: 5%
- 12 to 18 months: 20%
- 19+ months: 10%]
<table>
<thead>
<tr>
<th>Type of Physician</th>
<th>Age at which hearing aids can be fit</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>&lt;=1 mo</td>
</tr>
<tr>
<td>Pediatrician</td>
<td>36.3%</td>
</tr>
<tr>
<td>(n=1145)</td>
<td></td>
</tr>
<tr>
<td>Family Practice</td>
<td></td>
</tr>
<tr>
<td>(n=531)</td>
<td></td>
</tr>
<tr>
<td>Neonatologist</td>
<td></td>
</tr>
<tr>
<td>(n=52)</td>
<td></td>
</tr>
<tr>
<td>ENT</td>
<td></td>
</tr>
<tr>
<td>(n=58)</td>
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5. Coordination of screening with effective data systems will provide the data to dramatically improve programs

- Late-onset hearing loss
- Risk indicators
- CMV
- Auditory neuropathy
All Politics is Local

Lesson #6
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7. Good Begun … Is half done
Hearing Screening During Well Child Visits to Health Care Providers

- Pilot studies and materials development 2005-2006
- Worked with American Academy of Pediatrics to develop recommended policy changes
- Development of training and implementation materials funded by Oticon foundation

Materials available from www.HearAndNow.org
There is not an awareness out there. Another parent is going to find out their child is deaf and say, 'Thank goodness I have insurance' and they will find it isn't so. They will go through the same battle we have.
Lesson #8

I use research like a drunk uses a lamppost--

I use it for support, not illumination
However beautiful the strategy, you should occasionally look at the results.

Sir Winston Churchill

“Parachutes appear to reduce the risk of injury after gravitational challenge, but their effectiveness has not been proven with randomized controlled trials.”
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Never, never, never, never, never give up!
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Good work, but I think we might need just a little more detail right here.
Without lifting your pencil off of the paper, draw 4 straight lines that connect all of the dots.

Think Outside the Box!
Stopping by the woods on a snowy evening
Whose woods these are I think I know. His house is in the village, though;
He will not see me stopping here
To watch his woods fill up with snow. . .

The woods are lovely, dark, and deep,
But I have promises to keep,
And miles to go before I sleep,
And miles to go before I sleep.

---Robert Frost
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