The Status of EHDI Programs in the USA

presented by
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National Center for Hearing Assessment and Management
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at
Involving LENDs to Strengthen EHDI Programs
Washington D.C.
June 13, 2005
My goal for this presentation:

- Remind you of where we have come from and where we are now
- Identify areas where EHDI programs could be improved
- Help you think about an “action plan” that your LEND program could implement to improve EHDI services in your area
Spring is my favorite season. The sun shines bright. The flowers begin to grow. I like spring.
How have we gotten from.....

Earlier Identification of Hearing Loss

Improved Methods for Teaching LANGUAGE

Increased Availability of High Quality Early Intervention Programs

Better Assistive Listening Devices

There to Here?
Percentage of Newborns Screened for Hearing in the United States
Essential Components of a Successful Early Hearing Detection and Intervention (EHDI) Programs

- Screening before 1 month
- Diagnosis before 3 months
- Intervention before 6 months
- Medical Home
- Data Management and Tracking
- Program Evaluation and Quality Assurance
- Family Support!!
Child & Family Medical Home

- Deaf Community
- Birthing Hospital
- Genetics
- Audiology
- Policy makers
- Advocacy & Support Groups
- Public Health Programs
- Speech Therapy
- Early Intervention Programs
Status of EHDI Programs in the US: Universal Newborn Hearing Screening

- With ~95% of infants screened, newborn hearing screening has become the accepted standard of care.
- There are hundreds of excellent programs - regardless of the type of equipment or protocol used.
- Some programs are still struggling with high refer rates and poor follow-up.
- Only 40% of states have a system to attempt screening of home births.
- 35% of states collect data on JCIH Risk factors.
• 89% of states have created a statewide tracking system
  – information submitted for 80% of the births in 2003
  – 72% have individual identifying data --- up from 32% in 2001
• 57% track babies until at least 3 years of age
• Linkages with other Public Health Information systems are expanding (eg, Vital Statistics, heelstick, EI, Immunizations)
Status of EHDI Programs in the US: Audiological Diagnosis

- Equipment and techniques for diagnosis of hearing loss in infants continue to improve.
- Severe shortages in experienced pediatric audiologists delays confirmation of hearing loss.
- State coordinators estimate only 62% “receive diagnostic evaluations by 3 months of age.”
Status of EHDI Programs in the US: Early Intervention

- Current system designed to serve infants with bilateral severe/profound losses---but, majority of those identified have mild, moderate, and unilateral losses

- State EHDI Coordinators estimate:
  - Only 55% of infants with hearing loss are enrolled in EI programs before 6 months of age
  - Only 12% states notify EI system about screening results
  - Only 36% know whether hearing screening is done in early intervention programs
Part C of the Individuals with Disabilities Act (IDEA, 1997)

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

<table>
<thead>
<tr>
<th>State</th>
<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>Alabama</td>
<td>Elizabeth Trice, Part C Coordinator Early Intervention Program 2129 East South Boulevard P.O. Box 11596 Montgomery, AL 36111-0196 (334) 613-5345 Fax: (334) 613-5341 Email: <a href="mailto:etriece@alab.state.al.us">etriece@alab.state.al.us</a> <a href="http://www.earlyintervention.alabama.gov">http://www.earlyintervention.alabama.gov</a></td>
<td>Yes</td>
<td>Yes</td>
<td>Yes</td>
<td>State Plan: No</td>
</tr>
<tr>
<td>Alaska</td>
<td>Jane Smith, Part C Coordinator Maternal and Child Health State Department of Health and Social Services 3601 C Street, Suite 104, P.O. Box 20040 Anchorage, AK 99509-2040 (907) 269-3419 Fax: (907) 269-3465 Email: <a href="mailto:jsmith@dhss.state.ak.us">jsmith@dhss.state.ak.us</a> <a href="http://Health.HHS.state.ak.us/Default.htm">http://Health.HHS.state.ak.us/Default.htm</a></td>
<td>Yes</td>
<td>No</td>
<td>No</td>
<td>State Plan: No</td>
</tr>
</tbody>
</table>

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1. Notes:
   - "Are 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 considered eligible.
What Is a Medical Home?

• A primary care physician provides care which is:
  • Accessible
  • Family-centered
  • Comprehensive
  • Continuous
  • Coordinated
  • Compassionate
  • Culturally effective

American Academy of Pediatrics
DEDICATED TO THE HEALTH OF ALL CHILDREN®
Babies Diagnosed with Hearing Loss Are Not Referred to Some Medical Specialists As Often As Desired

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>Frequency</th>
</tr>
</thead>
<tbody>
<tr>
<td>Ophthalmological evaluation</td>
<td>0.6%</td>
</tr>
<tr>
<td>Genetic evaluation</td>
<td>8.7%</td>
</tr>
<tr>
<td>Otolaryngological evaluation</td>
<td>74.4%</td>
</tr>
</tbody>
</table>

Responses of 1375 physicians in 21 states
When can an infant be fit with hearing aids?

Percentage of Physicians

- birth
- 1 mo
- 2 mos
- 3 mos
- 4-5 mos
- 6 mos
- 7 to 11 mos
- 12 to 18 mos
- 19+ mos
Status of EHDI Programs in the United States

• Universal Newborn Hearing Screening
• Effective Tracking and Follow-up as a part of the Public Health System
• Appropriate and Timely Diagnosis of the Hearing Loss
• Prompt Enrollment in Appropriate Early Intervention
• A Medical Home for all Newborns
• Culturally Competent Family Support
Do current EHDI materials work?
Brochure Readability

Gold Standard Readability: ≤6th Grade

Percent

7th 8th-9th 10th-12th College+

Initial Screening / Retest Intervention
1. Is the layout user-friendly?

First impressions are important!

Does the pamphlet:

- Have ample white space?
- Limit paragraphs to 4 to 5 lines?
- Use bullets, boxes, indentation, bolding, vertical lists?
- Use bifold rather than trifold format?
- Use font that is 12 point or larger?
- Avoid use of ALL CAPS, italics and specialty fonts in large blocks of text?

Examples that illustrate key points:

- Why does my baby need another hearing test?
  - Some babies may need another test because:
    - The baby was moving a lot
    - The baby has hearing loss
  - Most babies do not need another test. Normal hearing test results are normal hearing.
  - Why is it important to have another hearing test as soon as possible?
    - Testing is the only way to know if a baby has a hearing loss.
    - The earlier a hearing loss is found, the better it is for a baby.
  - If your baby has a hearing loss, there are many ways we can help your baby.
  - Finding hearing loss early can make a big difference in your baby's life.

This layout lacks white space, headings, and attractive graphics that would help make the text easier and more inviting to read.

This layout has ample "white space", a bold heading, a clear illustration, and bullets that make the text easier to navigate.
2. Do illustrations convey the clear message?

A picture may be worth a thousand words – but which thousand?

Are pictures and captions:

• Serving a purpose (they are not just decorative)?
• Clear and realistic?
• Are familiar and likely to be understood?

Examples that illustrate key points:

Mothers preferred photographs of babies and mothers with babies.

Cute but abstract illustrations (e.g., the octopus) and detailed drawings of the inner ear were not as appealing and were often not understood.
3. Is the message clear?

- Is the message obvious on the cover, title, and headings?
- Are key messages easy to pick out?
- Does pamphlet get to the point quickly?
- Does pamphlet easily inform the reader of what she needs to know and do?

Examples that illustrate key points:

- The graphics on this cover do not help convey a newborn screening message. The title is obtuse.
- This cover uses large, clear, attractive graphic and a simple concrete title.
4. Is the information manageable?

Does the pamphlet:

• Use a conversational, personal tone or a bureaucratic one?

• Focus on “need to know” rather than “nice to know” (limits content)?

• Stick to a few key messages to avoid information overload?

• Limit the use of graphs and statistics (understanding brochures should not require much math skill)?

Examples that illustrate key points:

This description has a technical, textbook tone and provides too much specific information that, while nice to know, could confuse parents and make it difficult for them to understand the important, “need to know” messages:

“There are two types of hearing screening tests that may be used with your baby. Auditory Brainstem Response Testing (ABR) tests the infants’ ability to hear soft sounds through miniature earphones. Sensors measure your baby’s brainwaves to determine if sounds are detected normally. Otoacoustic emissions (OAE) are measured directly with a miniature microphone and sent to a special computer to determine your baby’s hearing status. Both tests are very safe and take only minutes to evaluate each ear. Most babies sleep through the hearing screening tests.” (College reading level)

This example includes only the “need to know” information in a conversational tone. It is far easier for parents to manage:

“A trained person will test your baby’s hearing. Your baby will feel no pain. In fact, the screening test can be given while your baby is asleep. It will show whether your baby’s hearing is normal or whether more testing is needed.” (6th grade reading level)
5. Does the pamphlet make the reader feel "this information is meant for me"?

Does the pamphlet:

- Target expectant mothers and parents of newborns, especially on the cover?
- Use familiar words, situations and pictures?
- Address the reader; personalize information ("your baby" not "the baby")?
- Show cultural sensitivity?

Examples that illustrate key points:

This introduction has an impersonal, bureaucratic tone.

The Department of Health Services (DHS), Children’s Medical Services Branch (CMS) has implemented a statewide comprehensive Newborn Hearing Screening Program to help identify hearing loss in infants. The program helps guide families to the appropriate services needed to develop communication skills.

This introduction has a friendly, personal tone and gets right to the “need to know” messages.

It is important to have your baby’s hearing checked.

- Your baby cannot tell you if he or she can hear your voice or lullaby.
- Babies who do not hear have trouble learning to talk.
- Hearing problems need to be found as early as possible to give your baby the best chance for a normal life.
- There is a quick, painless, easy way to test your baby’s hearing.
6. Is the reading grade level appropriate? Is the pamphlet easy to read?

Does the pamphlet:

- Limit long (3 or more syllable), scientific or unfamiliar words?
- Avoid long complex sentences (aim for 10-15 words)?
- Limit unnecessary words that make reading more complex?
- Aim for the 6-8th grade reading level?

Examples that illustrate key points:

This example uses a 30 word sentence and contains many abstract concepts:

The purpose of identifying newborns with hearing loss is to prevent or minimize the effects of hearing loss on language development, academic performance, and cognitive development through appropriate intervention services. (College level)

This example uses fewer words and shorter sentences (14-16 words) and is written in a conversational tone:

It is important to find...learning (6th grade level)
Hearing needs are going unheard for kids in Utah

By Amy Joi Bryson
Deseret Morning News

PLEASANT GROVE — Two years ago, Norm and Taunya Paxton discovered silence had crept into their home — a silence that would forever change their life. They learned their middle child, Chance, was profoundly deaf.

"It's like being thrown into the deep end of the pool and not knowing how to swim," Norm Paxton said.

The discovery left the couple flailing in their efforts to confront the mixed messages they received from doctors, the lack of coordinated support from hearing advocacy groups and the surprising indifference of the insurance industry.

"There's absolutely no guidance," said Taunya Paxton. "It was like shooting in the dark."

Beyond coping with their newly found disability, the Paxtons go through the frustration of the devices they did not want to purchase. Their hearing aids are not covered by most private health insurance plans, and while they can go to dentists, vision or even erectile dysfunction doctors, the hearing aids don't make the cut.

That can be problematic when the devices run thousands of dollars to as much as $7,200.

"Part of the industry's denial process is still trying to convince the public that it's a sensory issue," says Rich Harward, the statewide hearing loss advocate who works with the Utah Speech and Hearing Services.

"Most plans pay for eyeglasses; very few pay for hearing aids," he said. "There are some out there who have helped, but generally, there is no coverage."

The Paxtons, covered under Intermountain Healthcare, have made several appeals, having been told by IHC officials early this year it would be "irresponsible" for them to modify their plan to include coverage.

"There's absolutely no guidance. It was worse than shooting in the dark."
"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 then will find it isn't so. They will go through the same battle we have."

"The market is so incredibly price sensitive, we are being told to take away benefits rather than add them," said Kevin Bischoff, vice president of public and corporate affairs of Regence BlueCross BlueShield."
Lessons Learned from a Decade of Newborn Hearing Screening and Intervention

presented by
Karl R. White
National Center for Hearing Assessment and Management
www.infanthearing.org

at
1st International Conference on Early Diagnosis and Intervention in Hearing Impaired Children
Warsaw, Poland
April 22, 2005
All children are supposed to receive a hearing screen within 45 days of enrollment; however:

- Most programs rely on subjective screening methods such as hand clapping, bell ringing, and parent questionnaires to screen children 0 – 3 years of age

- Most programs did not know that OAE technology existed or could be used with young children
The Hearing Head Start Project

- Feasibility study from 2001-2004
- 69 programs participated
- 3486 children screened
OAE Screening/Referral Outcomes

78 children identified with a hearing loss or disorder:

- 6 permanent hearing loss
- 63 serious otitis media requiring treatment
- 2 treated for occluded Pressure Equalization tubes
- 7 treated for excessive ear wax
Lesson #1: Good Begun . . . . Is half done
However beautiful the strategy, you should occasionally look at the results.

Sir Winston Churchill
Lessons Learned

1. Good Begun .... Is half done
2. The power of ONE
3. Informed partnership is the key to success
4. Be wary of simple answers to complex problems
5. Don’t ignore or thoughtlessly embrace technological advances
6. Systematic ongoing evaluation is worth it’s weight in gold
Lesson #7
All Politics is Local
Lesson # 8


“Parachutes appear to reduce the risk of injury after gravitational challenge, but their effectiveness has not been proven with randomized controlled trials.”
Early Development of Children with Hearing Loss

• Purpose of the study is to evaluate children identified at three different ages, in programs using different communication modes

  – Three age-of-ID groups:
    • Before six months
    • Between 12 and 18 months
    • Between 24 and 30 months

  – Two communication groups:
    • Spoken only
    • Sign and spoken
Early Development of Children with Hearing Loss

- Outcomes being measured at 12, 18, 24, 30, 36, and 42 months of age by “blind” examiners
  - Auditory comprehension of language
  - Communicative expression
    - Communicative Intent
    - Acoustic structure of speech output
    - Expressive language
  - Cognitive development
  - Psychosocial development, including parenting stress
Lessons Learned

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7. “All politics is local” ....standardization is a double-edged sword
8. More research isn’t always the answer, ...but sometimes it is
Lessons Learned

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8. More research isn’t always the answer, ... But sometimes it is
9. Avoid sibling rivalries
Lesson #10
Without lifting your pencil off of the paper, draw 4 straight lines that connect all of the dots.

Think Outside the Box!
Lessons Learned

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8. More research isn't always the answer, ... but sometimes it is
9. Avoid sibling rivalries
10. Think outside the box!
Early Hearing Detection & Intervention Information & Resource Center

In the information & resource center one will find a wealth of information and resources concerning the many dimensions of early hearing detection and intervention. Information and resources include some of the following:

- Newborn Hearing Screening
  - Calculating The Cost
  - Implementation Guide
  - Selecting Equipment
- Diagnostic Audiology
- Early Intervention
- Legislative Activities
- Data Management
- Family Support
- National Technical Assistance System
- Status of EHDI in the U.S.
- State EHDI Grants
- Issues & Evidence
- Slideshows & Videos
- Abstracts & Citations
- EHDI Bulletin Board
- Equipment Loan Program
- Links