UNIVERSAL NEWBORN HEARING SCREENING

Irene Forsman
March 2006
Healthy People 2000
1988 Utah State University pilot in Rhode Island, Utah and Hawaii
1995 Technical Assistance by University of Colorado
1999 Legislation
HRSA Charge

- Develop and monitor the efficacy of statewide newborn and infant hearing screening, evaluation and intervention programs
  - (Early Intervention is defined in the law as referral to schools and agencies including community, consumer and parent-based agencies and programs mandated by Part C...)
Collect data on screening, evaluation and intervention...systems that can be used for applied research, program evaluation and policy
HRSA’s Program

- Universal newborn hearing screening prior to discharge
- Linkage to a medical home
- Audiologic diagnosis before 3 months
- Enrollment in a program of early intervention before 6 mos
- Linkage to family- to- family support
Collaboration

- Centers for Disease Control and Prevention
- National Institute of Deafness and Communication Disorders
- Dept of Education
- Administration on Children and Families’ Head Start Bureau
- American Academy of Pediatrics
- Family Voices
- 55 States/Territories funded
- TA center continued
Intra-Agency Agreement with CDC to examine reasons for loss to followup
State Chapter ”Champion” program with American Academy of Pediatrics
Head Start Screening Activities
Literacy contracts
JCIH 2006 Statement
Performance Measures

- 2005 All MCHB Discretionary Grant Programs report on selected performance measures
- Demographic and fiscal data
Purpose

- GPRA requirements
- Establish measurable goals
- Reported in budgetary process
- Link funding decisions with performance
Other Activities cont’d

- Series of targeted issues meetings
- Training grant targeted to audiologists
- Evaluation contract
- Learning Collaborative
Experience

- 93% of newborns are screened
- Data for about 40-50% of infants needing some f/up are missing
  - protocols for communication of screening results to parents uncertain
  - too few pediatric audiologists
  - health care professionals not all well informed of consequences of hearing loss
  - data and tracking systems not mature
Contact Information

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The Status of EHDI Programs in the USA

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

at
LEND Seminar on Newborn Hearing Screening
Logan, Utah
March 3, 2006
Percentage of Newborns Screened for Hearing in the United States
Why is Early Identification of Hearing Loss so Important?

- Hearing loss occurs more frequently than any other birth defect.
- Undetected hearing loss has serious negative consequences.
- There are dramatic benefits associated with early identification of hearing loss.
Spring is my favorite season. The sun shines bright. The flowers begin to grow. I like spring.
How have we gotten from.....

There to Here?

Earlier Identification of Hearing Loss

Better Assistive Listening Devices

Improved Methods for Teaching LANGUAGE

Increased Availability of High Quality Early Intervention Programs
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!!
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 system to attempt screening of home births
- 35% of states collect data on JCIH Risk factors
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
Status of EHDI Programs in the US: Audiological Diagnosis

- Equipment and techniques for diagnosis of hearing loss in infants continues 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

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

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a) ...A statewide system...shall include, at minimum, the following components
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.
What Is a Medical Home?

• A primary care physician provides care which is:
  • Accessible
  • Family-centered
  • Comprehensive
  • Continuous
  • Coordinated
  • Compassionate
  • Culturally effective
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
Newborn Hearing Screening Tool Kit

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:
    - "Jewel is the only baby to have hearing loss in her family.
    - "Baby was moving a lot in the nursery.
  - Most babies who need another test have normal hearing.
  - Some will have hearing loss.

- Why is it important to have another hearing test as soon as possible?
  - Testing is the only way to know if a baby has 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.
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, as they say is 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 new-found disability, the Paxtons have been blindsided by the realization that hearing aids are not covered by many private health insurance plans but are largely needed as a service best left to parents to pay for. And while it's easy to obtain eyeglasses or riders for dental, vision or even erectile aids don't make the list.

"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 they 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.
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
Physician Attitudes, Knowledge and Practices Related to NHS

Collaborative Effort of BTNRRH and NCHAM
Supported by NIDCD and MCHB
Project with Pediatrists

Pilot Focus Group Work (N = 27)

Internet Based Survey (N = 263); Paper Survey (N = 1,968)

Resource Development

Field test, revise & disseminate

NIDCD & MCHB supported
Survey Question Examples

• Attitudes:
  – Do you think NHS causes parents undue anxiety or concern?
  – Do you believe UNHS is worth what it costs?
  – Please list any concerns you have about NHS, diagnosis and intervention.
Survey Questions Examples

• Practices:
  – Approximately how many children with permanent hearing loss (EXCLUDING OTITIS MEDIA) have you had in your practice over the past 3 years?
  – List any specialists to whom you routinely refer the family of a child with permanent hearing loss (list the types of specialists).
Survey Question Examples

• Knowledge:
  – What is your best estimate of the earliest age at which:
    • A child not passing the screening should be seen for follow up testing
    • A child can be definitively diagnosed with permanent hearing loss
    • A child can begin wearing hearing aids
    • A child with permanent hearing loss should be referred to early intervention
  – Enter age estimates ____________________
States Involved in Survey of Physicians

N = 21 States + Puerto Rico
Physician Survey: Demographics

Gender:
- 53.2% Male
- 46.8% Female

Location:
- 62.5% Metro
- 24.1% Small town
- 13.3% Rural

N = 1,968
Children with SNHL in past three years of practice

<table>
<thead>
<tr>
<th></th>
<th>National</th>
<th>Pediatrists</th>
<th>Family Practice</th>
</tr>
</thead>
<tbody>
<tr>
<td>Mean Number of Children</td>
<td>3.13</td>
<td>3.32</td>
<td>1.25</td>
</tr>
</tbody>
</table>

ENT $\bar{X} = 16.95$
Importance of testing all newborns

3% Pediatricians;
6% Family Practice

p < .001
Does NHS cause undue parental anxiety?

![Bar chart showing percentage of respondents for different categories: Total Group, Pediatricians, Family Practice. The chart indicates the percentage of respondents for each category.
Things are changing…but

• 88.61% receive screening results

• But…12% - 17% receive < 50% of results!

• 89.2% refer < 3 mos

• But…24.3% unsure NHS is worth what it costs
Concerns about NHS

- Too many false positives
- Costs outweigh benefits
- Loss to follow up
- Need for training
- Unclear about procedures; complex
- Inconclusive results
- Need for parent education
- Need for funding & better equipment
Confidence in Counseling Parents following Screening

Level of Confidence

Percent Respondents

Very
Somewhat
Unsure
Not

11%
Risk for late onset SNHL

- Menigitis*
- NICU*
- Cleft Palate*
- CMV*
- Syphilis*
- Family*
- Mom >40
- Heart
- Colds
- Hypotonia

Percent Respondents

Risk Factor
Referral to Specialists

Percent Respondents

Specialist Type

ENT*  Audiology  SLP  EI  Neuro  OT  Genetics*  Eye*

9.7
Follow Up & Intervention

Age Diagnosis Possible

- 27% diagnosis possible in the first month

Wear Hearing Aids

- 41.5% wear hearing aids after 9-12 months
Candidates for Cochlear Implants

- **Bi Profound**: 74.3%
- **Bi Mild-Mod**: 15.5%
- **Unil Mild-Mod**: 5.9%
- **Unsure**: 27.1%

Hearing Loss Category

Percent Respondents

0 20 40 60 80 100
Primary Sources of Info on NHS

- Literature: 40%
- Hospital Program: 15%
- Ed Meeting: 10%
- State EHDI: 5%
- Other Physicians: 5%
- Audiolist: 5%
- OJT: 2%
- Grand Rounds: 2%
- Internet: 51.7%

Frequent Internet Use = 51.7%
Confidence in Talking with Parents about...

The bar chart shows the percentage of respondents' confidence in discussing various topics with parents. The topics include Causes, Communication Methods (Comm Meth), Unilateral/Mild (Unil/Mild), Profound, and CI. The chart indicates that a significant number of respondents feel very confident, with the highest confidence observed in the topic of Causes and CI.
# Policy Statement Awareness

<table>
<thead>
<tr>
<th>Organization</th>
<th>Percentage</th>
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<tbody>
<tr>
<td>AAP</td>
<td>56.8%</td>
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<tr>
<td>AAO</td>
<td>1.9%</td>
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<tr>
<td>AAFP</td>
<td>6.6%</td>
</tr>
<tr>
<td>State</td>
<td>1.1%</td>
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<tr>
<td>AMA</td>
<td>.3%</td>
</tr>
<tr>
<td>CDC</td>
<td>.5%</td>
</tr>
<tr>
<td>USPSTF</td>
<td>.7%</td>
</tr>
</tbody>
</table>
Topics Judged as Needs (In prioritized order):

1. Protocol for f/u
2. Early intervention
3. Contacts for more information
4. Screening for late onset SNHL
5. Patient Education Resources
6. Impact of HL on language
7. Screening at well-child visits
8. Hearing Aids and cochlear implants
9. Genetics and hearing loss
10. Counseling families about screening results
Usefulness of Resources

Percent Respondents

- Protocol Cards
- Brochures
- Website
- Online CME
- Grand Rounds
- CD/DVD Parents
- Videos

Very Helpful
Somewhat

Percent Respondents

0 10 20 30 40 50 60 70
Most Recommended Resources

1. Protocol cards
2. Patient brochures
3. Web sites
4. On-line CME*
5. Peer education
6. Grand rounds materials
Less Recommended Resources for Physicians

• CDs or DVDs to use in patient education
• Videotapes to use in parent education

…but some offices prefer this type of material

…reinforces need for multiple avenues
Big Picture: Physicians

- Positive changes seen...more education needed
- “One size” will not fit all
- “Just in time” resources; protocol steps
- Action-oriented
  - medical management
  - counseling families
- Clear, time efficient language
- Peer education and internet resources
Next Steps:

• Manuscript (in preparation)
• Working with National Organizations
  – Nurse practitioners & Pediatric nurses
  – Physician Assistants
  – Nurse Midwives
• Sound Health Connections Conference held in Oct, 2005
• Action plans developed & in progress
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Questions?