Sunrise Sessions
Inside Research at Utah State University

Regence
Early Identification of Children's Hearing Loss: A Silent Revolution

presented at the
Sunrise Session:
Inside Research at Utah State University

by
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Blindness separates people from things.
Deafness separates people from people.

--- Helen Keller
Little Known Facts About Congenital Hearing Loss

• Permanent hearing loss is the most frequent birth defect in the United States.

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

• Congenital hearing loss is often referred to as an “invisible disability.”

• If hearing loss is not identified and treated early, deaf children will require additional $400,000 per child in educational costs.

• The average deaf adult in the United States reads at the 4th grade level.
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 ....

Earliest 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?
How does your baby hear sound?
From 1988-1993 USU conducted the first large-scale clinical trial of universal newborn hearing screening -- the Rhode Island Hearing Assessment Project ---
Based largely on the results of this study conducted by Utah State University, the National Institutes of Health concluded in March 1993 that:

- “The average diagnosis of hearing impairment remains constant at about 2 ½ years of age.
- All infants should be screened for hearing impairment...this will be accomplished most efficiently by screening prior to discharge from the well-baby nursery.
- Identification of hearing impairment must be seen as imperative for all infants.”
Percentage of Newborns Screened for Hearing in the United States
Confirmation of Permanent Hearing Loss

Average Age in Months

- Coplan (1987)
- Eissman et al. (1987)
- Gustason (1987)
- Meadow-Orlans (1987)
- Stein et al. (1990)
- Mace et al. (1991)
- O'Neil (1996)
- Johnson et al. (1997)
- Vohr et al. (1998)
What enabled us to move from ....

Availability of Better Assistive Listening Devices

Earlier Identification of Hearing Loss

High Quality Early Intervention Programs that focus on teaching LANGUAGE

Advocacy and Public Policy Initiatives

There to Here?
What enabled us to move from ....

There to Here?

- 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
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 diagnostician as normal part of early intervention program.

Moeller, M.P. (1997). Personal communication moeller@boystown.org
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 that only 53% of infants with hearing loss are enrolled in EI programs before 6 months of age.

- 28% of parents of children who are DHH report that they had to move to a new location to receive the services they wanted for their child.
Most Early Intervention Programs for Children with Hearing Loss are “Missing the Mark”

- 95% of all newborns with hearing loss have parents with normal hearing.
- 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
- The number of cochlear implants for children under age 5 has quadrupled in the last 4 years (to 2000+ implants per year)


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.
...to ensure that all infants and young children with hearing loss are identified as early as possible and provided with timely and appropriate audiological, medical, and educational interventions.
NCHAM’s Annual extramural funding: ~$2.5 million

- Funding sources:
  - 68% Federal agencies (e.g., CDC, MCHB, NIH, ACF),
  - 25% State Departments of Health or Education,
  - 7% Private foundations

- Multi-disciplinary staff of 40 people from:
  - Psychology
  - Computer science
  - Audiology
  - Special education
  - Instructional technology
  - Health education
Oberkotter is considering a project with NCHAM to:

- Conduct and disseminate results of **applied research, needs assessment, and program evaluation studies** to guide policy and programmatic decisions regarding gaps in services, effectiveness of alternative models, needs of families, and allocation of training resources;

- Work with existing **pre-service and in-service professional training programs** to establish state-of-the-art curricula, promote collaboration, and recruit people to serve children who are deaf or hard of hearing;

- Coordinate with state agencies and professional organizations to **upgrade and strengthen certification and/or credentialing requirements** for professionals and programs specializing in early intervention for children who are deaf or hard of hearing;

- **Collaboratively establish and promote the best practices for educating children** who are deaf or hard of hearing and respond to gaps in services by working with state education agencies, state EHDI coordinators, Part-C administrators and others to develop and implement effective models for the delivery of services to children who are deaf or hard of hearing; and

- **Provide information and resources for parents and professionals** including printed materials, internet-based resources, professional speakers, seminars, videos, and CDs.
International Outreach

Advocacy, Education & Public Awareness

Training and Technical Assistance

Basic Research
Detecting mutations on biosensor silicon chips

Applied Research

Public Health Information Management

NCHAM
National Center for Hearing Assessment and Management
Utah State University™
Since 1996 NCHAM has been funded by the federal government as the

**National Resource Center for EHDI Programs**
*(EHDI=Early Hearing Detection and Intervention)*

- Provide training, technical assistance, and information to EHDI programs in every state
- **Collaborate with professional and advocacy groups (e.g., American Academy of Pediatrics, March of Dimes)** to promote effective screening and identification of hearing loss
- **Webcasts, working meetings, information dissemination**
- **National Network of EHDI Experts**
National EHDI Resource Center: Technical Assistance Network

Areas I & II
Antonia Brancia Maxon, Ph.D.
- E-mail

States: Connecticut, Maine, Massachusetts, New Hampshire, New Jersey, New York, Rhode Island, Vermont

Areas III
Diane L. Sabo, Ph.D.
- E-mail

States: Delaware, District of Columbia, Maryland, Pennsylvania, Virginia, West Virginia

American Samoa, Guam, Fed. of Micronesia, Marshall Islands, Northern Mariana Islands, Palau

Puerto Rico (Area V)
Are current EHDI materials effective?
Distance Education/Hands-on Audiology Training Workshops

Investing in Family Support Working Meeting

Meeting of Part C Coordinators at 2006 National EHDI Meeting
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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
Does a 2-stage (OAE/AABR) newborn hearing screening protocol miss babies with mild hearing loss?

**Study Sample**

Comprehensive Hearing Evaluation Before 6 Months of Age

**Comparison Group**

Comprehensive Audiological Assessment at 8-12 months of age
How Many Additional Babies with Permanent Hearing Loss were Identified?

<table>
<thead>
<tr>
<th></th>
<th>Comparison Group (Fail OAE/ Fail AABR)</th>
<th>Study Group (Fail OAE/ Pass AABR)</th>
<th>Total</th>
</tr>
</thead>
<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>
</tr>
</tbody>
</table>

*Adjusted for proportion of OAE fails that enrolled

Represents 23% of all babies with PHL in birth cohort

Costs of Newborn Hearing Screening in Utah

Linda D. Goetze, Kay W. Hansen, Karl R. White, and Scott Grosse

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Presented at:
National Early Hearing Detection and Intervention Conference
Washington, DC

February 20, 2004
What Causes Hearing Loss?

**Environmental**
- CMV meningitis
- rubella prematurity
- head trauma asphyxiation
- ototoxicity hyperbilirubin
- other infections

**Congenital Hearing Loss**
- ~40%
- ~60%
- ~30%

**Genetic**
- ~70%

**Syndromic**
- Alport Norrie
- Pendred Usher
- Waardenburg
- Branchio-oto-renal
- Jervell and Lange-Nielsen

**Non-syndromic**
- Autosomal dominant 21%
- Autosomal recessive 77%
- X-Linked ~1%
- Mitochondrial ~1%
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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, an early hearing detection and intervention (EHDI) program should comprise three basic components—newborn hearing screening, audiological diagnosis, and early intervention. Threaded throughout these components should also be some key elements—culturally-competent family support, medical home, data management, legislative mandates, and program evaluation tools. Follow the links below to find information about these basic components and key elements, and about other related EHDI resources and information.
Parents

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?
Partnership is the Key to Successful EDHI Programs

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

Child & Family Medical Home
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?:

<table>
<thead>
<tr>
<th>Specialist 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 graph showing the percentage of physicians who fit infants with hearing aids at various ages.]

- Birth and 1 month: 10%
- 2 months: 15%
- 3 months: 5%
- 4-5 months: 20%
- 6 months: 25%
- 7 to 11 months: 10%
- 12 to 18 months: 15%
- 19+ months: 5%
<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>
</tbody>
</table>
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
Policy and Legislative Initiatives with Local, State and Federal Partners
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Ah, but a man's reach should exceed his grasp. Or what's a heaven for?

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

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