Sunrise Sessions Inside Research at

Utah State University

ANONA

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



presented at the

Sunrise Session: Inside Research at Utah State University

by Karl R. White Director, National Center for Hearing Assessment and Management Professor of Psychology <u>www.infanthearing.org</u> September 28, 2006

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





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 parents⁴⁰ with hinddress per 10,100 of Conceptal Defects/Diseases
- Congenifal hearing loss is often referred to as an "invisible disability."
- If heaning lass is not identified and treated early, deaf children will require and additional \$400,000 per child in educational costs.
- The average deat adult in the 4th grade level 23, 200 and 100 adults in the 4th grade level 23, 200 and 100 adults in the 4th grade level 23, 200 adults in the 4th grade level 24, 200 adults in the 4th grade l





Spring is my favorite season. The sun shines bright. The flowers begin to grow. I like spring.





What enabled us to move from



From 1988-1993 USU conducted the first large-scale clinical trial of universal newborn hearing screening

-- the Rhode Island Hearing Assessment Project ---

SEMINARS IN HEARING-VOLUME 14, NUMBER 1 February 1993

UNIVERSAL NEWBORN HEARING SCREENING USING TRANSIENT EVOKED OTOACOUSTIC EMISSIONS: RESULTS OF THE RHODE ISLAND HEARING ASSESSMENT PROJECT

Karl R. White, Ph.D., Betty R. Vohr, M.D., and Thomas R. Behrens, Ph.D.

The earlier that hearing loss can be identified and intervention begun, the better the prognosis for the child in areas ranging from language development to academic success, social interactions, and successful participation in society.¹ Indeed, early identification of significant hearing loss is so important that the U.S. Department of Health and Human Services (HHS) recently set a goal to reduce to 12 months the average age at which signifiearth earling loss is inderviced 2 of using auditory brainstem response (ABR) to identify hearing loss among infants and toddlers.^{4,5} Such research certainly contributed substantially to the American Speech-Hearing Language Association's (ASHA) recommendation of ABR as the preferred method for screening the hearing of newborns.⁶ However, the expense of doing ABR testing of newborns was very likely what led to ASHA's recommendation that it be done only with infonts who exhibit one of the ten risk for Based largely on the results of this study conducted by Utah State University, the National Institutes of Health concluded in March 1993 that:

Volume 11, Number 1 March 1-3, 1993

NIH Consensus Statemen

Early Identification of Hearing Impairment in Infants and Young Children

NATIONAL INSTITUTES OF HEALTH Office of the Director

- "The average diagnosis of hearing impairment remains constant at about 2 ¹/₂ 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

What enabled us to move from

SIDE VIEW

FRONT VIEW

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 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.
- $\boldsymbol{\cdot}$ 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)

Mitchell RE and Karchmer MA. Chasing the mythical ten percent: Parental hearing status of Deaf and Hard of Hearing students in the United States. *Sign Language Studies*. 2004: 4(2), 138-163.

Brown C. Early intervention: *Strategies for public and private sector collaboration*. Paper presented at the 2006 Convention of the Alexander Graham Bell Association for the Deaf and Hard of Hearing. 2006 Pittsburgh PA.

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

self-report survey data from the 2004 and 2005 issues of the American Annals of the Deaf.

Training and Technical Assistance

Advocacy, Education &

Public Awareness

National Center for Hearing Assessment and Management Utah State UniversityTM

International Outreach

Public Health Information Management

to ensure that all infants and young children with best loss are to entired as early as possible and 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 up-grade 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.

Training and Technical Assistance

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Basic Research

Detecting mutations on biosensor silicon chips

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

Last Modifed: 05/19/2006

Areas

I & II Antonia Brancia Maxon, Ph.D.

E-mail

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

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

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

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

Training and Technical

National Center for Hearing Assessment and Management Utah State UniversityTM

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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? Comparison Group Comprehensive Hearing OAE Screening Prior to** AABR **Evaluation Before 6 Months Hospital Discharge** Screening Fail Fail of Age Pass Pass **Study Sample Comprehensive Audiological** Assessment at 8-12 months of age Discharge Discharge

How Many Additional Babies with Permanent Hearing Loss were Identified?

	Comparison Group (Fail OAE/ Fail AABR)	Study Group (Fail OAE/ Pass AABR)	Total
Number of Babies	158	21	179
Prevalence per 1,000	1.82	.55*	2.37
*Adjusted for proportion of OAE fails that enrolled Represents 23% of all babies with PHL in birth cohort			

Johnson J, White KR, Widen JE, Gravel JS, James-Trychel M, Kennalley T, Maxon AB, Spivak L, Sullivan-Mahoney M, Vohr BR, Weirather Y, & Holstrum J (2005). A multi-center evaluation of how many infants with permanent hearing loss pass a two-stage OAE/A-ABR newborn hearing screening protocol. *Pediatrics*, *116*(3), 663-672.

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

What Causes Hearing Loss?

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Last Modifed: 08/21/2006

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2006 SE Regional EHDI Conference •

Registration is open for the Southeast Regional EHDI Conference: Partnering for Progress to held on October 5-7, 2006 in Jackson, Mississippi Click for more information

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 kev 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.

Legislative

EHDI State EHDI Components Resources Information Activities NCHAM Items

Annual EHDI EHDI Meetings Workshops

Diagnostic Audiology

Newborn Hearing Screening

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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

American Academy of Pediatrics

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

Educating Primary Health Care Providers About 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, to which specialists would you refer the baby?:

Ophthalmological evaluation	Always or Often 0.6%		
Genetic evaluation	8.9%		
Otolaryngological evaluation	75.6%		

Responses of 1975 physicians in 21 states

Moeller MP, White KR, & Shisler L (in press). Primary care physicians' knowledge, attitudes and practices related to newborn hearing screening. *Pediatrics*.

When can an infant be fit with hearing aids?

Type of Physician	Age at which hearing aids can be fit					
	<=1 mo	2-3 mos	4-6 mos	7-11 mos	12+ mos	
Pediatrician (n=1145)	36.3%	16.9%	29.0%	2.1%	15.6%	

Hearing Screening During Well Child Visits to Health Care Providers

Early Identification of Hearing Loss

Conducting periodic Otoacoustic Emissions (OAE) hearing screening with infants and toddlers during well-child visits

- 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 <u>www.HearAndNow.org</u>

Policy and Legislative Initiatives with Local, State and Federal Partners

International Outreach

Basic Research

Detecting mutations on biosensor silicon chips

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Basic Research

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Poland

Malaysia

Costa Rica

India

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

---- Robert Browning

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