(((SOUND IDEAS

Volume 3, Issue 1 | *Some babies are born listeners...Others need your help.* | April 1, 2001

Implementing Newborn Screening: Where Do I Begin?

Getting started with a newborn hearing screening and intervention program can seem overwhelming. It seems like there are so many questions that need to be answered before you can even get started. For example:

* Should I use OAE or AABR?
* Which brand of equipment should I buy?
* Who should do the screening?
* Who will train the screeners?
* Do I need to write a Policy & Procedures Manual (and if so, how do I do it)?
* Where should screening be done?
* How should screening results be communicated to parents and physicians?
* How much should we charge and how will we pay for the program?
* To whom should babies be referred if they don't pass?
* Does MY state have legislation or regulations that have to be followed?

Now there is a comprehensive resource to assist you with the first major component of EHDI ... getting started with a hospital-based screening program. **Early Identification of Hearing Loss: Implementing Universal Newborn Hearing Screening Programs** was developed by the federal Maternal and Child Health Bureau (MCHB) to help people get started with newborn hearing screening and intervention programs. The booklet has been distributed to hospitals throughout the country and is now also available on the internet at www.infanthearing.org.

This booklet is based on the experiences of dozens of people who pioneered the development of hospital-based universal newborn hearing screening, diagnosis and early intervention programs. It is organized around a checklist of the following 13 activities which are central to the development and operation of a successful universal newborn screening program:

1. Enlisting Support for Newborn Hearing Screening,
2. Determining and Appropriate Protocol for Your Hospital.
3. Dealing with Procedural Issues,
4. Communicating with Parents, Physicians, and Hospital Staff,
5. Training Newborn Hearing Screeners,
6. Keeping Referral Rates Low,
7. Managing Data and Patient Information,
8. Financing the Program,
9. Caring for Equipment and Supplies,
10. Reporting,
11. Completing Audiological Diagnosis and Follow Up,
12. Coordinating with State Systems, and
13. Considering Legislative Mandates.

More than *15,000* copies of the booklet (often called The Implementation Guide) have already been distributed throughout the country. People have found them to be invaluable for starting hospital based universal newborn hearing screening programs.

Additional materials for helping you implement a successful program are available at NCHAM's web site. Keyed to the checklist described above these materials include examples from successful programs of brochures for parents and health care providers, quality assurance checklists, copies of policies and procedures and much, much more. Because no two hospitals are alike, these materials can be also used to generate new ideas and modified to fit your unique program needs. The Guide and Resource Materials can be downloaded for free at www.infanthearing.org and are also available from the National Maternal and Child Health Clearinghouse at no charge by calling *(703) 356-1964.*

NCHAM National Center for Hearing Assessment and Management

IN THIS ISSUE

(((SOUND IDEAS is a quarterly publication of the National Center for Hearing Assessment & Management (NCHAM). Its goal is to provide information to hospital staff, health care providers, early interventionists, families, and public health officials to help in the establishment and expansion of successful newborn hearing screening and intervention programs.

The newsletter is also be available at our website http://www.infanthearing.org. Send us your e-mail address at nchamhelp@coe.usu.edu and we will email you each time the newsletter is published. If you would like to submit an article, contact the editor, Karen Ditty at DittyKM@aol.com

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(((Benefits of Early Identification . . . and Amplification! "A Case Study"

Much media attention has been focused on early identification of hearing loss, and many states have passed legislation requiring the screening of all infants for hearing loss. In most cases, much work and extensive community education have preceded the passage of such legislation. The focus is on children and our goal of improving their quality of life, which includes interactions with their families and community. Long-term goals include improvement in educational outcomes and ultimately economic benefits to the individuals and society in general. Universal newborn hearing screening is just the start.

- What tools do we have at our disposal to reach the goals of Universal Newborn Hearing Screening (UNHS)?
- Are results of diagnostic audiological evaluations reliable at this young age?
- Do we dare amplify at such a young age?

Many different people must be involved if congenital hearing loss is to be identified and treated as early as desirable (physicians, nurses, audiologists, parents, etc.). We are just beginning to educate all of these groups of people that we really can obtain a definitive evaluation of a baby's hearing and provide appropriate intervention during the first few months of life.

A real-life example from our clinic illustrates the benefits of early identification and intervention. Patient KR was a twin born at 30 weeks gestation (GA) with APGAR scores or 1 at one minute and 5 at five minutes. She was identified with Goldenhar syndrome and exhibited associated anomalies, including right microtia and atresia, left atresia, preauricular tags bilaterally, recessed jaw, and cleft lip. Birth weight was approximately 1162 grams (2lbs.. 9oz.). She was treated on different occasions in the Neonatal Intensive Care Unit (NICU) for approximately nine weeks.

The initial Auditory Brainstem Response (ABR) was conducted at 40 weeks GA, and revealed elevated (60dbnHL) threshold. Central conduction times were within normal limits bilaterally. ABR by bone conduction was present with 20 dBnHL equivalent stimulus.

ABR was repeated at 41 weeks GA, and a bone conduction hearing aid (Oticon P11P body-worn hearing aid with separate bone oscillator) was fitted on a trial basis immediately following the ABR while the infant was in the NICU.

The parents and nursing staff were instructed (verbally and using a bedside visual) regarding the application, use, and maintenance of the hearing aid. The parents and staff were encouraged to place and use the hearing aid during all waking hours. Nursing staff, physicians, and other professional staff were all very positive and supportive.

Other related complications have included moderate to severly impaired oral stage feeding skills, gastrostomy feeding, and severe obstructive sleep apnea. Follow-up has included speech/

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An EHDI Bulletin Board: Quick Answers by the Experts to Your Questions About Newborn Hearing Screening

Ever had something to ask or say about *early hearing detection and intervention* (EHDI), but were uncertain where to go? The **National Center for Hearing Assessment and Management (NCHAM)** is pleased to announce its web based bulletin board dedicated solely to EHDI. The bulletin board is co-sponsored by the federal Maternal and Child Health Bureau, and the Centers for Disease Control and Prevention. You can ask any question about EDHI and comment on questions others have asked. This is a great way to get up-to-date information and stay informed about everything that is happening in the EDHI world. Best of all, it doesn't cost you anything! Our uniquely qualified staff and members of our outstanding technical assistance network monitor the bulletin board daily to make sure all questions are promptly answered. You now have easy access to their experiences and expertise. Moreover, you will have access to the special experiences and expertise of your fellow visitors from across the globe.

Why not sign on today and see if you like it? We believe everyone involved in newborn hearing screening, diagnosis, and intervention has something meaningful to contribute. You can begin seeing what others have to say on a variety of topics by browsing through the bulletin board. Then consider saying something yourself. Only when you choose to post a question or comment of your own will you need to register. Registration is free, unobtrusive, and confidential. Come join us. Begin sharing your questions, comments and experiences. ***Visit our bulletin board at: http://www.infanthearing.org.*** Or you can still contact us the old fashioned way at our telephone technical assistance hotline, (435) 797-3584, or email us at nchamhelp@coe.usu.edu.

Joint Committee on Infant Hearing : Year 2000 Position Statement, Principles and Guidelines for Early Hearing Detection and Intervention Programs

For many years, the Joint Committee on Infant Hearing (JCIH) has recommended policies and procedures to reduce the age of identification for infants and young children with hearing loss. The JCIH consists of representatives of 11 different professional organizations, who are concerned about the hearing health of infants and young children (e.g., American Academy of Audiology, American Academy of Otolaryngology, American Academy of Pediatrics, American Speech Language and Hearing Association, National Association of the Deaf, etc). The JCIH Year 2000 position statement expands substantially on previous statements in advocating a new level of comprehensiveness that sets the standard for all Early Hearing Detection and Intervention (EHDI) programs to achieve. This document is an excellent summary of how hospital-based screening is only the first step in what should be a comprehensive program of detection and intervention that also include diagnosis, integration with the baby's medical care, provision of family support services, and data management and tracking procedures.

JCIH endorses early detection of and intervention for infants with hearing loss through integrated, interdisciplinary state and national systems of universal newborn hearing screening, evaluation, and family-centered intervention.

The document also provides programmatic suggestions and benchmarks which program administrators can use to make sure they are meeting federal guidelines to provide family-centered, community-based EHDI systems which are comprehensive, coordinated, timely, and available to all infants. The following eight principles, which are discussed more fully in the JCIH position statement, provide the foundation for effective EHDI systems:

1. All babies (including home births) are screened for hearing loss by one month of age using a physiologic measure. Otoacoustic Emissions (OAE) and/or Auditory Brainstem Response (ABR).
2. Babies referred from screening begin appropriate audiologic and medical evaluations to confirm the presence of hearing loss before 3 months of age.
3. Infants with confirmed permanent hearing loss receive services before 6 months of age in interdisciplinary intervention programs and build on strengths, informed choice, traditions, and cultural beliefs of the family.
4. All infants who pass newborn hearing screening, but who have risk indicators for other auditory disorders and/or speech and language delay receive ongoing audiologic and medical surveillance and monitoring for communication development.
5. Infant and family rights are guaranteed through informed choice, decision–making, and consent.
6. Infant hearing screening and evaluation results are afforded the same protection as all other health care and educational information. (In regards to new standards for privacy and confidentiality.)
7. Information systems are used to measure and report the effectiveness of EHDI services.
8. EHDI programs provide data to monitor quality, demonstrate compliance with legislation and regulations, determine fiscal accountability and cost effectiveness, support programs reimbursement for services, and mobilize and maintain community support

Each of the preceding principles is discussed in detail with suggestions for how to achieve the benchmarks necessary to demonstrate high quality programs for each principle, what roles and responsibilities should be assumed by institutions and agencies, families, and professionals, and a discussion of what issues will need to be addressed in the future. References to recent research studies are used to support each of the principles and positions advocated.

Anyone who has responsibilities associated with newborn hearing screening and intervention would profit from reading this document and implementing the suggestions it contains. Although a great deal of progress has been made in recent years, much work remains for all newborns in the United States to have access effective newborn hearing screening and intervention programs. Implementing these Guidelines would bring us a lot closer to that goal.

The complete JCIH Position Statement can be viewed or downloaded at NCHAM's web site www.infanthearing.org.

Techniques and Tidbits!

1. Include a discussion of UNHS in pre-natal courses offered at the birthing hospital to better inform new parents of the importance of newborn hearing screening. Videos are often available from the manufacturer from whom you purchased your equipment. There is also a video available at the NCHAM website (*www.infanthearing.org).*
2. Consider making UNHS a standard of care for all infants born in your hospital. This is not unlike other procedures that are routinely performed on newborn infants and will decrease the cost of UNHS because you avoid spending time getting individual releases.
3. If the first screen is not a pass, at least one more screening examination should be performed on that ear during the birth admission.
4. Want to be on the cutting edge of science? Sign up for AG Bell's Summer Conference: **The Human Genome Project and Hearing Loss** on July 27-29, 2001 in Bethesda, Maryland. This conference on genetics and hearing loss (designed for non-scientists)will feature Francis Collins, M.D., Ph.D., Director of the Human Genome Project. Dr. Collins and a panel of seven distinguished scientists in the field will discuss the genetic implications of hearing loss, as well as potential therapies for people who are deaf or hard of hearing. Also scheduled are a series of educational sessions on topics ranging from hearing technology to mainstreaming, parenting, and more. AG Bell childcare is available. You can sign up for the conference on the web by visiting www.agbell.org.

Boys Town National Research Hospital Launches Project to Develop Educational Materials for EHDI

The National Institutes of Health recently awarded a grant to The Center on Childhood Deafness at Boys Town National Research Hospital to develop educational materials for health care providers, early intervention programs, and parents to support the expansion and improvement of Early Hearing Detection and Intervention (EHDI) programs. According to Mary Pat Moeller, who is directing the project, the development and dissemination of these materials should help in reducing time between when infants with hearing loss are identified and the time they receive appropriate medical, audiological, and educational intervention.

The first goal of the project is to increase knowledge and change attitudes of healthcare providers regarding newborn hearing screening and referral. Initial phases of the project will include focus groups, interviews, and assessments of healthcare providers' knowledge, beliefs, and attitudes related to early identification, intervention, consequences of hearing loss on development, and the genetics of hearing loss. Based on the data gathered from these activities, educational materials, in a variety of formats, will be developed and disseminated.

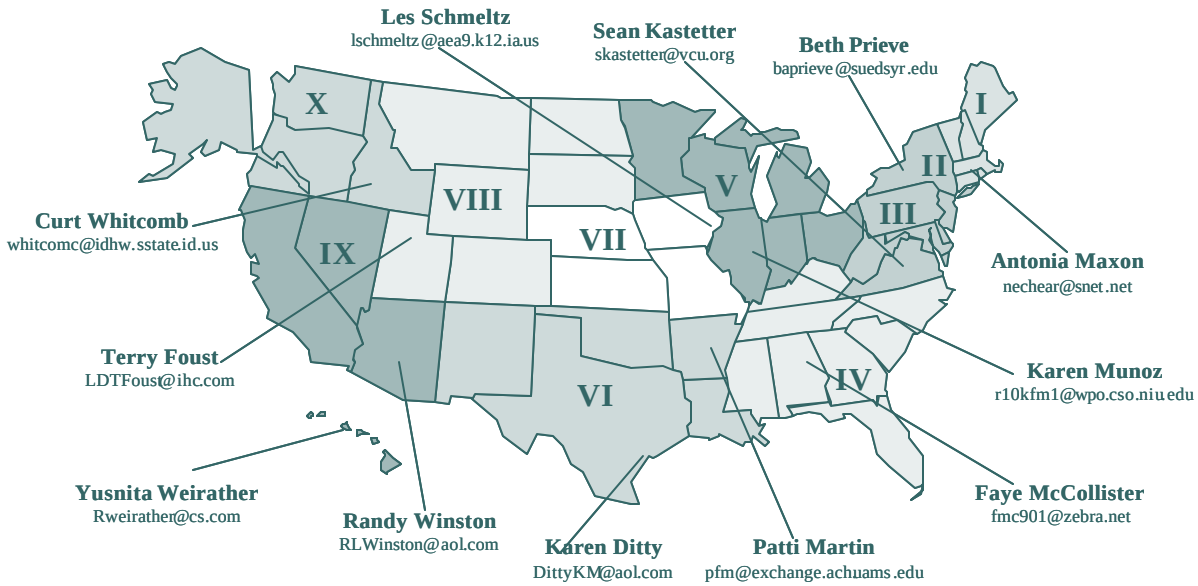
A second part of the program will be to increase the skills of early intervention program staff in implementing developmentally appropriate, relationship-focused interventions with infants who have hearing loss and their families. This will be done by: (a) developing resource materials in collaboration with leaders of successful parent-infant programs for 0-3 year old children with hearing loss; (b) developing an interventionist mentoring program, that includes provision of specific feedback on videotaped intervention sessions; and, (c) using the information from the preceding two activities, developing a web-based technical resource center designed specifically for interventionists serving newly identified infants with hearing loss.

The final part of the program is to develop materials which will increase parents' understanding and self efficacy related to the complex issues surrounding the diagnosis of hearing loss, genetics of hearing loss, and amplification options for infants and young children.

All of these materials will be available from the Center on Childhood Deafness at Boys Town National Research Hospital. To learn more about the project or see other excellent material already available from the Center, go to http://www.boystown.org/Btnrh/Chlc/index.htm

National EHDI Technical Assistance System
(Early Hearing Detection & Intervention)

To help states with the implementation and improvement of Early Hearing Detection and Intervention (EHDI) programs, the Maternal and Child Health Bureau (MCHB) awarded a grant to NCHAM to establish a National EHDI Technical Assistance System. One of the mechanisms being used to provide assistance is a National Network of audiologists who have extensive experience with the operation of EHDI programs. These advisors help hospitals, early intervention programs, health care providers, families, and state agency staff in their region to develop and improve sustainable and comprehensive EHDI programs. Network members can provide workshops, provide training and assistance to hospital staff, participate in Advisory Meetings, review materials, and help program administrators find materials and resources. If you need assistance in your region, contact the Network member in region at the email address shown on the map below or by calling the NCHAM help desk @ (435)797-3584.



Federal Government Funds Grants to Assist States in the Development and Expansion of EHDI Programs

The Maternal and Child Health Bureau (MCHB) has just announced that 16 additional states and territories were awarded grants to assist with the development and/or expansion of effective Early Hearing Detection and Intervention (EHDI) programs. This brings to 38 the number of states and territories with MCHB funding for the support of statewide EDHI programs. States receiving these grants are expected to address all components of universal newborn hearing screening and intervention, including procedures for ensuring timely and appropriate audiological diagnosis, provision of appropriate early intervention services, linkages with the child's medical home, provision of culturally competent family support, and development of effective tracking and data management systems.

Fifteen (15) states have also been awarded Cooperative Agreements with the Centers for Disease Control and Prevention to develop better EHDI tracking and data management systems and to link these systems with other public health information systems such as Vital Statistics (e.g., Electronic Birth Certificates), Heelstick Screening Programs, Birth Defect Registries, and Immunization Registries. Such linkages should result in much better and more efficient services for young children and their families.

States who have received funding from MCHB and CDC are listed at NCHAM's web site (http://www.infanthearing.org/ehdi/stategrants/index.html). Copies of the grant proposals are also listed. These are an excellent source of ideas for improving your state's EHDI program. Both MCHB and CDC have announced that another competition will be held this summer to award more grants or cooperative agreements.

Benefits of Early Identification...and Amplification

(Continued from page 2)

language therapy, occupational therapy, feeding therapy, and Continuous Positive Airway Pressure (CPAP).

At 26 months, KR follows two-part directions without gestures, uses single word utterances to communicate requests for action, and objects. She greets, protests (she says "no" very well!), and comments. Receptive language skills are approximately 20 months. Her expressive skills are also approximately 20 months. This represents only a six-month delay from her chronological age. Her overall gross motor developmental level approaches normal. Considering the length of NICU stay, degree of hearing loss, multiple hospitalizations, various illnesses, and premature birth-associated risk factors, this is excellent progress.

Even when specific audiometric thresholds are not known, but general audiometric information is available, amplification and intervention becomes not only possible, but critical.

KR now functions with greater independence and nearly fulltime hearing aid use. She continues in the development of her speech and language, and is currently receiving services from a local parent/infant early intervention program, Dysphagia Clinic, Neonatal Follow-Up Clinic, and Audiology Clinic.

Her parents are very pleased with the progress she is making, "We Speak to her with full sentences, the same as we speak to her twin brother, and she responds the same. She can say 'Hi Mommy,' 'Hi Daddy,' and 'I don't know,' and many one-word utterances.

Several factors contributed to this little girl's success:

1. The effect of the early identification and intervention cannot be emphasized enough.
2. Even when specific audiometric thresholds are not known, but general audiometric information is available, amplification and intervention becomes not only possible, but critical.
3. Early parent training and speech/language intervention reinforced the benefits of her early intervention.
4. Involvement and support of the medical staff on the patient care unit encouraged the parents to participate fully with the Audiologist in the early amplification process.

Early intervention will continue to offer challenges to the Audiology, Medical, and Early Intervention community as we identify children with hearing loss at younger ages. As Audiologists, even if we do not generally see infants and children, we must be strong proponents of early intervention and not turn our heads and wait for weeks or even months because we feel uncertain about what to do or how to do it!

We have spent years trying to convince others that no child is too young to test. Now we must move forward with the conviction that no child is too young to amplify with hearing aids.

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Upcoming Events

April 17-18, 2001	**What comes Next? A Practical Workshop for Diagnosis And Intervention after Newborn Hearing Screening.** San Diego, CA Sponsored by: American Academy of Audiology (AAA) Contact: Tel: (800) 222-2336 ext. 206; E-mail: molek@audiology.org
April 19-22, 2001	**American Academy of Audiology — Annual Meeting** San Diego, California Sponsored by: American Academy of Audiology Contact: Tel. (703) 610-9022 Fax: (703) 610-9005
June 21, 2001	**Otitis Media and Child Development: New Perspectives on Screening, Assessment and Treatment — Telephone Seminar:** Sponsored by: American Speech Language Hearing Association Contact: ASHA's Action Center: Tel: (800) 498-2071; Web: www.asha.org
June 22-25, 2001	**16th Annual SHHH International Convention** **Freedom to Hear: Something to Shout About!** Sponsored by: Self Help for Hard of Hearing People (SHHH) Cherry Hill, New Jersey Contact: www.shhh.org
July 27-29, 2001	**The Human Genome Project and Hearing Loss** Bethesda, Maryland Sponsored by: A. G. Bell Association Contact: www.agbell.org

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May is Better Hearing and Speech Month,
HEAR's to Early Hearing Screening for all babies!