

# Management of Hearing Loss in Infants: The UTD/Callier Center Position Statement

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## Abstract

As infants are being identified earlier and earlier by universal newborn hearing screening programs, there is a need to establish principles for professionals involved in habilitative processes. Recently, a panel of experts was convened for a 2-day conference entitled "Habilitative Issues for Infants with Hearing Loss," the Bruton Conference on Audiology/Communication Sciences, UTD/Callier Center for Communication Disorders. The purpose of this document was to summarize the panel's discussions on habilitative principles, state-of-the-art practices, and future needs for infants with hearing loss.

**O**n November 9 and 10, 2000, a meeting was held in Dallas, Texas, to address habilitative issues in infants with hearing loss. This conference resulted from recent advances in neonatal hearing screening programs and the need for strategies to apply to the infants with hearing loss who are being identified. During the conference, facilitators and presenters provided their views. The following individuals participated:

### Facilitators

Arthur Boothroyd	City University of New York and San Diego State University
Marion P. Downs	University of Colorado
James Jerger	The University of Texas at Dallas

### Participants

Robert Dobie	National Institute of Deafness and Other Communication Disorders
Terese Finitzo	Oz Systems

Judy Gravel	Albert Einstein College of Medicine
James Hall III	University of Florida
Deborah Hayes	University of Colorado at Boulder
David Luterman	Emerson College
Richard Seewald	Elborn College
Jon Shallop	Mayo Clinic
Bonnie Tucker	Arizona State University

The following is a summary of the major points that were made during the meeting.

## PREAMBLE

**H**earing loss is estimated to occur in 28 million people in the United States, with an estimated 1,465,000 individuals aged 3 years or older having bilateral losses. Estimates of the prevalence of congenital hearing loss (1 in 1000 live births) are presently increasing as universal newborn hearing screening (UNHS) programs are becoming available. Current statistics suggest that in the United States, as many as 33 children per day are born with significant hearing impairment. These data may, nevertheless, underestimate the public health problem since they do not include children born with normal hearing who experience a late-onset or progressive hearing loss or, depending on the screening technology, include children with very mild hearing losses and children with nonsensory auditory disorders such as neuropathies.

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Estimates of the average age of identification of congenital hearing loss, which range up to 3 years, are also decreasing as efforts toward early identification improve and UNHS programs become more prevalent. Yet the availability of assessment and management protocols for infant hearing impairment, especially for infants only days or weeks old, remains scarce.

Currently, UNHS is mandated by legislation in 32 states. To develop a position statement regarding the management principles associated with hearing loss in infants, a distinguished panel of professionals was convened to discuss the current state of the art in the management of infant hearing loss at a 2-day conference entitled "Habilitative Issues for Infants with Hearing Loss," the Bruton Conference on Audiology/Communication Sciences, The University of Texas at Dallas/Callier Center for Communication Disorders. As infants are being identified earlier and earlier by UNHS programs, there is a need to establish principles for those involved in the habilitative process. The purpose of this document is to provide habilitative principles, state-of-the-art practices, and future needs for infants with hearing loss.

Comprehensive, high-quality programs for the assessment and management of hearing loss in infants are essential given the ongoing establishment of UNHS worldwide. To be most effective, habilitative services for infants with hearing loss should be provided through the child's "Audiology Home."

#### **THE AUDIOLOGY HOME: A FAMILY-ORIENTED SERVICE CENTER**

**A** cornerstone to the management of infants with hearing loss should be the Audiology Home. Conceptually, the Audiology Home should be a one-stop, family-oriented center providing clinical services related to audiologic assessment and intervention, family counseling and support, community outreach and education, communication intervention, outcome assessments, and documentation of progress. Because a multifaceted approach is required to optimize intervention, the Audiology Home should include a team of professionals dedicated to assisting families of children with hearing losses. The team should include, but not necessarily be limited to, professionals with expertise in audiology, communication development, counseling, education, and technology.

Professionals in the Audiology Home should meet regularly and interface routinely with the

child's medical care givers and the educational personnel involved with the families of infants with hearing loss. Regular communications updating professionals regarding the progress of an infant with hearing loss should be implemented. As the child ages, the Audiology Home should work in close coordination with the child's educational program to ensure that the intervention/ treatment considerations are optimal for the educational/training considerations.

#### **PRINCIPLES FOR MANAGEMENT OF HEARING LOSS IN INFANTS**

**M**any steps are involved in the assessment and management of hearing loss in infants. These steps include (a) accurate *identification and specification* of the degree and type of hearing loss, (b) *family/parental counseling* regarding the hearing loss to promote family acceptance and understanding, (c) appropriate selection and fitting of *sensory aid technology* and follow-up, (d) *management and counseling to promote optimal development*, and (e) *outcome assessment and documentation*.

##### **Principle 1: Identification and Specification**

Accurate identification and specification of the degree, type, configuration, and symmetry of hearing loss require a diagnostic assessment. Particular attention should be given to assessing both threshold and suprathreshold functions. Comprehensive assessment of hearing loss in infants should take into account developmental, auditory, and linguistic factors and any related syndromes or disabilities accompanying the hearing impairment. This assessment should be as close in time as possible to the UNHS. For infants with hearing loss, appropriate medical evaluations should establish the etiology of the loss, any related physical disabilities, and any recommendations for medical treatments. The assessment should conclude by setting up an appropriate monitoring schedule that ensures periodic audiologic evaluations, refining the assessment tools and the characterization of auditory function as increasing age permits.

##### **Principle 2: Family/Parental Counseling**

Counseling should provide information regarding the hearing loss, different methods of communication and education available for

infants with hearing loss, and the recommended sensory aid technology. The inevitable grief and anxiety that hearing parents experience on learning that a newborn child has impaired hearing should be appropriately recognized and addressed. A family-oriented counseling process should be elected.

### **Principle 3: Sensory Aid Technology**

Sensory aid technology should be introduced by explaining the various options of hearing aids, cochlear implants, and assistive technology. The minimal protocol for hearing aid fitting should include (1) determining the hearing aid prescription, (2) selecting appropriate aids, and (3) evaluating and confirming the overall appropriateness of the fitting for the individual infant. The limitations unique to infants should be appropriately respected, such as the restrictions on the information characterizing auditory status, the lack of helpful acoustic transformations and correction factors commonly used with adults, and the lack of an infant's ability to adjust the instrument's settings in varying acoustic environments. The selection and fitting of the hearing aid should be viewed as an integral part of the audiometric assessment and verification/monitoring process, with fitting decisions based on rigorous scientific evidence. Consideration of cochlear implant technology should take into account the types of devices approved for young children by the US Food and Drug Administration (FDA) or undergoing FDA clinical study, surgery and medical aspects related to implantation, the challenges of appropriately mapping an implant in very young children, and the amount and complexity of follow-up visits needed to monitor performance over time.

Providing sensory aids for hearing loss in young infants and toddlers is an ongoing process, necessitating multiple visits. Minimum components of the ongoing monitoring process should include (1) validating the hearing status and the appropriateness of the technology, (2) refining the description of the hearing impairment and the fitting/signal processing strategies as increasing age permits, and (3) addressing maturational changes appropriately (e.g., those characterizing the real-ear to 2-cc coupler difference [RECD]). Once fitted, monitoring visits should occur at least every 3 months and provide ongoing counseling to the family. Information regarding the status of the infant

should be provided to clinical/educational personnel working with the family and updated when changes occur.

### **Principle 4: Management and Counseling to Promote Optimal Development**

The promotion of optimal development in an infant with hearing loss begins with the family. Professionals should ensure that parents and care givers have the knowledge, skills, self-confidence, and emotional well-being to promote maximum development in infants with hearing loss. The promotion of optimal development requires that professionals specializing in habilitation of infants with hearing loss are knowledgeable regarding the impact of social-emotional, auditory, and cognitive factors on the development of communication and of literacy skills.

### **Principle 5: Outcome Assessment and Documentation**

Health care in the new millennium requires accountability. Ongoing visits need to document progress and to specify outcomes. Outcomes are multidimensional and involve all aspects of communication development.

Each of the above five principles involves separate aspects of the assessment and habilitative process, but the principles incorporate interdependent activities. Although these habilitation activities may be viewed as hierarchical, they should not be addressed in isolation; they should be addressed in a comprehensive, family-oriented, service delivery model.

## **STATE-OF-THE-ART PRACTICES**

### **State-of-the-Art Practices in the Assessment of Hearing Loss in Infants**

Hearing loss in infants should be evaluated with physiologic measures and developmentally appropriate behavioral techniques. Ear-specific estimates of the degree, type, configuration, and symmetry of hearing loss should be obtained with a test battery approach using the cross-check principle (the results of a single test are cross-checked by the results of other independent measures). The minimal test approach should include the following:

1. A physiologic measure of threshold, such as air- and bone-conducted auditory brain-

- stem response (ABR) with frequency-specific stimuli,
2. Otoacoustic emissions,
  3. Tympanometry and acoustic reflex thresholds with an appropriate probe frequency, and
  4. Behavioral assessment of the infant's responses to threshold and suprathreshold auditory stimuli, including speech.

Insert earphones are the preferred audiometric signal transducer for testing infants. A monitoring schedule of periodic audiologic evaluations should be carried out with the ultimate goals of obtaining monaural behavioral responses to pure-tone and speech stimuli with visual reinforcement audiometry (VRA). The results of VRA should be reported in a manner that respects the distinction between threshold levels and minimal response levels and whether responses were obtained with or without a formal specified psychophysical procedure.

#### **State-of-the-Art Practices in Hearing Aids for Infants**

The selection and fitting of a hearing aid should be integrated into the audiometric assessment and verification/evaluation process. A formal electroacoustic selection protocol, such as the Desired Sensation Level method, should be employed. A goal should be to make speech sufficiently audible across as broad a band of frequencies as possible, without discomfort. Toward this goal, the audiologist should accomplish the following:

1. Determine the RECD;
2. Derive the appropriate electroacoustic parameters;
3. Select an appropriate instrument;
4. Verify the fitting and final settings, preferably with coupler-based measures that account for the individual RECD transform; and
5. Evaluate aided performance immediately and regularly thereafter.

It is critical that measures be taken to ensure that the maximum output level targets are never exceeded. Parents should be appropriately counseled regarding performance expectations, maintenance and care of the devices, and the need for routine follow-up. Finally, appropriate medical evaluation is part of the assess-

ment procedure for selecting and fitting a hearing aid.

#### **State-of-the-Art Practices in Cochlear Implants for Infants**

Candidacy for cochlear implantation should be considered for infants who receive little or no perceptual benefit from hearing aids. Currently, the FDA approves implantation in toddlers who are 12 months or older and in younger children when medical conditions dictate immediate intervention (i.e., ossification following meningitis). Counseling and discussion of performance expectations from cochlear implants should be an integral portion of the evaluation process. Evaluation for cochlear implantation in very young infants and children should minimally consist of the following:

1. A physiologic measure of threshold, such as air- and bone-conducted ABR responses with frequency-specific stimuli;
2. Otoacoustic emissions;
3. Tympanometry and acoustic reflex thresholds with an appropriate probe frequency;
4. Behavioral assessment of the infant's responses to threshold and suprathreshold auditory stimuli, including speech;
5. Documentation of developmental communication progress from a therapist; and
6. Communication assessment through parental questionnaire and direct observation.

Appropriate medical evaluation is an integral part of the assessment procedure for cochlear implantation.

The selection of a cochlear implant should be integrated into the audiometric and communication assessment process. A cochlear implant selection protocol should present and review the characteristics of FDA-approved devices and descriptions of devices currently undergoing FDA consideration. Parents should be appropriately counseled regarding performance expectations, maintenance and care of the devices, and the need for routine follow-up. The mapping procedures to be followed should reflect the capabilities of technology and be routinely updated as new technology with new capabilities becomes available. A conservative approach to making speech sufficiently audible, without discomfort, via electrical stimulation should be implemented. This approach should include the following:

1. Referring to current device protocols for choice of monopolar or bipolar stimulation,
2. Using either physiologic or behavioral observations to provide multiple maps with varying parameters,
3. Providing parents with schedules to provide their child with experience with the multiple maps,
4. Interviewing and using parental reports of behaviors with the multiple maps to make further adjustments to individual maps,
5. Verifying the map parameters with objective measures, and
6. Evaluating performance after an appropriate trial (1 week to 10 days) with the multiple maps and regularly thereafter.

### **State-of-the-Art Practices in Communication Intervention**

Communication intervention should be a family-oriented experience. Families should be provided with information regarding the developmental steps involved in communication acquisition and activities that enhance such acquisition.

### **State-of-the-Art Practices in Family Counseling**

Clinicians should be prepared to provide counseling for the families of infants with hearing loss. The clinical approach should recognize that counseling is an ongoing, active process that is never fully completed. Clinicians should avoid the use of the word “failure” when discussing the audiologic conditions of an infant with hearing loss. Counseling should include the following:

1. Providing families with accurate and up-to-date information regarding the audiologic progress of the child with hearing loss, educational options, and communication options;
2. Conveying information regarding strategies for assisting families in encouraging communication development;
3. Conveying information about the importance of family bonding with the infant;
4. Providing opportunities to meet and receive support from other parents who have children with hearing losses; and
5. Providing opportunities for the acknowledgment of feelings and of the need for emotional support.

### **State-of-the-Art in Educational Issues**

Educational programs for infants and toddlers with hearing loss must address not only the needs of the child but also the entire family. A family-first approach must be taken and the educational needs of each child addressed. UNHS presents unique opportunities to prevent, rather than remediate, delays of speech, language, learning, and cognition. In addition, increasingly sophisticated assistive and educational technologies permit inclusion of children with disabilities and their families into previously inaccessible community and learning environments by the following:

1. Building comprehensive early identification and intervention systems,
2. Establishing and monitoring benchmarks and quality indicators for early intervention, and
3. Developing professional expertise in intervention services for deaf and hard-of-hearing infants, thus allowing communities to establish accountable educational programs for infants with hearing impairment.

### **State-of-the-Art Legal Issues**

Although the costs of UNHS programs may vary regionally, some estimates of the costs appear to be as little as \$25 to \$40 per infant. The benefits of early identification of hearing loss and intervention have been supported. Nonetheless, some states have no laws requiring testing, and some states that do have laws do not cover all infants. For example, in some states, the laws apply only to those hospitals having more than 50 to 200 births per year. Moreover, some laws recommend that newborn hearing screening be offered to parents, not required. Parents are sometimes unable or unwilling to pay for the testing, and very few laws require third-party payers to cover the costs for such testing. No current laws apply to babies not born in hospitals or recognized birthing centers.

The Children’s Health Act of 2000 became law on October 27, 2000. The stated goals include the following:

1. All babies born in hospitals in the United States should have hearing screening before leaving the facility,
2. All babies born in the United States outside of the hospital should have hearing screening within the first 3 months of life, and

3. All newborn and infant hearing screening programs should include components for audiologic rehabilitation and medical and early intervention options before the age of 6 months.

In addition to the above goals, the law requires that early intervention be provided through the provision of appropriate services for the child, including nonmedical services. It also requires that families be provided with a full range of support, training, and information services and the opportunity to consider the full range of educational and program placements and options.

The Americans with Disabilities Act (ADA) requires insurers to act in a nondiscriminatory fashion and further requires that employers who provide their employees and their families with health insurance benefits must ensure that such benefits are provided in a nondiscriminatory manner. In our opinion, some employer-provided health insurance policies may be found inconsistent with Title I of the ADA if they do not cover the costs of hearing aids or cochlear implants since it may appear to discriminate against persons who are deaf. Some courts have indicated a willingness to hold an employer-sponsored health insurance plan's denial of health services a violation of Title I of the ADA. Most courts have held, however, that the ADA does not govern with respect to the content of insurance policies that are not provided as part of an employment package.

The Individuals with Disabilities Education Act (IDEA) is a comprehensive law that requires states to provide services to special needs children, including those with hearing loss. Part C of IDEA provides a comprehensive means of ensuring that children with hearing losses from 0 to 3 years of age are provided with appropriate early intervention services. However, to be effective, the law must be administered effectively.

## FUTURE NEEDS

### Future Needs in the Assessment and Management of Hearing Loss in Infants

1. Further research is needed on how developmental changes in ear canal resonance may differentially affect frequency-specific ABR thresholds and RECD.
2. Further research is needed to develop appropriate clinical tools or methodologies for

assessing the suprathreshold processing of complex stimuli (e.g., speech) in infants.

3. Further research is needed to determine the reliability of VRA for infants with moderate to profound sensorineural hearing losses.
4. Additional research is needed to reduce the number of false-positive identifications of hearing loss.
5. Finally, research advances should be incorporated into clinical practices in a timely and effective manner.

### Future Needs in the Fitting of Amplification in Infants

1. Further research is needed on the selection and fitting of sensory aids in infants, including hearing aids, cochlear implants, and other assistive devices.
2. Since the majority of infants being identified through UNHS have mild to moderate hearing impairments, further research is needed on the fitting of amplification in infants with mild to moderate losses. It is also important to determine whether the amplification needs of hearing-impaired children differ from those of adults and change developmentally. It is also important to understand whether there are behaviors that indicate a need to modify the amplification. It is also important to understand if there are significant individual differences in hearing aid benefit across infants.
3. Further research is needed on overamplification and its potential consequences.
4. Further research is needed on the comparative benefits of hearing aids, cochlear implants, assistive listening devices, and vibrotactile devices, used in isolation and in combination, in infants with various degrees of hearing impairments.
5. It is important to develop policy initiatives that promote greater public awareness about and acceptance of hearing impairment.
6. Finally, research and technological advances should be incorporated into clinical practices in a timely manner.

### Future Needs in the Fitting of Cochlear Implants in Infants

1. Further research is needed to develop effective protocols for intraoperative and postoperative electrophysiologic measures.

2. Additional research is needed to develop appropriate clinical behavioral assessments of speech perception skills in young infants and toddlers.
3. Further research is needed to examine the comparative benefits of earlier versus later implantation, unilateral versus bilateral implantation, and implantation of varying degrees of hearing loss.
4. Studies exploring communication output as a means of determining auditory plateauing, limited speech perception benefit, and responsiveness to cochlear implant stimulation are needed.
5. Research and technological advances need to be incorporated into clinical practice in a timely and effective manner.

#### **Future Needs in the Counseling of Infants with Hearing Loss**

1. Training programs should include coursework and clinical experience in the counseling of families.
2. Continuing education programs should be developed and evaluated for effectiveness for training other health professionals regarding hearing loss and its impact on families.

#### **Future Needs in Legal Issues for Infants with Hearing Loss**

1. Laws requiring UNHS programs for all infants, whether they are born in hospitals with a small number of annual births, in birthing centers, or in the home, should be passed. The laws should require third-party payers to provide funding for the testing and for intervention.
2. Laws should be enacted requiring insurance companies and providers of services under any federally enacted health plan to pay for hearing aids, cochlear implants, and audiologic services for infants, toddlers, and children requiring such devices and services.
3. Provisions need to be taken to ensure that appropriate intervention services specified in the IDEA be administered effectively.

#### **Future Needs in Educational Issues for Infants with Hearing Loss**

To meet the necessary level of service, current challenges for educational programs are the following:

1. Maximize the opportunities presented by UNHS,
2. Design intervention programs to prevent, rather than remediate, delays, and
3. Use all available technology for hearing, education, and family support to meet the needs of all infants, including those with multiple disabilities and/or from minority populations.

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