

**A BRIGHTER FUTURE FOR
CHILDREN WITH HEARING LOSS**

***Closing the Gaps in
Educational and Health Care Services***

**Meeting of Representatives of Federal Agencies that
Support Programs of Services to Children with Special Needs**

**The Office on Disability
US Department of Health and Human Services**

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Introduction

The major effect of hearing loss in children who are born with the condition or become deaf or hard of hearing before learning language is its impact on the ability to communicate. With newborn screening now mandated in most states, and voluntarily implemented in many others, children with hearing loss are identified in the first weeks of life.

Research has shown that early identification, when followed by immediate intervention, provides the potential that children with hearing loss can develop communication and language skills commensurate with their hearing peers. As a result, there may be less need for specialized educational services in later years. This, in turn, enhances prospects of greater scholastic gains and more employment options. Children who are identified early, and receive appropriate early intervention services, have a high likelihood of becoming self-supporting, contributing members of society. However, there exists a gap between early identification of hearing loss and the much needed follow-up intervention.

For children with hearing loss there are many communication approaches for them to choose. Parents must decide which approach best suits their child. The choices are American Sign Language, simultaneous communication (signing and talking), and spoken language. Within each of these approaches there are a number of variations. Parents need to be informed in a comprehensive manner of the characteristics and advantages of each communication approach.

The critical time for language development is from birth to three years of age. Research demonstrates that infants with hearing loss and no other disabling conditions who receive family-centered intervention by 6 months of age are often as capable of communicating as their hearing peers by the time they enter preschool or kindergarten. Infants, toddlers, and young children who receive appropriate intervention in this sensitive and opportune time of life are able to enjoy many of the same experiences as their normal hearing peers, often avoiding many long-range rehabilitative needs.

Office on Disability Initiative

As a result of the crisis in providing effective educational and health care services to infants and young children with hearing loss, the Office on Disability of HHS is initiating a new National Effort on Closing the Gaps in Services and Programs. The Office on Disability established an HHS Working Group on Hearing Loss in Children in October 2004.

Although some states are providing appropriate services after identification, there is still much more that can be done to assist children with hearing loss and their parents throughout the Nation. First, there is the problem of “loss to follow-up” where in some circumstances, 50% of the infants who failed the screening test do not return for a full

diagnostic examination (National Center for Hearing Assessment and Management, 2004). Second, after the child is assessed as having a hearing loss, many post-diagnostic services and programs do not meet the criteria of (a) a single point of entry into the system of care for the parents and the child, (b) comprehensive and effective evidence-based programs of care, (c) coordinated programs of care, and (d) continuous programs of care. These findings emanated from a recent Conference conducted by SUNY Upstate Medical University (Consensus Conference on Effective Education and Health Care Interventions for Infants and Young Children with Hearing Loss, Alexandria, VA, September 2004). As a result the Office on Disability decided to address these problems and their solutions identified by more than 70 experts who attended the Consensus Conference.

The purpose of the May 17 meeting is to seek input to specific recommendations for closing the gaps in services from representatives of Federal agencies that are considered stakeholders in the provision of health care and educational services for infants and young children with hearing loss. This broad representation will be asked to provide input about the (a) identification of gaps in services or programs for these children and (b) recommendations for addressing these gaps.

Recommendations by the HHS Working Group and the Office on Disability

Closing the Gaps in Comprehensive *Educational* Services

Recommendation 1: Increase funding to support a specialized program within Part C to assure infants and young children with hearing loss immediate access after identification to the expertise of professionals with knowledge about hearing loss.

Problem: The point of entry in most states relies on the non-categorical services provided by Part C. It is not realistic to expect service coordinators to have the necessary specialized expertise to provide appropriate information and support to infants and young children with hearing loss and their families especially given the dramatic increase in the number of children being identified as a result of implementation of newborn hearing screening programs. Most Part C services are delivered by professionals trained to work in a non-categorical manner. However, evidence supports outcomes for children with hearing loss that are comparable to hearing peers when immediate expert intervention specific to the needs of children with hearing loss starts before six months of age.

Solution: Each state will establish an organized, well-defined, specialized, and easily-accessible system of service coordination and direct services for all infants and young children with hearing loss. Each State Part C program *will be expanded* to provide a specialized program of services for infants and young children with hearing loss. This specialized system of services will take advantage of existing services from a variety of state and local agencies and programs.

Many different groups of children have unique needs that are not addressed in a non-categorical service delivery system. Children with hearing loss represent a particularly unique group because early access to specialized services enhances prospects that these children will function at or above grade level in school.

Recommendation 2: Provide funding to support demonstration projects that identify and develop the most effective methods to inform parents about their program options and the communication approaches available for educating their infants and young children with hearing loss.

Problem: Often, parents are not informed about the variety of approaches to language and communication development. Parents may be told about the options that are available locally and may not be informed about the full continuum of options for their child because they are offered in distant locations.

Solution: Parents need to be educated in a comprehensive manner regarding the characteristics and advantages of each communication approach. Evidence supports better outcomes for children when their families make a commitment to an approach which supports their child's and their family's needs.

Recommendation 3: Increase Part C funding so that all options of communication approaches and educational settings are presented to parents. When the parent chooses a specific communication approach and educational setting for their child, it must be provided regardless of where the family lives.

Problem: Families in most communities currently have a limited range of communication approaches available to them. The most effective communication approach for a child and their family is often not made available in a family's community that, in turn, jeopardizes speech, communication and language outcomes.

Solution: Ensure that access to expertise representing the full range of communication approaches is available to every family.

Recommendation 4: Increase financial support of pre-service and in-service training for professionals working with infants and young children with hearing loss to include teachers of the deaf/hard of hearing, pediatric audiologists, and speech/language pathologists.

Problem: There is a shortage of professionals with specialization in early intervention for infants and young children with hearing loss. Training programs for these professions typically do not focus on the provision of family-centered early intervention services for children with varying degrees of hearing loss.

Solution: States and professional training programs receive Federal support to provide comprehensive pre-service and in-service training for professionals working with infants and young children with hearing loss.

Recommendation 5: Increase funding to allow states to offer a continuation of family-centered services for children with hearing loss 37-60 months of age.

Problem: If children with hearing loss receive appropriate family-centered services during the first three years of life, evidence shows that they often have communication and language commensurate with their hearing peers. Unfortunately, very few, if any, of these children continue to receive these family-centered services. The result is a diminution of the development of language, cognitive and social skills.

Solution: In order for children 37-60 months of age to continue to make this progress, family-centered services that are delivered by professionals with expertise in hearing loss are needed during these critical preschool years.

Closing the Gaps in Comprehensive Health Care Services

Recommendation 1: Pertinent Federal agencies should establish regional *Centers of Excellence* to support the provision of appropriate services to all infants and young children with hearing loss in their catchment area.

Problem: Effective health care for infants and young children with hearing loss requires a multidisciplinary team of health care (medical and non-medical) providers, collaborating and sharing their perspectives and plans to formulate the best approach to diagnosis and intervention. .

Solution: With Federal support and guidelines, Centers of Excellence for Infants and Young Children with Hearing Loss should be established in each state or region. These Centers would provide a multidisciplinary approach to hearing health; and would coordinate with the infant's medical home and with other involved health professionals. When required by distance constraints, the communications with the Center of Excellence could occur via teleconferencing, videoconferencing and other electronic means.

Recommendation 2: **With increased Federal support, expand and improve existing state EHDI/CDC (Early Hearing Detection and Intervention) tracking and surveillance systems.**

Problem: Up to 50% of infants who fail newborn screening do not receive follow-up for definitive audiological diagnostic evaluation. Follow-up rates can be improved with a tracking system. Thirty six states have a tracking and surveillance system, but many of these are incompletely implemented, or collect only aggregate, instead of individual data, or are not coordinated with other public health information systems.

Solution: Increase Federal funding to CDC and state departments of public health to fully expand the tracking & surveillance system to involve all 50 states. All systems should collect individual data starting at the point of an abnormal screen and identify all infants who do not receive appropriate follow-up.

Recommendation 3: Federal agencies should increase funding for the training of health care professionals to meet the current critical shortages of qualified professional personnel.

Problem: Since implementation of newborn hearing screening, there has been a large increase in the number of affected infants identified, leading to a critical shortage of health care professionals with the specific skills and knowledge required to provide appropriate services to these infants.

Solution: Federal funding should support additional training for practicing professionals. This could occur through continuing education programs, web-based programs, short-term focused fellowships or longer term fellowships or post-doctoral experiences. Additional training opportunities for new professionals are also needed through traditional graduate training programs and fellowships to avoid future shortages. Centers of Excellence would be important providers of these educational experiences.

Recommendation 4: Federal agencies should ensure that infants and toddlers with hearing loss have immediate and free access to appropriate hearing aids.

Problem: Hearing aids are the primary tools that allow infants and children with hearing loss to have access to spoken language. Currently, the majority of infants with hearing loss in the United States identified through universal newborn hearing screening programs do not have timely provision of appropriate personal hearing aids. Delays can be months or a year or more until an amplification funding source is identified and the application process completed. Without early access to sound, the effectiveness of early identification programs is jeopardized. The fundamental basis for early intervention programs for most children with hearing loss is auditory access. Without amplification, federal and state funds spent on early intervention for children with hearing loss are of limited benefit. With appropriate and immediate intervention, research shows that the vast majority of the children with hearing loss can develop intelligible speech in early childhood.

Solutions: A variety of strategies and methods should be explored including, for example:

- Authorization of Part C funding for personal amplification provision.
- EPSDT regulations modified to ensure provision of hearing aids (assistive listening devices) for all eligible children with hearing loss.
- Implement a procurement system such as the one used by the Veterans Administration and the Department of Defense to purchase hearing aids.
- Provide funds for demonstration projects to enable every state to establish a program for short-term loaner hearing aids to fill the gap between confirmation of the hearing loss and acquisition of the child's own hearing aid or cochlear implant.

Closing the Gaps in Research

Recommendation 1: Fund multi-site, multi-disciplinary research collaborations

Problem: Research provides a foundation for comprehensive health care and educational services by establishing evidence for effective intervention approaches, technologies, and treatments. Reaching valid conclusions for the heterogeneous population of children with hearing loss requires gathering data from large, representative samples. With the advent of newborn hearing screening, there is an opportunity to collect critical, development data on the effectiveness of treatments at younger ages than ever before.

There is a major need to strengthen the evidence base in early intervention (educational, medical, and technological). Service providers need scientific evidence in support of the cause-effect relationships between interventions instituted during infancy and the subsequent outcomes in terms of language, communication, academic and social behaviors.

Solution: Provide funding for multi-site, multi-disciplinary research collaborations to conduct studies related to intervention outcomes. Preference should be given to prospective as well as longitudinal research.

- Studies should examine the complex interactions of factors such as child, family, cultural, demographic and geographic variables and their impact on outcomes. This research agenda should address which interventions work best for which children under what circumstances.
- Many critical questions about intervention remain unanswered. For example, there is need for research to address:
 - management of infants with unilateral hearing loss
 - decisions regarding age of cochlear implantation
 - methods for supporting families from diverse cultural and economic backgrounds
 - technological advances and adaptations for infants and young children
 - Impact of child maltreatment, substance abuse, and domestic violence

Recommendation 2: Increase the number of scientists who investigate questions about infants and young children with hearing loss.

Problem: There is a need for increased expertise to study the unique developmental needs of infants and young children with hearing loss. Additional emphasis should be placed on translational and outcomes research related to early intervention. Furthermore, the existing research community would benefit from training allowing them to adapt infant research paradigms used in the developmental sciences to infants with hearing loss.

Solution: Federal Agencies should support research training, including work in established infant development laboratories. Support for these scientists includes:

- Post doctoral fellowships
- Interdisciplinary research mentoring
- Fellowships for established researchers to learn new tools

Recommendation 3: Fund translation of existing research knowledge on infants and young children with hearing loss into practice.