

# Success of infant screening creates urgent need for better follow-up

By Judith Nemes



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**T**he old adage, “Be careful what you wish for, you might get it,” is the cautionary refrain heard among many professionals engaged in early hearing detection and intervention for newborns and young children.

In the few short years since state legislatures across the U.S. began mandating that hospitals screen all newborns for hearing loss, we’ve reached the point at which more than 90% of the infants born in the U.S. are undergoing routine hearing screenings before leaving the hospital, according to preliminary 2004 data from the Centers for Disease Control and Prevention.

But, while the relatively new universal newborn hearing screening initiative is being hailed as a great achievement, its real success cannot be measured until follow-up programs are fully implemented so that those babies who require diagnostic workups and intervention actually get the care and services they need from pediatric audiologists and other caregivers in a timely manner, experts say.

And that’s easier said than done, they add.

“The screening was the easy part,” observes Judith S. Gravel, PhD, director of the Center for Childhood Communication at Children’s Hospital of Philadelphia (CHOP) and a longtime advocate for improving hearing detection and services for newborns and infants. “We were so focused on [implementing] screening that few of us were really cognizant of how difficult the next part would be.”

Almost overnight, thousands of infants were failing the initial screenings before hospital discharge and, as a result, requiring follow-up evaluations. Those who were then identified with hearing loss needed fittings for hearing aids or other types of intervention.

Indeed, about 2% of all infants born in the U.S., or about 80,000 babies in 2005, failed their hearing screening and needed further attention to their potential hearing problem, according to the National Center for Hearing Assessment and Management (NCHAM), a Logan, UT-based research group that is a critical resource for early hearing detection and intervention (EHDI) programs around the country. Karl R. White, PhD, director of NCHAM, which is also affiliated with Utah State University, estimates that between 8000 and 12,000 of the 80,000 infants who failed the initial screening would ultimately be diagnosed with some degree of congenital hearing loss.

## MANY SLIP THROUGH THE CRACKS

Unfortunately, many families with infants who fail a screening quickly learn the sad truth that few—if any—pediatric audiologists are available in their communities to provide the necessary diagnostic follow-up. Or often, White explains, their pediatricians don’t know enough about early detection to make proper referrals in a speedy fashion. For those reasons and others, thousands of young children are falling through the cracks and failing to reap the benefits that early detection was intended to offer.

In fact, the Centers for Disease Control (CDC) reported that in 2003 only 55.2% of newborns and young children who failed a hearing screening received an audiologic evaluation soon after, says John Eichwald, an audiologist and team leader for the EHDI team at the CDC’s National Center on Birth Defects and Developmental Disabilities in Atlanta.



Why are so many of those identified as at risk being lost before they get to the critical next stage? The reasons are multiple and complex, according to professionals working in this area. They include the following:

- ❖ There is a severe shortage of pediatric audiologists skilled at evaluating infants and fitting them with hearing aids.
- ❖ In their professional education, audiologists receive too little training in the skills required to care for the very young.
- ❖ Inadequate reimbursement may deter some audiologists from providing such services.
- ❖ Many physicians aren't well enough informed to make the necessary referrals for infants who need diagnostic evaluation.
- ❖ Many states don't have adequate data systems to track and manage the reported cases of failed screenings.
- ❖ Many states lack adequate programs to offer appropriate services to the majority of infants who are diagnosed with milder forms of hearing loss.
- ❖ Many families do not understand the profound consequences for their child if he or she has a hearing loss that is not diagnosed and treated very early.

### PROBLEMS BEING ADDRESSED

The big problems have been identified and efforts are under way on many fronts to bridge the gaps that currently exist in follow-up care. The good news is that most of the stakeholders know there are significant problems and they are working diligently to weave a secure safety net for the infants and young children who fail newborn hearing screening.

In February, about 500 people gathered in Washington, DC, at the 2006 Early Hearing Diagnosis and Intervention (EHDI) Conference. The meeting centered primarily on ways to improve the follow-up aspect of early hearing detection and intervention, reports White, whose group was a co-sponsor of the event along with the federal Bureau of Maternal and Child Health, the American Academy of Pediatrics, and the CDC.

This article will explore some of the challenges and opportunities facing the audiology profession in dealing with permanent hearing loss among infants and young children. Hearing health-care practitioners can play a vital role in speeding up the process to get critical diagnoses and services to the kids who desperately need them.

"The gap between identification of hearing loss and enrollment in a hearing loss program should be as small as possible because those months are critical," says Gravel, who also serves on the Joint Committee on Infant Hearing, a national group of experts culled from a multitude of professional organizations focused on hearing issues for young children. "If we lose follow-up, we lose precious time."

### MORE PEDIATRIC AUDIOLOGISTS NEEDED

Many who work in the EHDI arena say the greatest barrier to follow-up care is the shortage of audiologists sufficiently skilled in providing diagnostic and intervention care to infants and young children.

Until recently, there was not an enormous demand for pediatric audiologists, and there was even less for ones trained in working with the youngest of that population. For professionals who chose to specialize in pediatrics, most of their training and work

involved older children who could give reliable behavioral responses to tests and were old enough to cooperate in a test situation, says Jackson Roush, PhD, professor and director of the Division of Speech and Hearing Sciences at the University of North Carolina School of Medicine.

"Infant audiology management is a relatively new thing, even for pediatric audiologists," Roush explains. "We haven't been identifying hearing loss at birth for very long, only in the last few years, and suddenly in growing numbers. Even experienced pediatric audiologists are finding new challenges in identification at birth."

Many pediatric audiologists don't have enough training in working with the newborn population, says Anne Marie Tharpe, PhD, an associate professor at Vanderbilt University's Bill Wilkerson Center for Otolaryngology and Communication Sciences. She says that audiologists need in-depth knowledge of causation of hearing problems in newborns, the risks, the diagnostic process, and the rehabilitative piece.

Tharpe, who also is associate director of education for the National Center for Childhood Deafness and Family Communication within the Wilkerson Center, adds, "Many audiologists are uncomfortable working with infants and young children because they can't tell you what's going on. You need a different diagnostic mindset, because you don't get the feedback" with this population.

What's more, she says, the kinds of skills audiologists need to care for the pediatric population—and the youngest patients in

particular—are much broader than those used with adult patients, who usually just need fittings for amplification to improve their hearing. In pediatric work, she explains, audiologists also must coordinate their services with early interventionists, speech-language pathologists, primary healthcare providers, and state and federal agencies. In addition, caring for infants requires an understanding of the EHDI programs in the state and federal Part C early intervention

programs, which are administered under the federal Individuals with Disabilities Education Act.

There are no hard data on how many audiologists already are providing services to infants. Currently, there is no certification for pediatric audiologists and state agencies compile referral lists based mainly on self-reports from practitioners who say they have the appropriate skills. But it's generally agreed there is a critical shortage of hearing care providers in the U.S. with the expertise, experience, and equipment to do diagnostic assessments of the infants who fail their newborn hearing screenings.

NCHAM's White adds, "At least 75% of the states are really struggling with connecting babies who failed the newborn tests to a quick audiological evaluation."



*Jackson Roush*



*Anne Marie Tharpe*



## NEW DEMAND FOR TRAINING PROGRAMS

Currently, few of the university AuD programs offer much pediatric training beyond a required course or two, says Tharpe, who adds that a very few universities permit students to specialize in pediatrics, but with little or no emphasis on infants.

That's changing, she says, in part because of the newly identified need for training and more recent funding availability. In addition, Tharpe, who sits on Vanderbilt's AuD admissions committee, has noticed in the last 5 years more students are expressing interest in pediatric audiology because of the newborn screening programs and the growing use of cochlear implants in infants.

This January, Vanderbilt unveiled a new specialty track concentration in early identification and management of infants and children with hearing loss for its AuD students. The university has had training grants for early intervention in the past, but this new initiative establishes a permanent program bankrolled by a private foundation.

AuD students, along with deaf education majors and speech-language pathology students enrolled in this program, will take up to eight courses in the area of pediatrics, work as weekly volunteers in the university's National Center for Childhood Deafness, and engage in a clinical practicum that includes exposure to infants and children, Tharpe says. They also will participate in a 1-month intensive clinical training session focusing solely on infants and young children.

The University of North Carolina received a grant last fall from the US Department of Education for training AuD students in pediatric audiology, says Roush. The grant will fund seven students a year over the next 4 years to receive specialized coursework and clinical education related to early identification and intervention in infants and young children. Roush says the funding will be targeted primarily at preparing students to work with infants, since the university already offers a significant amount of training in audiologic care for older children.

The Department of Education is providing similar funding to three other AuD programs: those at Vanderbilt, Gallaudet University in Washington, DC, and a collaborative program of two schools in Ohio—the University of Akron and Kent State University.

While a few universities are implementing pediatric specialties, Roush cautions that many AuD programs will have limited ability to offer such training because they lack the faculty expertise or availability of clinical settings for students to acquire hands-on experience. He recommends that university programs lacking the resources for pediatrics develop partnerships with institutions that have them.

Practicing audiologists who want to gain the skills and knowledge to work with infants and young children have some continuing education opportunities available to them.

For the past 3 years, NCHAM in Utah has offered in-service pediatric audiology training programs consisting of 6 to 8 weeks of online training and discussion groups, followed by 2 or 3 days of intensive hands-on training at several sites, says White (more information is available at [www.infanthearing.org/workshop/index.html](http://www.infanthearing.org/workshop/index.html)). More than 450 audiologists have completed this training, but White cautions that it provides only the beginning knowledge and expertise needed to do pediatric assessments and hearing aid fitting.

The Colorado State Health Department offers training sessions for audiologists to gain a core group of skills, says Albert Mehl, MD, a pediatrician at Kaiser Permanente in Lafayette, CO, and chairman of the American Academy of Pediatrics' Task Force on Improving Newborn Hearing Screening. Audiologists who complete the training session often are added to a list of professionals that EHDI coordinators in the state use as referrals for families seeking follow-up care. Mehl notes that public health agencies in other states may be offering or planning similar training programs.



*Albert Mehl*

In another example, the University of North Carolina has formed a partnership with the state's Public Health Department to provide a joint continuing education symposium in pediatric audiology. Since it began 4 years ago, 80 audiologists or AuD students have participated.

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## GUIDELINES UNDER DEVELOPMENT

AuD program administrators around the country may be reluctant to add a specialty track in infant hearing care because the skill set required for the work is not well defined. As a result, they may not know what kind of training to include, says Judith Gravel of the Children's Hospital of Philadelphia. Pediatric audiologists currently evaluating infants who fail the initial screenings aren't all using the same diagnostic equipment to determine if the child should proceed with intervention, she says.



*Judith Gravel*

For example, many practitioners employ the auditory brainstem response (ABR) as a diagnostic tool, but new technologies are being introduced all the time, explains Gravel. One newer device in particular, the auditory steady state response (ASSR), is being used more widely, but it may not yet be well understood how multiple instruments fit together into the wide range of testing possibilities, she cautions.

"The challenge for us right now is that the data for use of the equipment with infants are still insufficient so we cannot abandon one measure in favor of another," Gravel says.

Such inconsistencies and the need to outline some basic skills required for infant diagnosis and intervention have many people calling for a roadmap, she says. As a result, several efforts are under way to craft guidelines for audiologists—as well as for state agencies and physicians making referrals—so they have a solid baseline of skills to perform the job well.

Gravel notes that the Joint Committee on Infant Hearing is developing a new position statement that will focus on follow-



up diagnostics and intervention for young children who fail an initial hearing screening. Specifically, JCIH will consider which audiometric test battery to recommend for use in infants from birth to 6 months of age, then for infants and young children 6 months to 3 years. Separate recommendations for other professionals involved in the intervention process will also be included. The position statement will be published later this year.

Focusing specifically on the audiology community, the American Speech-Language-Hearing Association (ASHA) recently completed a set of guidelines outlining the roles, knowledge, and skills required for audiologists who provide services to infants and children with hearing loss, reports Vanderbilt's Tharpe, who serves on the committee that wrote the guidelines.

The document outlines the three roles audiologists should play if they want to provide services to young children. They are: diagnostician, counselor, and audiologic care coordinator, says Tharpe. The guidelines list the background knowledge and skills in each of those three areas that an audiologist should possess. The document will be available online to professionals and consumers later this spring.

### SEPARATE CERTIFICATION SUGGESTED

While voluntary guidelines can help define the baseline recommended skills for audiologists, some see a need for a specialized certification or license in pediatric audiology that would serve as a more stringent measure of qualification. Certification could more clearly define the skills required to care for infants and young children, and provide assurances to state agencies, referring health-care providers, and families looking for qualified practitioners that certain audiologists are fully qualified for the difficult task of providing professional services to infants and young children, says NCHAM's White.

The American Academy of Audiology (AAA), which created a set of pediatric amplification guidelines across a wide age range of children in 2003, has been exploring the establishment of a specialty certification in pediatric audiology.

The American Board of Audiology (ABA), which is closely associated with AAA, is in the developmental stage of creating a specialty certification for pediatric audiology and hopes to make it available in about 2 years, says Sara Lake, the ABA's director. In a survey the ABA conducted last year, about 78% of the 1217 audiologists who responded agreed that pediatric audiology should be considered a specialty area and 76% of that subgroup indicated an interest in obtaining certification if it was offered, says Lake.

She notes, "Any specialty certification would be voluntary, but it would be helpful to consumers and helpful to professionals to identify the skill set they need."

### POOR REIMBURSEMENT IS A DETERRENT

One factor that undoubtedly discourages some audiologists from pursuing work with children—and with infants and toddlers in particular—is economic, notes White. Between the high cost of care and equipment and the generally low rate of reimbursement by Medicaid and private health insurance companies, some audiologists who would otherwise be interested in getting involved in his area may wonder if they can afford to.

During a recent meeting with Medicaid staff and EHDI coord-

inators from a representative sample of 10 states, White broached the subject of inadequate reimbursement for some diagnostic audiology tests.

For example, he says, visual reinforcement audiometry (VRA), widely recognized as the "gold standard" for diagnosing hearing loss in children 9 to 15 months of age, requires \$50,000 worth of equipment and an assistant to help administer the test, which takes about an hour. Yet, he notes that the average reimbursement rate across

the 10 states in 2005 was only \$19.66. Worse yet, the average reimbursement rate actually declined by 5% from 2000 to 2005. "It's no wonder audiologists aren't flocking to this part of the practice," White says dryly.

Medicaid officials informed NCHAM that the only way to raise reimbursement rates would be for audiologists to band together and protest loudly enough for Medicaid program administrators to consider adjusting them.

But even if the audiologist is better reimbursed for a portion of the tests given to young children, other time committed to their care may not be reimbursed at all, says White. Audiologists have to work with a vast network of professionals to coordinate care for the infant in need of hearing care services. That means spending time in intensive meetings and follow-ups with the family. Little of that meeting time is reimbursable, he notes.

Despite the financial barriers, White is confident that more audiologists will pursue early intervention care for young children because of the tremendous benefits they bring to those kids. "There are professionals out there who care deeply about serving other people and are willing to work with these kids even though the reimbursement is so poor," he says.

### LINKS WITH PHYSICIANS ARE CRUCIAL

Before an audiologist can provide a thorough hearing evaluation to an infant who failed the hearing screening, a physician or state EHDI coordinator must point the child's family in his or her direction. Typically, the pediatrician or family practice doctor is the first healthcare provider to learn that an infant has failed a hearing screening. But, all-too-many physicians do not yet appreciate the urgency of early intervention and so may be complacent in recommending appropriate and speedy referrals to audiologists, observes Mehl, whose efforts on the AAP task force for the last 5 years have included physician education and promoting coordination between doctors and audiologists.

The task force has distributed more than 50,000 copies of educational material to pediatricians and family physicians around the country over the last 2 years to inform them of the benefits of early intervention and information on where to send patients for referral care. And while many physicians may have built-in biases about referring patients to their ENT physician colleagues for hearing care, Mehl says the task force and designated pediatricians in each state are making inroads at convincing physicians that audiologists and state EHDI coordinators may have the most up-to-date information and skills to provide aggressive care for young children that need it.



Karl White



"We have to develop a collegial relationship between the audiologist and the physician rather than continuing a neutral or adversarial relationship," Mehl asserts. "Audiologists have been the champions for educating the medical community about improved outcomes for young children. Fortunately, most physicians are responding positively."

Pediatric Medical Group, a national physician-based group that screens about 300,000 newborns a year in the hospital for hearing loss, takes on the role of facilitator by contacting primary healthcare providers to let them know about babies that fail the initial screen, says Gail Lim, vice-president of program development and clinical director of the Newborn Hearing Screening Program based in Sunrise, FL. They also assist in connecting the families with a community audiologist, says Lim. The group, which started its program in 1994, provides a model for bridging the gap between screening and intervention to ensure newborns who fail the screen don't get lost in the system.

### BETTER TRACKING SYSTEMS NEEDED

The CDC has awarded funds to 30 states and territories to develop data systems for newborn hearing screening tracking and surveillance so professionals engaged in EHDI programs can monitor their progress, says Eichwald of CDC. An important part of that effort is to integrate the state EHDI data systems with other child health information systems (such as newborn blood screenings and immunization registries) to develop a comprehensive child health profile. Compiling a profile that contains the "big



John Eichwald

picture" of a child's overall health status can help healthcare providers, audiologists, and other caregivers make sure young children don't fall between the cracks in receiving various kinds of follow-up care and intervention they might need, Eichwald explains.

So far, the CDC data show that almost half of the infants who should be receiving follow-up care after failing a hearing screening aren't showing up for those evaluations. However,

Eichwald cautions that a higher percentage of children may actually be getting evaluated, but not counted because some audiologists and other providers are failing to report all their evaluations. He urges audiologists to report all diagnostic results for the infants and young children they see after failing an initial screening, even when they find no significant hearing loss that requires intervention.

"Audiologists are a key component in the success of these EHDI programs because they need to help us gather accurate information so we can share it with all parties involved," he says. Audiologists and other caregivers engaged in EHDI can find more information on the subject from links on the CDC's web site, [www.cdc.gov/ncbddd/ehdi](http://www.cdc.gov/ncbddd/ehdi).

### OBSTACLES ARE NOT INSURMOUNTABLE

Narrowing the chasm between screening newborns' hearing and getting those who fail the audiologic evaluation and possible intervention they need must seem a daunting task. Indeed, the road ahead in the near term is fraught with obstacles and challenges. However, most stakeholders are optimistic that the barriers currently impeding successful implementation of these programs and services will be overcome.

Karl White at NCHAM predicts that it may take another decade to get to a point where all those who need follow-up will get the right services as quickly as they should. Judith Gravel and many of her professional colleagues are confident that more audiologists will pursue pediatric specialties and meet the growing demand for hearing care at the earliest stage of life.

Besides, the AAP's Albert Mehl predicts many caregivers will jump at the chance to make a difference in children's lives once they learn how dramatically their quality of life can be changed if hearing loss is identified and addressed aggressively in the first 2 years of life.

"It's not often in our careers that we experience major change in the care we're providing that can prevent the poor outcomes we've seen in the past," Mehl says with passion. "Audiologists used to work with kids who would have poor language outcomes no matter how much service they provided because they got to them too late. Now they have an opportunity to get to them early enough to change that outcome."

Judith Nemes is a freelance writer based in Chicago and a regular contributor to *The Hearing Journal*.

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