



SOUND IDEAS

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Some babies are born listeners . . . Others need your help.

What is the best equipment to use for newborn hearing screening?

The first principle listed on the Joint Committee on Infant Hearing (JCIH): Year 2000 Position Statement, Principles and Guidelines for Early Hearing Detection and Intervention Programs states:

All infants have access to hearing screening using a physiologic measure.

What does physiologic measurement mean? This means the hearing is screened by a scientific, objective measurement versus a subjective measurement.

OAE and ABR are both acceptable screening tools, and each tool is capable of providing an objective automated interpretation of hearing status at the completion of the test.

Hearing screening equipment falls under two general types: Otoacoustic Emissions (OAE)—transient or distortion product—and Automated Auditory Brainstem Response (AABR). Neither type of hearing screening equipment is a direct measure of

hearing. Instead, each one measures slightly different physiological mechanisms which are related to hearing. OAE and ABR are both acceptable screening tools, and each tool is capable of providing an objective automated interpretation of hearing status at the completion of the test.

OAEs provide information up to and including the cochlea. There is substantial agreement that transient otoacoustic emissions will be detected if hearing threshold is 25 dBnHL or better. The advantages of OAE screening are:

- It only requires a small probe.
- Time to conduct the screening is usually very fast.
- Supply costs are low.

The technology is now available in handheld units. Reported costs range from \$8 to \$30 per infant, with supply costs running about \$1 per baby. This type of equipment is also very flexible and can be used to screen hearing with children and adults. The relative disadvantage is that more tests might need to be done—the percentage of infants who do not pass is higher, around 3-12%, with an average referral

rate at hospital discharge of about 7%. It may take more practice to use OAEs well. Also, children with neural or central auditory pathology may pass. Although definitive prevalence data are not available, most experts agree that such neural losses represent less than 1% of all children with hearing loss.

The AABR provides information about the auditory pathway up to the brainstem (including the middle ear, inner ear, and VIII nerve). As used in most programs, a 35dBnHL click stimulus is used. Thus, children with very mild sensory hearing losses (25 or 30 dB) might be missed. AABR screening also has several advantages:

- Generally requires less practice to use.
- It may detect neural or central auditory pathologies.
- Referral rates at time of discharge are usually lower (1-8%, with an average of about 4%).

The relative disadvantage is that reported costs are higher compared to OAE (from \$20 to \$75 per baby), with supply costs running about \$5 to \$10 per baby. You must apply electrodes to the newborn's scalp to record the brain activity, and it may take a little longer to complete a screening test.

It must be emphasized that every screening site is individual and unique. Other factors to consider when deciding on what equipment to buy are:

- Who will be doing the screening?
- Do you have a large or small birthing census?
- Some larger sites use both technologies for hearing screening.
- Will the data

management software you plan to use work with the equipment you plan to purchase?

In other words, **there is no one correct answer.** To help you think about the issues involved in selecting screening equipment,

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Linking EHDI and IDEA Part C programs

Hospitals and state departments of health continue to struggle with completing audiological evaluations of newborns being referred from hospital-based hearing screening programs. According to Dr. Margaret Lubke at the National Center for Hearing Assessment and Management (www.infanthearing.org), one source of assistance which is frequently not used as much as it could be is Part C of the Individuals With Disabilities Education Act (IDEA). This federal law requires states to provide appropriate education and related services to all children with disabilities. Part C of IDEA requires states to provide certain services to birth to 3-year-old infants and toddlers.

The following excerpt from 34.C.F.R. Part 303.321 describes the Comprehensive Child Find System required by the law:

(b) **Procedures.** The Child Find System must include the policies and procedures that the state will follow to ensure that...

(1) All infants and toddlers in the state who are eligible for services under this part are identified, located, and evaluated... The procedures required in paragraph (b) (1) of this section must:

- (i) Provide for an effective method of making referrals by primary referral sources.
- (ii) Ensure that referrals are made no more than 2 working days after a child has been identified.

- (iii) Include procedures for determining the extent to which primary referral sources, especially hospitals and physicians, disseminate the information—as described in Sec. 303.320—prepared by the lead agency on the availability of early intervention services to parents of infants and toddlers with disabilities...

(e) **Timelines for public agencies to act on referrals.**

- (1) Once the public agency receives a referral, it shall appoint a service coordinator as soon as possible.
- (2) Within 45 days after it receives a referral, the public agency shall...
 - (i) Complete the evaluation and assessment activities in Sec. 303.322, and
 - (ii) Hold an IFSP meeting in accordance with Sec. 303.342

According to Lubke, “This means that the lead agency in the state for Part C of the IDEA program is responsible to ensure that evaluations are completed for all children for whom there is suspicion that a disability might be present. Although states can set their own criteria for what constitutes sufficient reason for suspicion, most people would agree that failure to pass a newborn hearing screening test constitutes sufficient grounds for thinking that the child might have a hearing loss.

When a child does not pass what the hospital or state department of health has defined as the continued, page 5

THE WEB

www.infanthearing.org

Want to know what is happening where you live?

Get to know your area's early hearing detection and intervention (EHDI) profile at <http://www.infanthearing.org/states/index.html>. This information will keep you current on the state of EHDI and let you know about current events where you live!

- Who is your EHDI contact?
- Which hospitals are performing universal hearing screening where you live?
- What are the screening statistics for your area?
- What information is available for families in your area?
- What is happening in other areas, such as American Samoa, Guam, and the Virgin Islands?

These Web sites are frequently updated to provide the latest in information as well as links to sites already established in your area. Check it out on the Web!



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WE'RE ELECTRONIC!

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

What is a medical home & what does it have to do with Early Hearing Detection & Intervention (EHDI)?

The Maternal and Child Health Bureau—as a part of their efforts to promote universal newborn hearing screening, diagnosis, and intervention—has encouraged that EHDI services be linked with a medical home. This is consistent with the JCIH 2000 Position statement:

Pediatricians act in partnership with parents in a medical home to identify and access services needed in developing a global plan of appropriate and necessary health and habilitative care for infants identified with hearing loss.

The American Academy of Pediatrics believes that all children should have a medical home where care is accessible, family-centered, continuous, comprehensive, coordinated, compassionate, and culturally competent. Let's consider how this applies to EHDI programs.

Accessible

The hearing screening test is only one part of a comprehensive EHDI program, but it is important that it be available to all newborns. This is what "accessible" means—that all babies, regardless of the family's ability to pay or geographic location, will be able to obtain EHDI services.

Family-Centered

A screening program should provide appropriate educational materials and hearing screening results to the parents and pediatric health-care professional upon completion of the hearing screening. These materials should be provided in a format which is understandable, culturally appropriate, and sensitive to the situation and concerns of the family. Having printed materials in different

languages is an important part of this goal, but there are other issues. In every situation, parents should be made to feel that they are an important part of the process, that their input is valued, and they should be treated with respect and sensitivity.

If further audiological testing is necessary, the medical home provider should tell the parents about audiologists in their community who can provide comprehensive audiologic assessment. (The audiologist should be a pediatric audiologist with equipment available to do comprehensive audiological evaluations with the pediatric population.)

Continuous

The audiologist works in conjunction with the family and the infant's medical home provider to provide continuous audiological care. In other words, services should be provided in a way that transitions between care providers are rapid, smooth, and considerate of the family's time and resources. For the early intervention component, audiologists provide timely fitting and monitoring of amplification with family consent, family education, counseling, and ongoing participation in the infant's service plan.

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TECHNIQUES AND TIDBITS

I have a referral!!! What do I say? What do I do?

Ideally, communication regarding hearing screening performed in the hospital should begin in the prenatal classes. Parents should not be surprised to hear that their infant was screened for hearing loss. Educating parents early diffuses fear and misunderstanding about newborn hearing screening procedures. Some points to remember are:

- 1 ALWAYS** be sure that the parents of each newborn who does not pass the hearing screening are informed in person of the test results by a well-trained screener, audiologist, or managing nurse/physician. Tell the parents that their baby did not pass the hearing screening test. Explain that he/she may not have passed the screen because of debris in the ear canal, such as vernix or moisture. If this is the case, it may be preventing the baby from hearing as they should and needs to be rechecked by an audiologist to see if it clears. If debris is not the cause, the audiologist will be able to better determine the problem at that follow-up visit.
NEVER SAY... "Fluid in the ear caused the baby to fail the hearing screening." (You do not know that to be true!)
"This happens all the time, don't worry."
"The equipment wasn't working." (Unless that is really the case.)
"The baby was fussy, and we couldn't do it."
"Your child may have a hearing problem." (This is only a screening test!)
- 2** The parents should be provided educational materials regarding the screening procedures and what the results mean. They should also be provided educational materials concerning normal developmental milestones for infants and toddlers.
- 3** The parents should be provided with a plan regarding follow-up services. (A list of pediatric audiologic care providers can be provided.)
- 4** An appointment for follow-up services should be scheduled as soon as possible after discharge from the hospital. This may be done by the hospital program manager for universal hearing screening or by the infant's medical home provider.
- 5 ALWAYS** encourage the parent to keep their follow-up appointment!

American Academy of Pediatrics advocating for EHDI programs

Recently, the National Campaign for Hearing Health sponsored Hearing Healthy Kids' Day on Capitol Hill in Washington, DC. The event was attended by members of Congress, staff from the Department of Health and Human Services, and various national organizations. The following remarks were made by Dr. Louis Cooper, MD, FAAP, who is currently serving as the president of the American Academy of Pediatrics. His remarks underscore the progress made during the last few years and emphasizes the need for various groups to work together to develop effective EHDI programs.

Thanks for the privilege of being here to learn of the progress toward Universal Newborn Hearing Screening

Increasing the number of newborns screened for hearing loss from 25% to 65% in less than 2 years is a remarkable achievement.

(UNHS) just reported to you by Dr. Karl White. Increasing the number of newborns screened for hearing loss from 25% to 65% in less than 2 years is a remarkable achievement. On behalf of the

55,000 members of the American Academy of Pediatrics (AAP), we congratulate all who have helped in making such dramatic progress!

The American Academy of Pediatrics was founded 71 years ago with a simple, clear mission: To work for the optimal physical, emotional, and social health of all children. We have not—and will not—waiver from that mission. Securing optimal hearing health for every child—the mission of our hosts, the National Campaign for Hearing Health—is receiving our Academy's full support.

As many of you know, the Academy has participated actively in the Joint Committee on Infant Hearing, has a policy statement describing and fully supporting UNHS, and has sent model legislation to each of its state chapters to help pediatricians work within their own states and communities toward our shared goals. (EDITOR'S NOTE: Copies of these materials are available at www.aap.org.)

But I must tell you that for me, this is not just another of our important clinical, advocacy, and educational campaigns. My life and my family's life have been profoundly impacted by congenital deafness. Thirty-seven years ago, I was working to develop a rubella vaccine when a major epidemic swept across the United States. In New York, because of the special techniques developed by our lab, we saw many pregnant women and then their babies, hundreds of whom were deaf. Time does not allow me to share with you the lessons I have learned from being part of those families' lives for over three decades,

but let me focus on two aspects of the story, not well-known but very relevant today.

First, the role of the pediatrician is unique. S/he is the only professional working with the family from the moment of each baby's birth. Who else can help the family understand what screening results mean, the importance of proper diagnosis and how to get it, and can advocate for the early intervention services essential to making screening meaningful? In fact, absence of services after screening can be a cruel hoax.

Second, our pediatricians are not equally skilled in these tasks, and the AAP's mission includes helping our members be absolutely current about the new science around hearing loss. We must be sure every child has that kind of medical home.

The federal role in the federal/state/public/private/professional and family partnership is critical. States need federal financial help and technical assistance. Successfully implementing newborn hearing screening programs will be difficult. Our experience after the rubella epidemic of 1964 is instructive. At that time, our country had perhaps 20,000 new deaf infants. In places like New York, with long traditions of services for children with hearing loss, we were able to expand services for many infants, but we had no place for those who were both deaf and blind. In fact, we discovered there were service slots available for only about 400 children across the United States. A small group of us presented the problem to Congress, and a bill was passed in 1967 to create Centers and Services for Deafblind Children. That allowed a dramatic increase in services, so that within 3 years, over 4,000 children were getting multidisciplinary services—and that program exists today with over 10,000 children included. It couldn't have been done without the federal support which catalyzed state and local effort. In the same way, the funds allocated last year to the MCHB and CDC to assist with the implementation of statewide newborn hearing screening, and intervention programs must be preserved and expanded if we are to ensure we will be able to find and appropriately serve the 33 babies born every day with hearing loss. We have no time to lose.

The presence here today of staff from Secretary Thompson's office, whose own state has some model programs, and distinguished members of Congress speaks to federal recognition of what needs to be done. On behalf of the AAP, I am here to celebrate the progress and to pledge our full commitment to the work that remains.

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What is the best equipment . . .

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you may want to go to <http://www.infantheating.org/resources/equipment/index.html> where you can download a table summarizing how different types of equipment fare on various criteria.

Ultimately the most important decision is to make a decision and move forward. Successful hearing screening programs are functioning throughout the world using both types of screening equipment. Do not wait for the next, newer model to come out before deciding to purchase your equipment. As in computers, changes are a way of the industry. You can be certain that the equipment you buy today will be successful and last a number of years before you will need to replace it. By delaying, you delay identifying infants with hearing loss. That would be the worst decision of all!

Linking EHDI and IDEA . . .

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complete hearing screening test, the agency responsible for Part C must make sure a referral for a complete evaluation is made within 2 working days, and the evaluation (including the complete diagnostic audiological evaluation) is completed within 45 working days.

This point is emphasized by the Year 2000 Position Statement from the JCIH as follows:

In accordance with the Individuals With Disabilities Education Act (IDEA), referral to a public agency must take place within 2 working days after the infant has been identified as needing evaluation. Care can be facilitated by involving a public agency, as the role of this agency is to appoint a service coordinator; identify an audiologist to complete the audiologic evaluation, and identify other qualified personnel to determine the child's level of functioning.

Unfortunately, many newborn hearing screening programs are not taking advantage of the assistance available from Part C programs. This is probably because many statewide newborn hearing screening programs have been developed in different agencies than those responsible for implementing the Part C programs.

Coordinating the Part C is not a quick fix for the difficulties people have had completing diagnostic evaluations for babies referred from screening programs. However, it is an important part of the solution. By working together and using the experience and expertise of Part C, programs can substantially increase their ability to diagnose all hearing loss by 3 months of age.

A listing of Part C coordinators in each state is available at www.nectas.unc.edu/contact/ptccord.html.

Medical Home . . .

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Comprehensive

In partnership with the infant's medical home provider, the family is linked to support, educational, and community-based where information is centralized. Information and contacts concerning alternative educational opportunities for the deaf or hard-of-hearing child is also made available. Information about other recommended services (e.g., ophthalmology, genetics, social services) should also be provided in an understandable and appealing format.

Coordinated

Children with hearing loss often need many different types of services. Unless these services are coordinated, it can be frustrating, unnecessarily expensive, and confusing for families. The medical home provider can help families navigate the services provided by audiologists, early interventionists, speech pathologists, and other medical specialists. Because many physicians are not aware of advances in audiology during the last few years, audiologists can play a crucial role in helping them understand what services are available and needed.

Compassionate and culturally competent

The goal of accessing all the medical and nonmedical services needed to help these deaf or hard-of-hearing children achieve their maximum potential cannot be reached without factoring in the family's emotional state throughout the process and recognizing cultural issues. For example:

- An EHDI program manager and pediatric health-care professional may be surprised to have deaf parents who are disappointed their newborn child passed the hearing screen. Such reactions should not be criticized.
- It is important to recognize that deaf parents often have concerns that need to be addressed. For example, they may be wondering how they will communicate with their child and may have concerns about their child not being a part of their "deaf culture."
- An audiologist may be surprised when deaf parents refuse to have hearing aids placed on their newly identified, severely hearing-impaired infant. The audiologist needs to accept that the parents has the right to their views.
- Some infants develop profound sensorineural hearing loss due to medical emergencies during the newborn period. In such situations, parents are more concerned about the baby's survival than about its hearing. Although it is important to deal with the hearing loss in a timely manner, the baby's health is even more important.

An EHDI program must work in partnership with the child's parents and pediatric health-care professional and can be a part of the medical home, where care is truly family-centered, accessible, continuous, comprehensive, coordinated, compassionate, and culturally competent.



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www.infanthearing.org

UPCOMING EVENTS

October 20-24, 2001 • American Academy of Pediatrics (AAP) National Conference and Exhibition, San Francisco, California. **Contact:** AAP, 847.434.4000, www.aap.org.

November 8-12, 2001 • Second International Conference, "A Sound Foundation Through Early Amplification," Chicago, Illinois. *Sponsored by* Phonak. **Contact:** www.phonak.com.

November 9-10, 2001 • Advanced Bionics Conference on Cochlear Implants. *Sponsored by* Audiology Online and NOVA Southeastern University. **Contact:** www.audiologyonline.com.

November 10, 2001 • Twelfth Annual Audiology Videoconference. *Sponsored by* Mayo Clinic. **Contact:** Ann Roeder, 507.538.0090.

November 10-15, 2001 • American Speech-Language-Hearing Association (ASHA), New Orleans, Louisiana. **Contact:** ASHA, 301.897.3279, E-mail: actioncenter@asha.org, www.professional.asha.org.