

When a Newborn Doesn't Pass the Hearing Screening: How Medical and Other Health Professionals Can Help Increase the Number of Infants Who Return for a Follow-up Evaluation

Each year, approximately 12,000 babies are born with hearing loss in the United States. If hearing loss is discovered during the “critical period” for children to develop their speech and language skills—from birth to the first two to three years of life—they will have a much better chance of keeping up with their peers in learning language and speech skills. If they miss this critical period of development, they can fall far behind their peers in these areas. This delay, in turn, can affect a child’s ability to learn and interact socially.

Medical and allied health professionals across the United States have played a vital role in helping identify hearing loss during a child’s first months of life. As of July 2003, mandatory newborn hearing screening programs have been implemented in 38 states and the District of Columbia. As a result, roughly 86.5 percent of all infants are now screened for hearing loss, usually before they leave the hospital.

But screening is only the beginning of a successful path for infants who are deaf or hard-of-hearing. Newborns who don’t pass the screening should receive an audiometric evaluation and medical diagnosis before the child is three months of age. An audiologist is a health professional who conducts a series of tests to determine whether the child has a hearing problem and, if so, the type and severity of that problem. An otolaryngologist, or ear, nose, and throat doctor, will try to find out the reason behind a hearing loss and offer treatment options. These professionals will help direct parents or other caregivers to resources that can help them. (See the NIDCD fact sheet *Milestones in Your Child’s Speech and Language Development*.)

In the year 2000, only approximately half of the children who were referred for a follow-up examination were brought back for one. Parents of deaf or hard-of-hearing children in this group were much less likely to take advantage of the many resources that could give their children the best start possible and the best long-term outcome.

Why don't some parents return for a follow-up examination?

A working group of the National Institute on Deafness and Other Communication Disorders identified several important factors regarding why some parents do not bring their child back for a follow-up examination. They concluded that the number of children who return for the follow-up examination could be improved if:

- Parents fully understood their child's screening results,
- Parents fully understood the importance of the diagnostic evaluation, and
- Parents were provided with necessary contact and resource information.

A few of the most commonly cited reasons for the low response rate are included below, along with communication initiatives that you, the medical professional, can implement to help improve the outcome.

“With so many people involved in the process, it's difficult to be sure that the information is being relayed to parents.”—Charles

- **Take responsibility**

This is particularly true if the child is sent to the neonatal intensive care unit (NICU). A NICU physician may not see the parents again until several days after the child is born, if ever. A person on the medical team should be responsible for understanding and being able to interpret and carefully explain to parents the infant's screening results. It is extremely important that this individual be able to explain to parents why a follow-up examination is needed. Outdated wisdom that “parents can check back in a year to see if there is a change” is shortchanging children who could benefit from early intervention services.

- **Develop a protocol**

Develop a protocol to ensure that all parents receive the same information during their baby's birth and hospital stay. The more consistent the procedure and message, the less likely that a family will leave the hospital without understanding the next steps they need to take and why. With shortened maternity stays, this protocol becomes even more critical.

“There's no system in place to make sure that parents make and keep the follow-up appointment.”—Jocelyn

- **Obtain the family's contact information**

Medical staff should check in with families after they leave the hospital to make sure they've taken their child to the diagnostic evaluation. To facilitate ongoing communication, ask families to complete a discharge questionnaire before they leave the hospital, including names, addresses, phone numbers, e-mail addresses, and any other useful contact information.

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- **Connect the child with a ‘medical home’**

As soon as a child is born, the family should be linked to a “medical home,” a term that, according to the American Academy of Pediatrics (AAP), refers to healthcare services that are coordinated, comprehensive, family-centered, and accessible, among other things. This centralized system makes it easier for medical staff to track a child’s medical visits, recognizing immediately from his or her records whether the follow-up examination has been completed. To learn more about the “medical home” concept, and how your role and the role of your staff would be affected, contact the AAP for possible training sessions in your state or region at www.aap.org.

- **Give office staff a lead role**

Office staff should help families navigate the healthcare system, which can be quite complicated for individuals who are unfamiliar with it or who have difficulty reading or understanding the English language. By providing easy-to-read checklists and contact information, volunteering to schedule the follow-up appointment, and checking in with families to make sure that the appointment has been kept, office staff can help provide the needed push to ensure that this important task is completed.

- **Offer broad-based institutional support**

When feasible, hospitals should develop a support structure that will help medical staff better perform their duties in this area. This might include:

- modeling the hearing screening and diagnostic evaluation after an already-established program, such as metabolic screening;
- integrating health information systems to ensure that each child’s records are readily available to all health professionals who need to access them; and
- coordinating the billing for hospital services with the receipt of all follow-up information.

“There aren’t enough people or resources available to handle the screening and follow-up process.”—Miguel

- **Cross-train staff**

In communities where resources or staff are lacking, hospitals could cross-train medical staff to perform screening and follow-up testing. With adequate supervision, technicians, paramedics and emergency medical personnel, volunteers, nurses (as well as nurse aides and assistants), lab technicians, and respiratory therapists can be trained to perform some of these tasks on an as-needed basis.

“Parents don’t seem to understand the importance of the follow-up exam.”—Deborah

- **Communicate accurately and carefully**

Parents need to be told plainly what their child’s screening results mean and why the follow-up examination is important. A flier or brochure, no matter how well written or designed, is not enough on its own: some parents may have difficulty reading it or

■ For more information, contact:

NIDCD Information Clearinghouse
1 Communication Avenue
Bethesda, MD 20892-3456

1-800-241-1044
1-800-241-1055 (TTY)
E-mail: nidcdinfo@nidcd.nih.gov
Internet: www.nidcd.nih.gov

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comprehending certain medical terms. Or they may toss it away without a glance. Assign the “communicator” role to a designated staff person, making sure that parents are encouraged to ask questions. To further guarantee their understanding, have parents explain in their own words the next step they need to take and why. If you’d like to give parents something in writing at the end of the sit-down meeting, the NIDCD fact sheet *What to Do if Your Baby’s Screening Reveals a Possible Hearing Problem* is available at the NIDCD Web site. See the Web address listed below.

- **Be sensitive to cultural and other differences**

Your message can be filtered or even skewed by a number of factors, such as a parent’s culture, ethnicity, race, and socioeconomic background. For example, concepts that are generally accepted by some groups may be entirely unfamiliar to others. When communicating with parents, pay attention to these differences, and avoid using terms or expressions that may be easily misinterpreted.

- **Explain how a hearing loss can hamper a child’s speech and language development**

Parents may not understand how a possible hearing loss might impact their life and the life of their child. Furthermore, they may mistakenly think that little can be done about it. For these reasons, it’s important to explain to parents how detecting a hearing loss early—before their child reaches three months of age—and introducing intervention by the time the child reaches six months of age can keep a child on the right track developmentally and ensure he or she achieves the appropriate milestones for successful school, work, and social experiences.

“Returning for an appointment can be burdensome for some parents.”—Tia

- **Use incentives, when appropriate, such as travel vouchers**

Transportation can present a problem for families, particularly those who live in rural areas or who use public transportation. If possible, provide incentives such as free travel vouchers to help defray the cost. Another suggestion is to offer an instant photograph of the child at birth, at the follow-up examination, and during intervention.

- **Perform the follow-up exam while parents are still at the hospital**

If an audiologist is on site, explore ways for infants who don’t pass the screening to receive a definitive auditory brainstem response (ABR) test before they leave the hospital. The ABR involves attaching electrodes to the head and recording electrical activity in the brain when a sound is generated.

- **Combine follow-up exam with well-baby check-ups**

Families who are unable to transport themselves to a medical facility may rely on home health nursing to conduct their well-baby check-ups. In these cases, an audiologist may be able to provide follow-up testing during one of the home visits.

“Parents sometimes feel powerless and ‘out of the loop’ regarding their child’s health-care.”—Gavin

- **Involve the entire family in the screening**

When possible, make the infant’s hearing screening an interactive experience for the family by checking several family members’ hearing at the same time. The more involved

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a family is, the greater their appreciation for the importance of the screening and follow-up evaluation.

- **Equip parents with information for decision-making**

When a child is found to be deaf or hard-of-hearing, parents and other family members must make a difficult and highly personal decision regarding how the child will communicate. For example, the child may use a combination of oral and auditory skills together with assistive or augmentative devices, such as hearing aids, cochlear implants, FM transmitters, and other technologies. Or the child may learn American Sign Language (ASL), speechreading, cued speech, or a combination of oral and manual measures. Medical and other health professionals can provide information that enables parents to explore communication options, research findings, and informal support mechanisms before making their choice. (See the NIDCD fact sheets *Communication Considerations for Parents of Deaf and Hard-of-Hearing Children*, *Silence Isn't Always Golden*, and *Milestones in Your Child's Speech and Language Development*.)

- **Use a family-centered approach**

During office or home visits, physicians should involve the child's family. In this way, families are trained to serve as the first line of care for their infants and are empowered to make sure that their child receives the best health treatment possible.

What all parents need to know before they leave the hospital:

- The time frame in which parents need to respond:
 - By 1 month:** Parents should have their babies screened by 1 month of age.
 - By 3 months:** If the baby does not pass the screening, parents should take him or her to a follow-up evaluation by 3 months age.
 - By 6 months:** If hearing loss is confirmed, parents should have their child enrolled in some type of intervention by 6 months of age.
- Speech and language developmental milestones and how hearing loss affects their child's ability to achieve these milestones. (See the NIDCD fact sheet *Milestones in Your Child's Speech and Language Development*.)
- The results of their child's hearing screening and what the results mean. (See the NIDCD fact sheet *Has Your Baby's Hearing Been Screened?*)
- For parents of children who do not pass the screening:** Why a follow-up examination is necessary and how to go about getting one. (See the NIDCD fact sheet *What to Do if Your Baby's Screening Reveals a Possible Hearing Problem*.)
- Contact information for making the follow-up appointment for a diagnostic evaluation.

This might include a list of certified audiologists and otolaryngologists in the area along with addresses and phone numbers. Office staff may also volunteer to make the appointment for the parents.
- State, federal, and nonprofit resources available to them if their child should have a hearing problem (see list below).

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Bethesda, MD 20892-3456

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Internet: www.nidcd.nih.gov

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Free publications from the NIDCD

The following titles are just a sample of those available for free on the NIDCD Web site. Spanish versions are also available for each of the titles below. Hard copies can be ordered from the NIDCD Clearinghouse and reproduced free of charge.

- Communication Considerations for Parents of Deaf and Hard-of-Hearing Children
www.nidcd.nih.gov/health/hearing/commopt.asp
- Milestones in Your Child's Speech and Language Development
www.nidcd.nih.gov/health/voice/thebasics_speechandlanguage.asp
- Silence Isn't Always Golden
www.nidcd.nih.gov/health/hearing/silence.asp
- What to Do if Your Baby's Screening Reveals a Possible Hearing Problem
www.nidcd.nih.gov/health/hearing/baby_screening.asp
- Has Your Baby's Hearing Been Screened?
www.nidcd.nih.gov/health/hearing/screened.asp

The NIDCD Clearinghouse has additional information on speech and language development, communication options, cochlear implants, hearing aids, American Sign Language, and other topics covered in this fact sheet. There are several ways to contact us:

1 Communication Avenue
Bethesda, MD 20892-3456
Toll-free: (800) 241-1044
Toll-free TTY: (800) 241-1055
E-mail: nidcdinfo@nidcd.nih.gov

Contact the NIDCD Clearinghouse to be added to our mailing list. You'll receive the biannual newsletter *Inside* and a copy of our national directory of resources.

Resources for parents of a child with hearing loss

Educational Services

Families and Advocates Partners for Education (FAPE) is a partnership funded by the U.S. Department of Education that strives to improve the educational outcomes for children with disabilities. It informs parents, administrators, service providers, and policymakers about the Individuals with Disabilities Education Act (IDEA).

PACER Center

8161 Normandale Boulevard, Minneapolis, MN 55437-1044

Voice: (952) 838-9000

TTY: (952) 838-0190

Fax: (952) 838-0199

E-mail: fape@fape.org

Internet: www.fape.org

Head Start Information and Publication Center supports the Head Start community and other organizations working in the interest of children and families by providing information products and services; conference and meeting support; publication distribution; and marketing and outreach efforts.

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U.S. Department of Health and Human Services

1133 15th Street, N.W., Suite 450
Washington, DC 20005
Voice: (202) 737-1030
Toll-free: (866) 763-6481
Fax: (202) 737-1151
E-mail: askus@headstartinfo.org
Internet: www.headstartinfo.org

Office of Special Education Programs (OSEP) is dedicated to improving results for infants, toddlers, children, and youth with disabilities, ages birth through 21, by providing leadership and financial support to assist states and local districts.

Office of Special Education and
Rehabilitative Services
U.S. Department of Education
400 Maryland Ave., S.W.
Washington, DC 20202
Voice: (202) 205-5507
Internet: www.ed.gov/offices/OSERS/OSEP/index.html

Support Services

Beginnings for Parents of Children Who Are Deaf or Hard of Hearing, Inc. provides impartial information on communication options, placement, and educational programs to parents of children who are deaf or hard-of-hearing.

P.O. Box 17646
Raleigh, NC 27619
Voice/TTY: (919) 850-2746
Fax: (919) 850-2804
E-mail: beginnings@beginningssvcs.com
Internet: www.beginningssvcs.com

Center for Children's Policy, Practice and Research is an interdisciplinary center that helps protect the health and welfare of children by providing clinical assessments and legal testimony, conducting research, offering advice and consultation, influencing public policy, and disseminating information.

4200 Pine Street, 3rd Floor, Philadelphia, PA 19104
Voice: (215) 573-5442
Fax: (215) 573-2791
E-mail: ccppr@ssw.upenn.edu
Internet: www.ssw.upenn.edu/CCPPR

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National Association of the Deaf (NAD) is the nation's largest consumer organization safeguarding the accessibility and civil rights of 28 million deaf and hard-of-hearing Americans in education, employment, health care, and telecommunications. NAD focuses on grassroots advocacy and empowerment, captioned media, deafness-related information and publications, legal assistance, policy development and research, public awareness, certification of interpreters, and youth leadership development.

814 Thayer Avenue

Silver Spring, MD 20910-4500

Voice: (301) 587-1788

TTY: (301) 587-1789

Fax: (301) 587-1791

E-mail: nadinfo@nad.org

Internet: www.nad.org

General Information and Referral Services

American Academy of Audiology (AAA) is a professional membership organization of individuals dedicated to providing high-quality hearing care to the public.

8300 Greensboro Drive, Suite 750

McLean, VA 22102

Voice/TTY: (703) 790-8466

Toll Free: (800) 222-2336

Fax: (703) 790-8631

Internet: www.audiology.org

American Academy of Otolaryngology—Head and Neck Surgery (AAO-HNS) is a non-profit association that strives to unite, serve, and represent the interests of ear, nose, and throat specialists and their patients to the public, government, other medical specialists, and related organizations.

One Prince Street

Alexandria, VA 22314

Voice: (703) 836-4444

TTY: (703) 519-1585

Fax: (703) 683-5100

E-mail: webmaster@entnet.org

Internet: www.entnet.org

American Academy of Pediatrics (AAP) is a professional membership organization of pediatricians dedicated to the health, safety, and well-being of all infants, children, adolescents, and young adults.

141 Northwest Point Boulevard, Elk Grove Village, IL 60007-1098

Voice: (847) 434-4000

Fax: (847) 434-8000

Internet: www.aap.org (general); www.aap.org/advocacy/shrinersorder.htm (medical home training)

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American Speech-Language-Hearing Association (ASHA) promotes the interests of and the highest quality services for professionals in audiology, speech-language pathology, and speech and hearing science, and advocates for people with communication disabilities.

10801 Rockville Pike
Rockville, MD 20852
Voice: (301) 897-3279
Fax: (301) 897-7355
Toll-free: (800) 638-8255
E-mail: actioncenter@asha.org
Internet: www.asha.org

AT&T HealthLine is a health-information hotline sponsored by the Centers for Disease Control and Prevention and the National Center on Birth Defects and Developmental Disabilities.

Toll-free: (888) 232-6789

Laurent Clerc National Deaf Education Center at Gallaudet University responds to inquiries about a diverse range of topics related to deaf and hard-of-hearing children from infancy to age 21.

KDES PAS-6, 800 Florida Avenue, N.E.
Washington, DC 20002-3695
Voice: (202) 651-5051
TTY: (202) 651-5052
Fax: (202) 651-5054
E-mail: clearinghouse.infotogo@gallaudet.edu
Internet: clerccenter.gallaudet.edu

National Information Center for Children and Youth with Disabilities (NICHCY) is a national information and referral center that provides information on disabilities and disability-related issues for families, educators, and other professionals. NICHCY's special focus is children and youth (birth to age 22).

P.O. Box 1492, Washington, DC 20013-1492
Voice/TTY: (202) 884-8200
Toll-free: (800) 695-0285
Hours: 9:30 a.m. – 6:30 p.m., Eastern Time
Fax: (202) 884-8441
E-mail: nichcy@aed.org
Internet: www.nichcy.org

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Communication Options

Alexander Graham Bell Association for the Deaf and Hard of Hearing (A.G. Bell) is a membership-based information center on hearing loss, emphasizing the use of technology, speech, speechreading, residual hearing, and written and spoken language.

3417 Volta Place, N.W.

Washington, DC 20007

Voice: (800) HEAR-KID or (202) 337-5220

TTY: (202) 337-5220

Fax: (202) 337-8314

E-mail: info@aol.com

Internet: www.agbell.org

American Society for Deaf Children (ASDC) is a national organization of families and professionals committed to educating, empowering, and supporting parents and families of children who are deaf or hard-of-hearing. The ASDC helps families find meaningful communication options, particularly through the competent use of sign language, in their home, school, and community.

P.O. Box 3355

Gettysburg, PA 17325

Voice/TTY: (717) 334-7922

Toll-free: (800) 942-ASDC

E-mail: ASDC1@aol.com

Internet: www.deafchildren.org

National Cued Speech Association (NCSA) promotes the effective use of cued speech for communication, language acquisition in more than 50 languages, and literacy.

23970 Hermitage Road

Shaker Heights, OH 44122

Toll-free Voice/TTY: (800) 459-3529

Fax: (216) 360-0359

E-mail: cuedspdisc@aol.com

Internet: www.cuedspeech.org

Clinical Studies

Boys Town National Research Hospital (BTNRH) conducts research into and treatment of childhood deafness and communication disorders. Areas of study include neurobiological studies of hearing; hereditary communication disorders; and clinical, educational, and behavioral studies of human communication.

555 North 30th Street, Omaha, NE 68131

Voice: (402) 498-6511

TTY: (402) 498-6543

Toll-free: (800) 282-6657

Fax: (402) 498-6755

E-mail: moeller@boystown.org

Internet: <http://www.boystown.org/btnrh>

