



Legislation related to Newborn Hearing Screening

Legislative mandates have played a significant role in the expansion of newborn hearing screening programs. Beginning in 1990 with legislation passed in Hawaii, there are now 37 states with legislation related to universal newborn hearing screening. The content of each state's legislation is available at www.infanthearing.org/legislative/index.html, and the table summarizes the key provisions of each state's legislation. Reviewing the information in the table underscores a number of important issues related to the implementation and operation of EHDI programs:

- **The influence of professional organizations and research should not be underestimated.** About two-thirds of the legislation (27 of 37 states) has been passed since 1999. This was probably due in part to the publication of the American Academy of Pediatrics Position Statement published in February 1999 and the publication in prestigious journals in 1998 of major articles about the feasibility and benefits of implementing large-scale universal newborn hearing screening programs (e.g., Finitzo et al., 1998; Mason & Herrmann, 1998; Mehl & Thomson, 1998; Vohr et al., 1998; Yoshinaga-Itano et al., 1998).
- **Much of the legislation does not support "UNIVERSAL" newborn hearing screening.** Only 22 of 37 states (59%) require all newborns to be screened for hearing loss. Others set a goal based on a certain percentage of births or do not require babies born in small hospitals to be screened. The fact that some laws set the standard as low as 85% of all newborns raises significant issues about whether these are really laws for "UNIVERSAL" newborn hearing screening. Unfortunately, such laws don't guarantee access for all newborns in that state.
- **Tracking and data management is an essential component.** Twenty-four of 37 states (65%) require hospitals to report data from newborn hearing screening to the State Department of Health, thus underscoring the

intent of making Early Hearing Detection and Intervention (EHDI) a public health program.

- **Newborn hearing screening is becoming the standard of care.** The fact that only 5 states (14%) require parents to provide written informed consent emphasizes that most states are viewing hearing screening as a routine part of newborn health care.
- **Reimbursement issues are inadequately covered in existing legislation.** Seventeen of 37 states (46%) include a provision indicating that newborn hearing screening should be a covered benefit of health insurance policies issued in the state. However, very few of these laws define what is meant by making it a covered benefit, and most of these laws have had little effect on payments being made to hospitals.
- **Legislation outlines the minimum expectations of state policy makers but does not necessarily define all that state EHDI programs are doing.** For example, Rhode Island has one of the nation's best tracking and reporting systems and has an advisory committee, even though those issues are not addressed in the Rhode Island legislation.

Legislation is an important tool to ensure that newborns with hearing loss and their families receive the services they need. Existing legislation provides a good foundation, but much more work is needed. As you review how legislation

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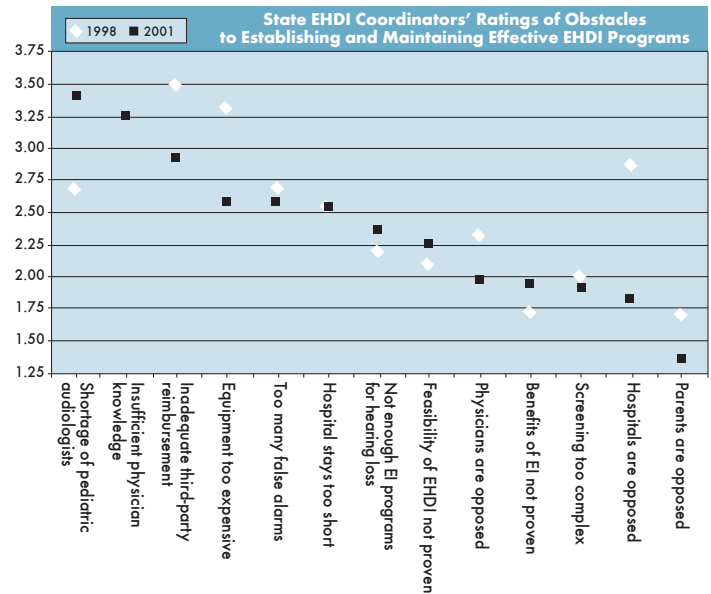
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Obstacles to successful implementation of EHDI programs

What are the biggest obstacles to implementing a successful Early Hearing Detection and Intervention (EHDI) program? Each year since 1998, the National Center for Hearing Assessment and Management (NCHAM) has asked state EHDI coordinators to rate the degree to which various factors interfere with establishing and maintaining an effective universal newborn hearing screening program in the state. Coordinators are asked to rate each potential obstacle on a scale from A1 (definitely not an obstacle) to A5 (an extremely serious obstacle).

The accompanying figure shows the results of these ratings at the end of 1998 (based on responses from 46 of 50 state coordinators) and at the end of 2001 (based on 50 out of 50 state coordinators). As can be seen from the figure, there are some interesting similarities and differences between the ratings over the 3-year period. Keep in mind that the percentage of babies being screened prior to discharge went from about 25% at the end of 1998 to approximately 66% at the end of 2001. The three most serious obstacles at the end of 1998 (inadequate third-party reimbursement, screening equipment being too expensive, and opposition by hospitals) were rated substantially lower at the end of 2001. In fact, even though hospital opposition was rated the third most serious obstacle in 1998, it was rated 12th out of 13 potential obstacles in 2001. As more and more newborn hearing screening programs have been implemented, it appears that hospital staff members have recognized the feasibility and benefits of such programs and have become supportive.

The only potential obstacle to be ranked significantly higher in 2001 than in 1998 was the shortage of pediatric audiologists. This has emerged as one of the most serious challenges in implementing successful EHDI programs. Close behind, according to EHDI coordinators, is the fact that physicians don't know enough about newborn hearing screening, diagnosis, and intervention to encourage and



support parents. Although inadequate third-party reimbursement was rated significantly lower in 2001 than in 1998, it is still the third most highly rated obstacle by state EHDI coordinators. Items rated as significantly less serious obstacles, but still a concern to many state EHDI coordinators, include that equipment is a substantial expense, false alarm rates are too high, and hospital stays are too short.

With the exception of having enough experienced pediatric audiologists to do diagnostic evaluations and hearing aid fitting for infants and young children, there appears to be substantial progress in overcoming most of the obstacles that have interfered with implementation of successful EHDI programs. Not surprisingly, the item rated each year as the least-serious obstacle was opposition by parents.

THE WEB

www.infanthearing.org

National campaign for hearing health

Want to know more about federal funding to assist states in the development and operation of EHDI programs? The National Campaign for Hearing Health (NCHH) maintains a legislative update link on their Web site at www.hearinghealth.net. They do a good job of keeping this up to date about the current status of congressional action regarding EHDI. This site also helps you to contact your representative in an easy-to-manage format. Whatever your views concerning the hearing health care of infants, stay informed and stay involved!



SOUND IDEAS, February 2003, Vol. 5, No. 1. *Sound Ideas* is a quarterly publication of the National Center for Hearing Assessment and Management (NCHAM). Its goal is to provide information to hospital staff, health-care providers, early interventionists, families, and public health officials to help in the establishment and expansion of successful newborn hearing screening and intervention programs.

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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.

Getting a hearing head start

NCHAM is currently exploring the feasibility of extending physiologically based hearing screening to young children in early childhood education settings. With funding and support from the Administration for Children and Families, Head Start Bureau, and the Maternal and Child Health Bureau, the goal of the 2-year Hearing Head Start Project is to demonstrate model strategies for enhancing the capacities of Migrant, American Indian, and Early Head Start providers to screen children 0- to 3-years of age for hearing loss using otoacoustic emissions (OAE) technology. During the past year, NCHAM has trained Head Start staff serving approximately 2,500 children in three states (WA, OR, and UT) to screen children enrolled in their programs.

Head Start has a long-term, standing commitment to ensure that all children they serve are provided with hearing screenings. Despite this requirement, most Head Start providers have not felt like they had appropriate tools for doing effective hearing screening with birth to 3-year-old children. A wide range of methods are being used by Head Start providers—the most common of which are parent questionnaires and behavioral observations. The purpose of the Hearing Head Start Project is to determine whether current hearing screening practices can be improved through the use of OAE technology and a hearing screening protocol that Head Start staff can use in their center- and home-based programs.

Participants in the project receive training, OAE hearing screening equipment, and resources for documenting hearing screening, tracking children, and follow-up intervention. In turn, participants are expected to screen all of the birth to 3-year-old children they serve and provide information about screening and follow-up results on a regular basis. Staff from a

total of 19 Head Start programs were trained between December 2001 and January 2003. Of the 19 participating grantees, 12 were Early Head Start, four were Migrant Head Start, and three were American Indian Head Start Programs, representing approximately 2,500 children served annually.

Preliminary data gathered for approximately 1,200 children indicate that Head Start providers have been successful in learning to use handheld screening equipment to make appropriate referrals to primary health-care providers and audiologists. Approximately 3% of the children who were screened (n=40) have been referred for follow-up, and 12 have been diagnosed with a hearing loss requiring treatment, one of which has a severe bilateral sensorineural loss and another who has a mild-moderate bilateral, permanent conductive loss.

During 2003, approximately 1,700 additional children will be screened by participating Early Head Start grantees. Activities are also underway to link participating Head Start grantees with EHDI resources within their states. For more information, contact the director of the project, Dr. William Eiserman, at hearingheadstart@aol.com. Information about the project is also available at www.infantheating.org by clicking on “Research Projects.”

TECHNIQUES AND TIDBITS

Improving your hospital's return rate of infants

Nationally, the average number of infants who complete a follow-up hearing test after they are referred from their hospital hearing screen is between 50 -70%. How can your hospital improve the return rate of infants who refer on their initial hearing screen? Here are some suggestions you may want to consider:

- 1 Schedule the baby to return within 2 weeks to the screening hospital if outpatient testing is a possibility. This appointment may coincide with other tests that the infant needs.
- 2 Schedule the family for a follow-up hearing screen/audiological appointment with a designated provider (consistent with their health insurance plans) before they are discharged from the screening hospital. Provide maps to the appointment site.
- 3 Provide the parent(s) with a list of providers (consistent with their health insurance plans) that can provide the audiological services necessary for follow-up hearing testing. Provide maps, phone numbers, and contact individuals to make scheduling easier for the parent.
- 4 Report all test results to the infant's primary care physician with the specific recommendation that a follow-up screen is necessary.
- 5 Provide inservices for pediatricians and primary care physicians on the importance of this follow-up hearing screen/audiological test.
- 6 Provide the infant's parent(s) and their physician educational materials concerning the hearing screen and provide a list of expected developmental milestones for infants and children.
- 7 Perform a follow-up telephone call to the parent(s) of those infants that do not pass the initial hearing screening test to encourage them to go for a follow-up test.
- 8 Document test results for the infants that receive the follow-up testing at your hospital to establish a quality assurance indicator for your program to continually evaluate the process you have chosen.

Pick the suggestion or combination of suggestions that works best for your facility and track the number of infants that return for follow-up. The best hearing screening program in the world is only as good as the follow-up that is provided to the infant.

AROUND THE WORLD . . .

The Newborn Hearing Screening Programme (NHSP) in England

by Dr. Sally E. Hind, Developmental Psychologist/Information Coordinator for the NHSP

During 2002, the Institute for Hearing Research located at Nottingham University made significant progress in the implementation of a nationwide newborn hearing screening programme (NHSP). The “rollout” of universal newborn hearing screening is anticipated to cover all newborns in England by the end of 2005. The first 23 sites went live during 2002. These will offer the screen to approximately 20% of all babies born per annum in England. The mission statement of the NHSP is threefold:

- To enable high-quality parent-child interaction in the first months of life for all children
 - To empower parents of hearing-impaired children concerning communication options
 - To put in place an evaluative culture of service provision
- The ethos of the screen is embedded in family friendliness.

During 2002, the Institute for Hearing Research located at Nottingham University made significant progress in the implementation of NHSP.

To this end, considerable effort has been afforded the development of written, verbal, and audio-visual information for parents (see www.nhsp.info for more details).

A recent quality assurance check

of the materials demonstrated that parents value the information substantially. As a further method of reducing likelihood of anxiety from false-positive outcomes, the program avoids using the terms “pass” or “fail” throughout the screening process. The expressions “clear response” and “no clear response” are substituted respectively. Because screening is often done within 24 hours of birth, screeners are trained to provide verbal information designed to ameliorate anxiety in the parent and minimize any possible impact on the parent-child relationship.

Models

The main model for implementation is hospital-based. Babies are offered the screen before discharge. In keeping with the family-friendly ethos, screening is usually done in the presence of the mother, preferably at the bedside. The screeners are trained how to deliver the screen such that the mother can observe both the baby and the equipment. In a few areas, due to geography or population make up, a community-based model has been implemented. In these cases, screening is done by specifically trained public health nurses in the child’s home or in a community clinic.

Protocol

For babies born with no known problems, a two-stage protocol is implemented: Stage 1 is an automated transient evoked otoacoustic emission screen (AOAE), and Stage 2 is an automated auditory brainstem response screen (AABR). In other words, the AABR screen is only done if there is “no clear responses” for one or both ears. When bilateral clear responses are obtained, the parent is given two checklists that provide general guidelines for expected behavior in reaction to sounds and sounds produced by the baby/child at various developmental milestones. Babies who have required intensive care for over 48 hours are always screened with AABR regardless of the outcome of the AOAE, because these children are known to be at greater risk of neural hearing impairment.

At the end of the first year of that national rollout (2002), the local programmes are running well. Even though several sites had been operational for only a very short period, average coverage was over 90%, and identification of true cases was in line with expected epidemiology.

RECENT RESEARCH NEWS YOU CAN USE

Severe neonatal respiratory failure as an indicator of late-onset hearing loss

After they have implemented a universal newborn hearing screening program, many people wonder about the advisability of doing audiological follow-up of babies who pass the newborn hearing screening test but have one or more “risk indicators.” Research continues to provide information that is enabling us to make such follow-up programs more efficient. For example, Robertson, Tyebkhan, Hagler, Cheung, Peliowski, & Etches recently published an article [(2002, May). Late-onset, progressive sensorineural hearing loss after severe neonatal respiratory failure. *Otol Neurotol*, 23(3), 353-6.] showing that more than half of survivors of severe neonatal respiratory failure will have sensorineural hearing loss by the time they are 4 years old.

Robertson et al. conducted a prospective longitudinal study in which 81 survivors of severe neonatal respiratory failure received repeated audiological assessments until they were 4 years old. Subjects were born in one of nine tertiary referral centers in Canada between 1994 and 1996.

By the time they were 2 years old, 30 of the 81 children had been diagnosed with permanent hearing loss (18 of which were progressive). By 4 years of age, an additional 13 children were diagnosed with permanent hearing loss. Thus, a total of 43 of the 81 children (53%) were diagnosed with permanent sensorineural hearing loss. One hundred percent of the children (15 of 15) whose respiratory failure included a congenital diaphragmatic hernia were later diagnosed with hearing loss.

These data provide convincing evidence that children who survive severe respiratory failure must receive long-term audiological surveillance regardless of their results on a hearing screening test at the time of hospital discharge.

Legislation related to Newborn Hearing Screening

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initiatives might be used to enhance the EHDI program in your state, you may find it helpful to go to <http://www.infanthearing.org/legislative/provisions/index.html> and see the exact wording of various legislative provisions in other states.

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NOTE: The table shows only what is required by the law, which may be different from what states are doing.

Newborn Hearing Screening Legislation in the United States

State	Year Passed	Requires Screening of . . .	Advisory Committee?	Covered by Health Insurance?	Report Results to State?	Provide Educational Materials?	Informed Consent by Parents?	Parental Objection Exclusion?
AR	1999	Hospitals >50 Births	Yes	Medicaid only	Yes	Yes		Yes
CA	1998	Acute Care Hospitals		Medicaid only		Yes	Yes	
CO	1997	85% of Newborns	Yes			Yes		
CT	1997	All Babies		Yes		Yes		Yes
FL	2000	All Babies		Yes		Yes		
GA	1999	95% of Newborns	Yes			Yes		
HA	1990	All Babies			Yes			
IL	1999	All Babies	Yes			Yes		Yes
IN	1999	All Babies	Yes	Yes	Yes	Yes		
KS	1999	All Babies					Yes	
KY	2000	Hospitals >40 Births	Yes		Yes			
LA	1999	All Babies	Yes					
ME	1999	>85%	Yes	Yes	Yes	Yes		
MD	1999	All Babies	Yes	Yes	Yes	Yes		
MA	1997	All Babies	Yes	Yes	Yes			Yes
MS	1997	All Babies	Yes		Yes	Yes		
MO	1999	All Babies	Yes	Yes	Yes	Yes		Yes
MT	2001	All Babies	Yes		Yes			
NE	2000	>95%		Yes	Yes	Yes		Yes
NV	2000	Hospitals >500			Yes	Yes		Yes
NH	2000							
NJ	2000	All Babies	Yes	Yes	Yes	Yes	Yes	Yes
NM	2001	All Babies						
NY	1999	Hospitals >400 Births			Yes			
NC	1999	All Babies			Yes	Yes		Yes
OH	2002	All Babies	Yes	Yes	Yes	Yes		Yes
OK	2000	All Babies						
OR	1999	Hospitals >200 Births	Yes		Yes	Yes		Yes
PA	2001	85% of Newborns	Yes		Yes	Yes		
RI	1992	All Babies		Yes				Yes
SC	2000	Hospitals >100 Births	Yes	Yes	Yes	Yes		
TX	1999	Hospitals >100 Births		Yes	Yes	Yes	Yes	
UT	1998	All Babies	Yes		Yes	Yes		
VA	1998	All Babies	Yes	Yes	Yes	Yes		Yes
WV	1998	All Babies	Yes	Yes	Yes			
WI	1999	88% of Newborns			Yes			
WY	1999	All Babies				Yes	Yes	

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Future editions of this newsletter will primarily be distributed electronically at www.infanthearing.org.

To have a printed copy sent, register at www.infanthearing.org. HEAR's to early hearing screening for all babies!

UPCOMING EVENTS

February 23-27, 2003 • Association for Research in Otolaryngology (ARO) Midwinter Meeting, Daytona Beach, Florida. **Contact:** www.aro.org.

February 24-26, 2003 • 2nd Annual National Early Hearing Detection and Intervention (EHDI) Conference, Atlanta Georgia. **Registration and materials online:** www.desainc.com/ConfEHDI.htm.

March 17, 2003 • The 2003 RIHAP Seminar Creating Positive Environments—For Children With Hearing Loss—For Their Families—For Their Friends, The Rhode Island Convention Center, Rhode Island. **Contact:** 401.277.3700 (voice), 401.277.3701 (TDD), RIHAP@wihri.org.

March 27-28, 2003 • The American Auditory Society Annual Meeting, Holiday Inn Sunspree Resort, Scottsdale, Arizona. **Contact:** www.amauditorysoc.org.

April 2-5, 2003 • American Academy of Audiology 15th Annual Convention and Exposition, San Antonio, Texas. **Contact:** American Academy of Audiology, 8201 Greensboro Drive, Suite 300, McLean, Virginia 22102, 703.610.9022, Fax: 703.610.9005, www.audiology.org.

April 24-26, 2003 • Ninth Symposium Cochlear Implants in Children, Transforming the World of Sound, The Ronald Reagan International Trade Center, Washington, DC. *Sponsored by* Listening Center at Johns Hopkins and the River School. **Contact:** www.ci2003.com.