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THE CURRENT STATUS OF EHDI PROGRAMS IN THE UNITED STATES

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The importance of identifying congenital hearing loss during the first few months of life has been recognized for almost 60 years. Unfortunately, until more effective newborn hearing screening equipment and procedures were developed in the late 1980s, it was not practical to implement programs for identifying hearing loss during the first few months of life. This paper reviews the activities implemented by the federal government in the last 15 years to promote more effective Early Hearing Detection and Intervention (EHDI) programs, and summarizes legislation passed by states related to universal newborn hearing screening. In surveys conducted in 1998 and 2001, State EHDI Coordinators were asked to rate the degree to which various issues were obstacles to implementing effective EHDI programs. The most serious obstacles are the shortage of qualified pediatric audiologists, inadequate reimbursement for screening and diagnosis, and lack of knowledge among primary health care providers about EHDI issues. Opposition to EHDI programs by hospital administrators was rated substantially lower in 2001 than in 1998. State EHDI Coordinators were also surveyed about how well their EHDI program is addressing issues related to screening, diagnosis, early intervention, linkages to medical home providers, tracking and data management, and family support programs. Although substantial progress has been made, many gaps remain with current EHDI programs.

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Key Words: newborn hearing screening; EHDI programs; infant hearing loss

An average of 33 babies with congenital hearing loss are born everyday in the United States, making it the nation's most frequent major birth defect [Stierman, 1994; White, 1997; Leonard et al., 1999]. Until recently, most of these children were not identified until they were two to three years old [Toward Equality, 1988]. According to the U.S. Department of Health and Human Services [1990], such late identification means that:

". . .it is difficult, if not impossible, for many [children with congenital hearing loss] to acquire the fundamental language, social, and cognitive skills that provide the foundation for later schooling and success in society. When early identification and intervention occur, hearing impaired children make dramatic progress, are more successful in school, and become more productive members of society. The earlier intervention and habilitation begin, the more dramatic the benefits (p. 460)."

During the last 15 years, there has been dramatic growth in newborn hearing screening, diagnosis, and intervention programs commonly referred to now as EHDI (Early Hearing Detection and Intervention) programs. The purpose of this paper is to summarize the status of EHDI programs in the United States. To do that, some important historical activities that laid the foundation for universal newborn hearing screening programs will first be summarized, followed by an overview of legislative actions that have guided many of the current EHDI programs. Next, the degree to which state EHDI coordinators view various issues as obstacles to the successful implementation of EHDI programs will be presented as a context for discussing the status of current EHDI programs.

HISTORICAL HIGHLIGHTS

The importance of identifying hearing loss as early as possible has been recognized for decades. Almost 60 years ago, Ewing and Ewing [1944] stated:

"There is an urgent need to study further and more critically methods of testing hearing in young children. . .. During this first year, the existence of deafness needs to be ascertained. . .. Training needs to be begun at the earliest age that the diagnosis of deafness can be established. (p. 309)."

Since the Ewings' call to action in 1944, substantial resources have been devoted to reducing the age at which children with congenital hearing loss are identified. For example, the Babbidge report, issued by the U.S. Department of Health, Education, and Welfare in 1965, recommended the development and nationwide implementation of ". . .universally applied procedures for early identification and evaluation of hearing impairment" (p. C-10). Following the pioneering work of Marion Downs [Downs and Sterritt, 1964; 1967], the Joint Committee on Infant Hearing (JCIH) was established in 1969, with the goal of improving early identification of congenital hearing loss [Northern and Downs, 1974]. Because appropriate hearing screening technology was not available at the time, the JCIH focused on screening only high risk babies until their 1994 Position Statement [AAP, 1995].

As new hearing screening technologies became available in the late 1980s and early 1990s, increased resources from the federal government were devoted to reducing the age at which hearing loss was identified. The impetus for this came in part from the congressionally-mandated Commission on Education of the Deaf created as a result of legislation sponsored by Senator Lowell Weicker from Connecticut. In their 1988 report entitled, **Toward Equality**, the Commission recommended that

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Table 1. Federal Initiatives to Support Early Hearing Detection and Intervention: 1988–2000

Year	Activity	Description
1988	Commission on the Education of the Deaf issues Toward Equality report	Report recommended that the federal government undertake systematic initiatives to reduce the age at which children with hearing loss are identified. Federal agencies required to report progress.
1989	Rhode Island Hearing Assessment Program funded by MCHB and OSERS	RIHAP was the first large-scale clinical trial of universal newborn hearing screening and demonstrated conclusively that such screening was feasible, economically practical, and resulted in identification of many infants with congenital hearing loss.
1990	HHS issues Healthy People 2000 report	Included a goal to "reduce the average age at which children with significant hearing impairment are identified to no more than 12 months." Federal agencies were required to track and report progress.
1993	NIH Consensus Conference on Early Identification of Hearing Impairment in Infants and Young Children	In March of 1993, a panel of experts, who were appointed by NIH as being non-advocates, non-federal, and independent, reviewed evidence and recommended "that universal screening be implemented for all infants."
1993	MCHB funds Consortium for Universal Newborn Hearing Screening	The Maternal and Child Health Bureau awarded a grant to Utah State University to organize a consortium of hospitals to demonstrate and advance knowledge about universal newborn hearing screening.
1996	MCHB funds Marion Downs National Center for Infant Hearing	MCHB awarded a grant to the University of Colorado to establish the Marion Downs National Center for Infant Hearing. This Center worked with State Departments of Health in 17 states to assist in the development of statewide systems for newborn hearing screening programs.
1999	"Walsh Bill" for Early Hearing Detection and Intervention Programs is passed	Under the leadership of Congressman James Walsh from New York, money was included in the FY2000 budget for MCHB and CDC to fund states to enhance their EHDI programs. Fifty-three states and territories now have federal funds to assist in the development of statewide EHDI programs. MCHB also funded Utah State University to operate a National Technical Assistance System for EHDI.

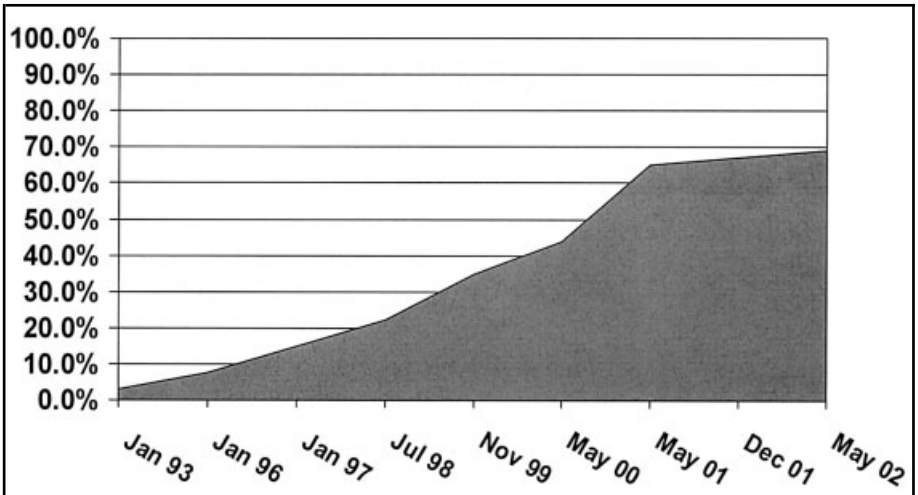

Fig. 1. Percentage of newborns screened for hearing prior to hospital discharge.

"the Department of Education, in collaboration with the Department of Health and Human Services, should. . .assist states in implementing improved screening procedures for each live birth."

A short time later, the U.S. Surgeon General, Dr. C. Everett Koop, issued a challenge to reduce the age at which congenital hearing loss was identified:

"Deafness in infants is a serious concern because it interferes with the development of language—that which sets humans apart from all other living things. . . . Many research studies have demonstrated that early intervention with hearing impaired children results in improved language development, increased academic success, and increased lifetime earnings. Early intervention actually saves money since hearing impaired children who receive early help require less costly special education services later. . .. I am optimistic. I foresee a time in this country. . .when no child reaches his or her first birthday with an undetected hearing impairment [as reported in Northern and Downs, 1991, p 2–3].

Dr. Koop's optimism was a little surprising given that less than 3% of all newborns were screened for hearing loss at the time [Bess, 1993]. However, as a result of federally-funded initiatives summarized in Table 1, the percentage of newborns being screened for hearing loss began to increase dramatically. As shown in Figure 1, the percentage of newborns being screened for hearing prior to hospital discharge had risen to approximately 70% by May of 2002 [NCHAM, 2002a]. Of course, such progress would not have been possible without the technological developments in using automated Auditory Brainstem Response [AABR–Herrmann et al., 1995] and otoacoustic emissions [OAE-Kemp, 1978; Lonsbury-Martin and Martin, 1990; Kemp and Ryan, 1993) for newborn hearing screening programs.

In March 1993, the National Institutes of Health (NIH) Consensus Development Panel recommended "screening of all newborns. . .for hearing impairment prior to discharge." Some people expected immediate implementation of universal newborn hearing screening programs. Such was not to be the case, however, as others pointed out that the research evidence and experience for such broad-scale implementation was lacking. Indeed, shortly after the NIH Consensus Panel's recommendations were issued, Bess and Paradise [1994] concluded that ". . .the Consensus Panel's recommendation of universal infant screening falls short of being justified on grounds of practicability, effectiveness, cost, and harm-benefit ratio." Two years later, while recognizing that "congenital hearing loss is a serious health problem associated with developmental delay in speech and language function," the U.S. Preventive Services Task Force [1996] concluded that ". . .there is little evidence to support the routine universal screening for all neonates."

Although the conclusions of Bess and Paradise and others who urged caution for the implementation of newborn hearing screening were widely criticized [e.g., White and Maxon, 1995], the fact is that there was very little research from large, systematically-implemented universal newborn hearing screening programs to support the recommendations of the NIH Consensus Panel. Other than the report of the Rhode Island Hearing Assessment Project [White and Behrens, 1993], research about newborn hearing screening available at that time was based on small samples of infants (primarily from NICUs) over a short period of time. The recommendations of the NIH Consensus Panel and the controversy generated by the Bess and Paradise article stimulated a great deal of activity over the next five years, and by the late 1990s an impressive body of research about the feasibility, costs, and benefits of newborn hearing screening had been reported [e.g., Maxon et al., 1995; Barsky-Firkser and Sun, 1997; Finitzo et al., 1998; Mason and Herrmann, 1998; Mehl and Thomson, 1998; Vohr et al., 1998], and dozens of large-scale universal newborn hearing screening programs had become operational in various states [White, 1997].

As shown in Figure 2, the number of hospitals reporting universal newborn hearing screening programs increased more than twenty-fold between 1993 and 1998; and by the end of 2001, more than two-thirds of all hospitals where newborns were born or cared for were reporting universal newborn hearing screening programs. The demonstrated feasibility of hospital-based screening, coupled with the results of ongoing research, led to more recommendations for universal newborn hearing screening by other governmental, professional, and advocacy organizations, including the American Speech-Language-Hearing Association, the American Academy of Audiology, the National Association of the Deaf, March of Dimes, and the American College of Medical Genetics. By the end of 2001, EHDI programs were clearly established as a part of the public health system in the United States, with all 50 states having identified a state EHDI coordinator. Furthermore, in 1998, the federal Maternal and Child Health Bureau [MCHB, 2002] began requiring states to report "percent of newborns screened for hearing impairment before hospital discharge" as one of 18 core performance measures that states reported annually to receive federal MCHB block grant funding.

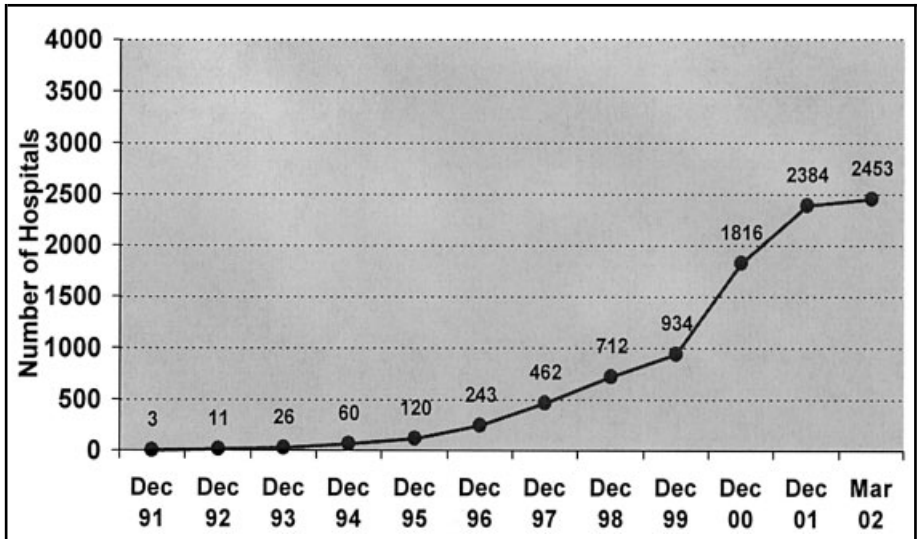

Fig. 2. Number of hospitals doing universal newborn hearing screening

The increase in the number of babies being screened for hearing loss has led to the realization that screening is only the beginning of a process necessary to identify infants and toddlers with hearing loss and provide them and their families with appropriate services and assistance. As a result of work done by JCIH [JCIH, 2000], MCHB, and the Centers for Disease Control and Prevention [CDC, 2002], there is now consensus that successful EHDI programs must include all of the components listed below:

- All newborns are screened for hearing before discharge from the hospital or before one month of age
- Babies referred from hearing screening programs are diagnosed as soon as possible, but no later than three months of age
- Babies diagnosed with hearing loss begin receiving appropriate intervention services (medical, educational, and audiological) as soon as possible, but no later than six months of age
- All EHDI activities are coordinated with the infant's medical home
- All states have systematic data management and tracking procedures to minimize loss to followup, to provide data for ongoing program improvement and quality assurance, and to communicate with stakeholders
- Families of newborns participating in hearing screening, diagnosis, and intervention services are given appropriate information and culturally-competent support in conjunction with EHDI activities where issues associated with hearing loss are well understood

LEGISLATION RELATED TO NEWBORN HEARING SCREENING

A major contributor to the increase in EHDI programs has been state-based legislative activity. Beginning in 1990 with legislation passed in Hawaii, there are now 37 states with legislation related to universal newborn hearing screening [NCHAM, 2002b]. Texts of each state legislation are available at www.infanthearing.org/legislative/index.html, and Table 2 summarizes the key provisions of each state's legislation. Several important points about the current status of EHDI programs are evident from the information in Table 2:

- About two-thirds of the legislation (27 of 37 states) has been passed since 1999. The increase in successful legislation was probably influenced by the publication of the Position Statement by the American Academy of Pediatrics 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 and Herrmann, 1998; Mehl and Thomson, 1998; Vohr et al., 1998; Yoshinaga-Itano et al., 1998].
- Only 22 of 37 statutes (59%) require screening of all babies. The

Table 2. 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	Yes	Yes		Yes
CA	1998	Acute Care Hospitals		Medicaid		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	

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

fact that some statutes set the standard as low as 85% of all newborns raises significant issues about accessibility and coverage.

- Twenty-four of 37 statutes (65%) require hospitals to report data from newborn hearing screening to the State Department of Health, thus underscoring the intent of making EHDI a public health program.
- The fact that only 5 states (14%) require parents to provide written informed consent emphasizes that states are viewing hearing screening as a routine part of newborn health care.
- Seventeen of 37 statutes (46%) include a provision indicating that newborn hearing screening should be a covered benefit of health insurance policies issued in the state.

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, reports data to the Department of Health, and has an Advisory Committee, even though those issues are not addressed in the Rhode Island legislation.

OBSTACLES TO SUCCESSFUL IMPLEMENTATION OF EHDI PROGRAMS

To understand the current status of EHDI programs, it is useful to know what state EHDI coordinators view as the most serious obstacles to the implementation of successful programs. Each year since 1998, the National Center for Hearing Assessment and Management (NCHAM) has surveyed state EHDI coordinators and asked them to rate the degree to which a series of "factors are currently obstacles to establishing (or maintaining) universal newborn hearing screening programs for all babies born in your state." Each potential obstacle is rated on a scale from "1" (definitely not an obstacle) to "5" (an extremely serious obstacle). Figure 3 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). With the exception of the item about the degree to which "physicians know enough about newborn hearing screening, diagnosis, and intervention to encourage and support parents," exactly the same items were rated in each year.

As can be seen from the information in Figure 3, there are some interesting similarities and differences between the ratings over the three-year period. Keep in mind that the percentage of ba-

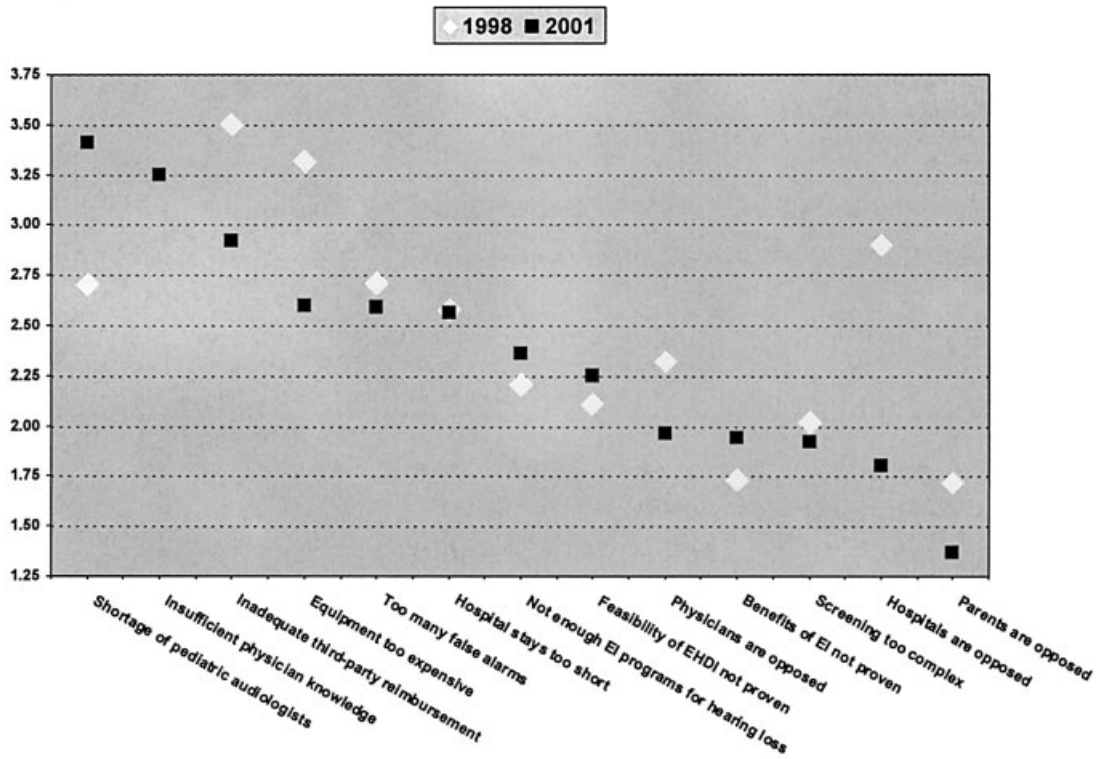

Fig. 3. State EHDI coordinators' ratings of obstacles to establishing and maintaining effective EHDI programs

bies being screened prior to discharge went from about 25% at the end of 1998 to approximately 66% at the end of 2001 (see Fig. 1). 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. It appears that as implementation of EHDI programs has expanded, hospital staff have recognized the feasibility and benefits of such programs and have become supportive.

The only potential obstacle to be ranked dramatically 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 is the fact that EHDI coordinators believe 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 rated as the third highest obstacle by state EHDI coordinators. Rated as significantly less serious obstacles, but still a concern to many state EHDI coordinators, is the fact 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 which have contributed to difficulties in the implementation of successful EHDI programs. Not surprisingly, the item rated as the least serious obstacle in each year was opposition by parents.

CURRENT STATUS OF PROGRAMS

As a part of the survey done each year by NCHAM, state EHDI coordinators are also asked to respond to questions related to each of the following components of a successful EHDI program:

- Screening all newborns for hearing loss before one month of age.
- Diagnosing referred infants no later than three months of age.
- Enrolling babies diagnosed with hearing loss in appropriate intervention programs before six months of age.
- Coordinating EHDI activities with the baby's medical home.
- Having a systematic data management and tracking system for EHDI programs.
- Providing culturally-competent family support.

The current status with regard to each of these issues is discussed briefly below.

Screening

As noted previously in Figures 1 and 2, there has been dramatic increase in the past ten years in the number of babies being screened for hearing loss prior to discharge and the number of hospitals doing universal newborn hearing screening (defined here as screening more than 90% of all births or admissions). Interestingly, no particular protocol or type of equipment has emerged as the method of choice. As shown in Table 3, approximately 53% of all screening programs use OAE in some way, and approximately 67% use AABR in some way (percentages sum to more than 100 because some programs use both OAE and AABR). Forty-two percent of programs do all of their screening prior to hospital discharge, while about 58% of programs use a two-stage protocol in which screening is not completed until an outpatient screening is done following discharge. These data suggest that no single protocol is "best" for all situations.

Table 3. Protocols Used in EHDI Programs

Screening Procedures		
Before Hospital Discharge	After Hospital Discharge	Percent of Newborns Screened
OAE	—	11.6%
ABR	—	23.3%
OAE/ABR	—	6.7%
OAE	OAE	21.4%
OAE	ABR	4.2%
ABR	OAE	2.8%
ABR	ABR	23.2%
OAE/ABR	OAE/ABR	6.4%
Other protocol	—	0.3%

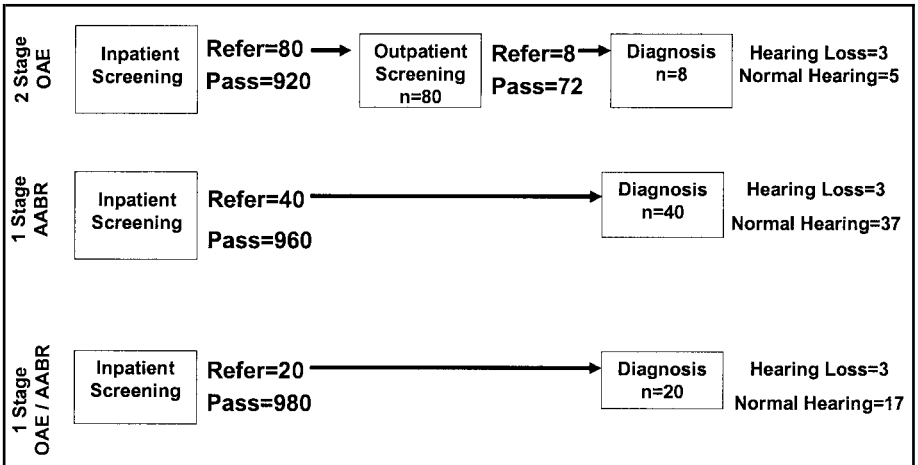

Fig. 4. Typical EHDI screening protocols

Although state EHDI coordinators report a great degree of variability in refer rates among hospitals in their state, expected refer rates based on three of the most widely used protocols are shown in Figure 4. Deciding which newborn hearing screening protocol is "best" appears to be similar to deciding whether Windows-based or Macintosh computers are "best." In other words, selecting equipment and protocol depends on the circumstances of the program and personal preferences of the people responsible. One of the most important variables is how difficult it is to get babies to come back for a second-stage or outpatient screening. It should also be noted that even though there are hundreds of screening programs reporting rates similar to those shown in Figure 4, most state EHDI coordinators report that some hospitals are struggling with much higher refer rates and/or poor coverage.

Most state EHDI coordinators leave the decision about which type of screening equipment should be used and what protocol should be followed to the individual hospitals. In fact, only 74% of state EHDI coordinators even keep track of what equipment is being used by various hospital-based screening programs.

Diagnosis Before Three Months of Age

When a baby is referred from a screening program, audiological diagnosis should be completed as soon as possible, with three months being the outer limit. Thus, the average age at which diagnosis occurs should be substantially lower than three months of age. Unfortunately, this is not occurring. State EHDI coordinators estimated that only 56% of all infants referred from newborn hearing screening programs in their state received a diagnostic evaluation by three months of age. Such delays in diagnosis are probably attributable in large part to the shortage of pediatric audiologists, which was rated by coordinators as the most significant obstacle in implementing successful EHDI programs. About half the states (57%) have developed written guidelines for conducting diagnostic audiological evaluations, and most (74%) have compiled a list of centers or individuals who are qualified to do diagnostic audiological evaluations for infants under three months of age. Unfortunately, there is not general agreement on what constitutes a qualified pediatric audiologist, and these lists are mostly comprised of self-defined pediatric audiologists. Creating uniform standards or even a separate licensure for pediatric audiologists would be a major step forward.

Enrollment in Intervention Before Six Months of Age

As described elsewhere in this volume, intervention with infants who have hearing loss is a complex, multi-faceted undertaking. Such intervention should include medical, educational, and audiological components. The shortage of experienced and qualified pediatric audiologists certainly interferes with fitting appropriate assistive listening devices as early as desired. The lack of understanding among many primary care physicians regarding early identification of hearing loss also interferes with appropriate referrals to genetics, ophthalmology, and other specialties as recommended by JCIH [2000]. In fact, only 13% of the states indicated that they had a brochure for parents about the genetics of hearing loss.

According to state EHDI coordinators, appropriate educational intervention programs for infants and toddlers with hearing loss are also not as widely available as they should be. Although Part C of the Individuals with Disabilities Education Act (IDEA) requires all states to provide appropriate early intervention programs for all children with disabilities, it appears that most programs serving children with hearing loss have been developed to serve those with severe to profound bilateral loss. This is not surprising given that most of these programs were developed and staff were trained before hospital-based newborn hearing screening programs became widespread.

Most children in Part C-funded early intervention programs are enrolled based on the fact that they exhibit significant delays from normal development. Infants and toddlers with diagnosed hearing loss usually do not exhibit such delays in language, cognitive, or social skills until they are 18–24 months of age. Even though federal regulations provide for serving children who have "established conditions that are likely to lead to developmental delays," only five of the 50 state plans for Part C provide an operational definition of how children with hearing loss would qualify for such services [NCHAM, 2002c]. Thus, it is not surprising that state EHDI coordinators estimate that only 53% of infants and

Table 4. Examples of Typical Follow-Up Rates in Universal Newborn Hearing Screening Programs

Location of Program (Time)	Cohort Size	Primary Screening Technique	% of Refers Lost to Follow-up	Prevalence Per 1000 of Hearing Loss*
New Jersey Barsky-Firkser & Sun, 1997 (1/93-12/95)	15,749	ABR	41%	3.30
New York Prieve and Stevens, 2000 (1/96-12/96)	27,938	OAE &AABR	23%	1.96
Colorado Mehl & Thomson, 1998 (1/92-12/96)	41,976	AABR	52%	2.56
Texas Finitzo et al., 1998 (1/94-6/97)	54,228	OAE	31%	2.15

*This prevalence is based on those children successfully followed. If all children had been followed, it would probably be higher.

toddlers identified with hearing loss begin an appropriate early intervention program by six months of age.

Coordination With the Infant's Medical Home

The American Academy of Pediatrics [2002] and the Maternal and Child Health Bureau advocate that all children should have access to medical care which is accessible, family-centered, comprehensive, continuous, coordinated, compassionate, and culturally effective. More detail on what constitutes a medical home is available elsewhere [HHS, 1999; AAP, 2002], but it is clear that for infants and toddlers with hearing loss to receive such care, it is critical that they be connected soon after birth to a primary care physician who is familiar with their circumstances, knowledgeable about the consequences and treatment of children with hearing loss, and who is known and trusted by the family.

Unfortunately, according to state EHDI coordinators, this is not now the case for many infants and toddlers with hearing loss. Coordinators estimate that the name of the physician who will care for the baby during the first three months of life is only known for about 75% of newborns discharged from the hospital. In many cases, these physicians are not well-informed about issues related to early identification of hearing loss. This is not surprising given the rapid changes that have occurred in our knowledge about identification and treatment of hearing loss during the last ten years. Expecting all physicians to remain up to date about a condition that affects only about three babies per thousand is unrealistic. Thus, states must find ways of providing this information to physicians on an "as needed" basis. The American Academy of Pediatrics is actively working with state EHDI coordinators to develop such informational materials, but much remains to be done. According to MCHB [2002], State Title V Directors estimate that only 63% of babies are connected with a medical home.

Systematic Data Management and Tracking

Making sure that babies who are referred from screening programs receive appropriate and timely diagnostic and intervention services remains a significant challenge. Table 4 shows the percentage of children in various studies of newborn hearing screening who were referred from the screening program and known to have received a diagnostic evaluation. As can be seen, even in these research studies where it is likely that greater attention was paid to making sure that children came back for diagnostic evaluations, it is unknown whether such diagnostic evaluations were completed for a substantial number of children (23% to 52%).

CDC has awarded grants to 30 states to develop better tracking and data management systems that can be linked with other state public health information systems (a listing of these grants is available at www.infanthearing.org), but the development of such systems will require several years and much coordination among agencies. In the meantime, the followup of children remains one of the biggest challenges to the successful implementation of EHDI programs. Closely related to the development of tracking and data management systems is the implementation of systematic evaluation and quality assurance programs. There is little evidence that most state EHDI programs have had time or resources yet to implement such systematic evaluation and quality assurance programs.

Culturally-Competent Family Support

Having a newborn identified with a hearing loss is a difficult and challenging experience for most families. State EHDI coordinators report that they are actively working to provide these families with appropriate support and assistance. Most states (77%) provide information for parents about what to do if their child is identified with a hearing loss, but only 18% of states provide these materials in the other languages that are spoken most frequently in their state. EHDI coordinators estimate that only 22% of parents are confident about what to do next when their baby is diagnosed with a hearing loss, and only 31% indicate that parents in their state have a range of choices of early intervention programs which emphasize different communication alternatives (e.g., total communication, cued speech, auditory oral, etc.). Most states (72%) indicate that they have a system in their state to assist parents of babies identified with hearing loss in making contact with other parents of babies previously identified with hearing loss.

Summary About Current Status of EHDI Programs

Table 5 summarizes the status of EHDI programs with regard to each of the six components discussed above. Clearly, much work remains to be done before such programs are fully operational.

HAS NEWBORN HEARING SCREENING BECOME THE STANDARD OF CARE?

Obviously, there are still important gaps that need to be addressed in the implementation of effective EHDI programs. Notwithstanding those challenges, it appears that newborn hearing screening has already become the de facto medical/legal standard of care in the United States. The importance of this issue is discussed by Marlowe [1996]:

"Every medical and allied health practitioner and every hospital administrator should be keenly aware

Table 5. Summary of Current Status of EHDI Programs in the United States

Component #1: All newborns are screened for hearing before discharge from the hospital or by one month of age	Although 37 states have now passed legislation related to EHDI, only about two-thirds of the hospitals have Universal Newborn Hearing Screening (UNHS) programs and only about 70% of newborns are screened prior to discharge. Although there are many examples of exemplary UNHS programs, it is not unusual to find other hospitals with unnecessarily high refer rates (e.g., >20%), and most hospitals do not have procedures in place for quality assurance and program improvement. Even though many people assume universal newborn hearing screening is a *fait accompli,* the reality is that there is still a lot of work to do to achieve high quality hearing screening for all newborns.
Component #2: Babies referred from hearing screening programs are diagnosed by 3 months of age	Connecting babies who are referred from screening programs with appropriate and timely diagnostic services continues to be a major problem. Published reports of UNHS programs report that an average of about 40% of referred babies are lost to follow-up before diagnosis and intervention. It is likely that UNHS programs which are not systematically collecting follow-up data are even worse. Exacerbating the problem with follow up is the fact that most state coordinators report a serious shortage of audiologists with the necessary skills, equipment, and interest to do diagnostic assessments on newborns and infants referred from UNHS programs.
Component #3: Babies with hearing loss are enrolled in appropriate early intervention programs before 6 months of age	Infants and toddlers diagnosed with severe or profound bilateral hearing losses generally receive reasonably good services, but this is only about one-third of all the babies being identified with hearing loss. Babies with mild to moderate bilateral or unilateral losses frequently do not receive good services because early intervention programs operated under IDEA are often not prepared to deal with the needs of such children. Although IDEA programs have many resources and activities which should be of great assistance to EHDI programs (Child Find, Case Management, etc.), coordination between EHDI and IDEA is just beginning in many states.
Component #4: All EHDI activities are coordinated with the baby's Medical Home	EHDI programs are finding it very difficult to link with the Medical Home. Even though the 1999 AAP statement and recent published studies have convinced a significant number of Primary Health Care Providers (PHCP's) that EHDI programs are practical and beneficial, many PHCP's do not understand the importance of early hearing detection, nor are they knowledgeable about recent developments in screening and diagnosis.
Component #5: Data management and tracking is used to minimize loss to follow up and for program improvement	Although the value of EHDI data management and tracking is now widely recognized, most hospitals have not implemented such systems and only a few statewide systems are operational. The recently-funded CDC Cooperative Agreements to 30 states for developing tracking and data management systems will lead to improvements, but functioning systems for most of these states are at least 2–4 years in the future.
Component #6: Families are given appropriate information and culturally competent support in conjunction with EHDI activities	Parents of babies identified with hearing loss are faced with difficult choices regarding educational, medical, and audiological alternatives (e.g., auditory oral vs. total communication modes, whether to have a cochlear implant, what type of early intervention program to enroll in, etc.). Helping parents make informed choices about these issues is a significant challenge—especially because it comes at a time when they are experiencing significant stress and anxiety as a result of learning their baby has a hearing loss.

that they are held to a hypothetical standard of care whenever their professional conduct is being evaluated legally. . .. Definition of a standard of care is complicated by the fact that it is not usually articulated in a specific, identifiable form and it may be subject to clarification on a case-by-case basis should legal actions arise" [see also Ginsburg, 1993; Hoffman, 1995].

Although there have not yet been court cases that establish newborn hearing screening as the legal standard of care, it is instructive to consider the guidelines that have been used in the past in the context of current EHDI programs.

Expectations for a Reasonable Practitioner Under Similar Circumstances

An oft-cited case in determining what constitutes a standard of care in a particular situation was the 1898 *Pike v. Honsinger* case, in which the Court of Appeals decision stated that:

"A physician. . .impliedly represents that he possesses. . .that reasonable degree of learning and skill. . .ordinarily possessed by physicians in his locality. . .. [It is the physician's] duty to use reasonable care and diligence in the exercise of his skill and learning. . .[he must] keep abreast of the times. . .departure from approved methods and general use, if it injures the patient, will render him liable."

The fact that newborn hearing screening is now being done for over 70% of all babies in every state in the country means that it would be difficult for any health care provider to successfully argue that no one in their area is doing universal newborn hearing screening. Further, health care providers are expected to "keep abreast of the times." The fact that successful EHDI programs have been operating for almost ten years makes it difficult to argue that such programs are still so new that they should be viewed as experimental or unproven.

The Support for EHDI Programs From Governmental, Professional, and Advocacy Groups Is Particularly Strong

Indeed, it is difficult to think of health care procedures that are not yet routinely implemented which have been endorsed by so many different authoritative groups ranging from the American Academy of Pediatrics to the National Institutes of Health to the March of Dimes. The only group that has carefully considered the evidence related to newborn hearing screening and not unequivocally endorsed it is the U.S. Preventive Services Task Force [Thompson et al., 2001], but their conclusions have been widely misunderstood. Although they concluded that there is not yet clear evidence about whether newborn hearing screening results in better language outcomes, they clearly stated that universal newborn hearing screening is feasible to implement, results in earlier identification of hearing loss, and can be done with equipment which is accurate, practical to use, and economical [NCHAM, 2002d].

Availability of Appropriate Technology to Implement the Practice

Ginsburg [1993] suggested that one of the criteria for establishing a standard of care:

". . .is when an inexpensive reliable device comes onto the market, the technology and concept of which have already been adopted by a group who specializes in the concept. . .a guideline becomes a

standard of care when the device behind the guideline is available and readily usable" (p. 125).

Clearly, newborn hearing screening equipment is now widely available and relatively inexpensive. More importantly, the fact that newborn hearing screening equipment is continually improving (i.e., become faster and easier to use and less expensive) means that it easily meets the standard defined by Ginsburg of being "available and readily usable."

CONCLUSIONS

The current status of EHDI programs in the United States is like the proverbial glass that is half-full or half-empty. Certainly, the likelihood that an infant or toddler with permanent hearing loss will receive timely and appropriate services is better than ever. The substantial accomplishments of the last ten years provide an excellent foundation for future progress.

- More than 70% of all newborns being screened for hearing loss prior to discharge.
- Legislation related to universal newborn hearing screening passed by 37 states.
- The availability of federal funding for all states to develop statewide EHDI programs.
- Substantial involvement and support from prestigious federal and professional organizations such as MCHB, CDC, NIH, the American Academy of Pediatrics, and March of Dimes.

At the same time, we are still a long way from accomplishing the goal set by Dr. Koop in 1990 that "no child [would reach] his or her first birthday with an undetected hearing loss." In fact, given the current technology, most people working on EHDI programs would agree that for the vast majority of children, hearing loss should be detected before three months of age. To reach that goal, significant improvement is needed in the availability of pediatric audiologists, tracking and data management, program evaluation and quality assurance, availability of appropriate early intervention programs, and linkages with medical home providers.

Different from the early 1990s, there is now a solid research and experiential basis for addressing all of these issues, but it will continue to require the commitment and resources of state health officials, hospital administrators, health care providers (particularly physicians and audiologists), and parents. The issues that need to be resolved are complex and will require stakeholders to work together over a sustained period of time. As a result of continuing such work, infants and young children with permanent hearing loss will be able to acquire the "fundamental language, social, and cognitive skills that provide the foundation for later schooling and success in society" as foreseen more than ten years ago in the **Healthy People 2000** report. ■

REFERENCES

American Academy of Pediatrics. 1995. Joint Committee on Infant Hearing 1994 position statement. Pediatrics 95:152–156.

American Academy of Pediatrics. 1999. Newborn and infant hearing loss: Detection and intervention. Pediatrics 103:527–530

American Academy of Pediatrics. 2002. The Medical Home Policy Statement. Pediatrics 110. Retrieved Dec. 18, 2002 from http://www.aap.org/policy/s060016.html.

Babbidge H. 1965. Education of the deaf in the United States: Report of the Advisory Committee on Education of the Deaf. Washington, DC: U.S. Government Printing Office.

Barsky-Firkser L, Sun S. 1997. Universal newborn hearing screenings: A three-year experience. Pediatrics 99:E4.

Bess FH. 1993. Early identification of hearing loss: A review of the whys, hows, and whens. The Hearing Journal 46:22–25.

Bess FH, Paradise JL. 1994. Universal screening for infant hearing impairment: Not simple, not risk-free, not necessarily beneficial, and not presently justified. Pediatrics 93:330–334.

Centers for Disease Control and Prevention. 2002. The Early Hearing Detection and Intervention Program: Promoting communication from birth. Retrieved Dec. 2, 2002 from http://www.cdc.gov/ncbddd/ehdi/documents/fact_sheet.pdf.

Downs MP, Sterritt GM. 1964. Identification audiometry for infants: A preliminary report. Journal of Audiological Research 4:69–80.

Downs MP, Sterritt GM. 1967. A guide to newborn and infant hearing screening programs. Arch Otolaryngol 85:37–44.

Ewing IR, Ewing AWG. 1944. The ascertainment of deafness in infancy and early childhood. J Laryngol Otol 59:309–333.

Finitzo T, Albright K, O'Neal J. 1998. The newborn with hearing loss: Detection in the nursery. Pediatrics 102:1452–1460.

Ginsburg WH Jr. 1993. When does a guideline become a standard? The new American Society of Anesthesiologists guidelines give us a clue. Ann Emerg Med 22:1891–1896.

Herrmann BS, Thornton AR, Joseph, JM. 1995. Automated infant hearing screening using the ABR: Development and validation. Am J Audiol 4:6–14.

Hoffman AC. 1995. Medical malpractice. In Sanbar SS, Gibofsky A, Firestone MH, LeBlang TR, editors. Leg Med 129–140. St. Louis: Mosby.

Joint Committee on Infant Hearing. 2000. Year 2000 Position Statement: Principles and guidelines for early hearing detection and intervention programs. Available at: http://www.infanthearing.org/jcih/.

Kemp DT. 1978. Stimulated acoustic emissions from the human auditory system. J Acoust Soc Am 89:2027–2067.

Kemp DT, Ryan S. 1993. The use of transient evoked otoacoustic emissions in neonatal hearing screening programs. Seminars in Hearing 14:30–45.

Leonard DR, Shen T, Howe HL, et al., editors. 1999. Trends in the prevalence of birth defects in Illinois and Chicago 1989 to 1997. Epidemiologic Report Series 99:4. Springfield, IL: Illinois Department of Public Health.

Lonsbury-Martin BL, Martin GK. 1990. The clinical utility of distortion product otoacoustic emissions. Ear Hear 11:144–150.

Marlowe JA. 1996. Legal and risk management issues in newborn hearing screening. Seminars in Hearing 17:153–164.

Mason JA, Herrmann KR. 1998. Universal infant hearing screening by automated auditory brainstem response measurement. Pediatrics 101:221–228.

Maternal and Child Health Bureau. 2002. National core and performance outcome measures. Retrieved Dec. 2, 2002 from http://205.153.240.79/search/core/cormenu.asp.

Maxon AB, White KR, Behrens TR, et al. 1995. Referral rates and cost efficiency in a universal newborn hearing screening program using transient evoked otoacoustic emissions (TEOAE). J Am Acad Audiol 6:271–277.

Mehl AL, Thomson V. 1998. Newborn hearing screening: The great omission. Pediatrics 101. http://www.pediatrics.org/cgi/content/full/101/1/e4, p 1–6.

National Center for Hearing Assessment and Management. 2002a. Universal newborn hearing screening: Summary statistics of UNHS in the United States. Retrieved Dec. 2, 2002 from http://www.infanthearing.org/status/unhsstate.html.

National Center for Hearing Assessment and Management. 2002b. Legislative activities. Retrieved Dec. 2, 2002 from http://www.infanthearing.org/legislative/summary/index.html.

National Center for Hearing Assessment and Management. 2002c. Criteria for infants and toddlers with hearing loss to be eligible for early intervention services under IDEA. Retrieved Dec. 2, 2002 from http://www.infanthearing.org/earlyintervention/eligibility.pdf.

National Center for Hearing Assessment and Management. 2002d. U.S. Preventive Services Task Force report on newborn hearing screening. Retrieved Dec. 2, 2002 from http://www.infanthearing.org/newsletter/backissues/si_v3n3.pdf.

National Institutes of Health. 1993. Early identification of hearing impairment in infants and younger children. Rockville, MD: National Institutes of Health.

Northern JL, Downs MP. 1974. Hearing in children. Baltimore: Williams and Wilkins.

Northern JL, Downs MP. 1991. Hearing in children. 4th Ed. Baltimore: Williams and Wilkins p 2–3.

Prieve BA, Stevens F. 2000. The New York State Universal Newborn Hearing Screening Demonstration Project: Introduction and overview. Ear Hear. 21:85–91.

Stierman L. 1994. Birth defects in California: 1983–1990. The California Birth Defects Monitoring Program, California Department of Health Services.

Thompson DC, McPhillips H, Davis RL, et al. 2001. Universal newborn hearing screening summary of evidence. JAMA 286:2000–2010.

Toward Equality. 1988. A report to the Congress of the United States: Toward equality - Commission on Education of the Deaf. Washington, DC: U.S. Government Printing Office.

U.S. Department of Health and Human Services. 1990. Healthy People 2000: National health promotion and disease prevention objectives. Washington, DC: Public Health Service.

U.S. Department of Health and Human Services, Health Resources and Services Administration. 1999. Measuring success for Healthy People 2010: National agenda for children with special health care needs. Washington, DC: US Department of Health and Human Services.

U.S. Preventive Services Task Force. 1996. Screening for hearing impairment. In: US Preventive Services Task Force Guide to Clinical Preventive Services, 2nd ed. Baltimore, MD: Williams & Wilkins. 1996:393–405.

Vohr BR, Carty LM, Moore PE, et al. 1998. The Rhode Island Hearing Assessment Program: Experience with statewide hearing screening (1993–1996). J. Pediatr. 133:353–357.

White KR. 1997. Universal newborn hearing screening: Issues and evidence. Retrieved Dec. 2, 2002 from http://www.infanthearing.org/summary/prevalence.html.

White KR, Behrens TR, editors. 1993. The Rhode Island Hearing Assessment Project: Implications for universal newborn hearing screening. Seminars in Hearing 14.

White KR, Maxon AB. 1995. Universal screening for infant hearing impairment: simple, beneficial, and presently justified. Int J Pediatr Otorhinolaryngology 32:201–211.

Yoshinaga-Itano C, Sedey AL, Coulter DK, et al. 1998. Language of early- and later-identified children with hearing loss. Pediatrics 102:1161–1171.