The Evolution of Early Hearing Detection and Intervention Programs in the United States

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Identifying and treating children with congenital hearing loss during the first few months of life is a relatively new concept. To assist states in the development of statewide Early Hearing Detection and Intervention programs, the federal government provides grants and/or cooperative agreements to almost all states and has established “National Goals, Program Objectives and Performance Measures” to guide the development and implementation of those systems. This article reviews the history of newborn hearing screening programs in the United States, summarizes the content of legislation and regulations passed by states related to universal newborn hearing screening, and describes how well each National Goal has been addressed. Although substantial progress has been made in the percentage of infants screened for hearing loss before hospital discharge, significant improvement is needed with respect to the availability of pediatric audiologists, implementation of effective tracking and data management systems, program evaluation and quality assurance, availability of appropriate early intervention programs, and linkages with medical home providers.

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The US Department of Health and Human Services has established national health objectives to be achieved by the end of 2010. It is notable that these objectives, known as Healthy People 2010,1 included the following goal related to Early Hearing Detection and Intervention (EHDI) programs:

“. . . Increase the proportion of newborns who are screened for hearing loss by age 1 month, have audiologic evaluation by age 3 months, and are enrolled in appropriate intervention services by age 6 months.”

The value of identifying congenital hearing loss during the first few months of life has been recognized for decades,2 but the belief that it could be achieved is relatively new. For example, as recently as 1996, the United States Preventive Services Task Force,3 while noting that “congenital hearing loss is a serious health problem associated with developmental delay in speech and language function,” concluded that “there is little evidence to support the use of routine, universal screening for all neonates.” Similarly, in a 1999 article,4 Paradise concluded the following:

“. . . universal newborn hearing screening in our present state of knowledge is not necessarily the only, or the best, or the most cost-effective way to achieve [early identification of hearing loss], and more importantly . . . the benefits of universal newborn hearing screening may be outweighed by its risks.”

Despite such skepticism about the practicality of newborn hearing screening, Dr C. Everett Koop, when he was serving as the Surgeon General of the United States in 1989, called for increased efforts to identify congenital hearing loss during the first few months of life.

“. . . 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.”

Dr Koop’s enthusiasm for newborn hearing screening and his optimism that it could be successfully implemented was a little surprising given the fact that fewer than 3% of all newborns in the United States were screened for hearing loss at that time. That situation has changed dramatically during the last 15 years as shown in Fig. 1. An increase from 3% to 94% of newborns being screened for hearing loss before being discharged from the hospital is no small feat.

**Factors Contributing to the Expansion of Newborn Hearing Screening Programs**

The establishment and expansion of newborn hearing screening programs has been facilitated by (1) policy initiatives by government, professional associations, and advocacy groups; (2) financial assistance from the federal government; (3) improvements in technology; (4) legislative initiatives; and (5) the demonstrated success of early implementations.

**Policy Initiatives**

The federal government has been encouraging earlier identification of permanent hearing loss for many years. For example, the Babbidge Report issued by the US 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.” A short time later in 1969, based on the pioneering work of Marion Downs, the Joint Committee on Infant Hearing (JCIH) was established by a group of professional associations (eg, American Speech Language and Hearing Association, American Academy of Pediatrics [AAP], American Academy of Otolaryngology - Head and Neck Surgery, among others). Even though the JCIH had little or no budget and no formal authority, they became a powerful force in advocating for earlier identification and better treatment of congenital hearing loss. Because appropriate hearing screening technology was not available at the time, the JCIH focused on screening only high-risk infants until their 1994 Position Statement when they endorsed universal newborn hearing screening.

As new hearing screening technologies became available in the late 1980s, the federal government began devoting more resources to reducing the age at which hearing loss was identified. These efforts were consistent with a recommendation from the congressionally mandated Commission on Education of the Deaf that "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 few years later, Healthy People 2000 included an objective to “reduce the average age at which children with significant hearing impairment are identified to no more than 12 months.” The accompanying rationale for this objective stated the following:

“. . . 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).”

Healthy People 2000 included an objective to “reduce the average age at which children with significant hearing impairment are identified to no more than 12 months.” The accompanying rationale for this objective stated the following:

Although the rationale for this objective was similar to what people had been advocating for many years, inclusion of this objective in Healthy People 2000 changed the landscape because it was linked to a federal mandate that progress toward each objective had to be tracked and reported at regular intervals.

In March 1993, the National Institutes of Health (NIH) convened a Consensus Development Panel to review the extant evidence on early identification of hearing loss and make recommendations to improve practice. The panel concluded that, “All hearing impaired infants should be identified and treatment initiated by 6 months of age . . . [T]he consensus panel recommends screening of all newborns . . . for hearing impairment prior to discharge.”

Many people expected immediate implementation of universal newborn hearing screening programs because of the NIH panel’s recommendation. However, research evidence about the value of universal newborn hearing screening and experience for such broad-scale implementation was lacking. Indeed, shortly after the NIH Consensus Panel’s recommendations were issued, Bess and Paradise 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.”

**Federal Support for EHDI Initiatives**

The policy initiatives of the late 1980s and early 1990s resulted in significantly more federal funding being devoted to research, demonstration, and technical assistance projects focused on reducing the age at which congenital hearing loss was identified. Some of the best known are the Rhode Island Hearing Assessment Project, the Marion Downs Hearing.
Center, and the National Center for Hearing Assessment and Management (NCHAM) at Utah State University, but there were many others. The timing of these projects was important because they were carried out just as the recommendations of the NIH Consensus Conference referred to above were beginning to be debated.

Successful Implementation of Screening Programs

Although the cautions about newborn hearing screening expressed by Bess and Paradise were widely criticized, the fact is that less research was done in 1993 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, research about newborn hearing screening available at that time was based on small samples of infants (primarily from neonatal intensive care units) over a short period. The recommendations of the NIH Consensus Panel and the controversy generated by Bess and Paradise stimulated a great deal of activity over the next 5 years as the percentage of infants being screened for hearing loss before hospital discharge increased steadily (Fig. 1). By 1998 there was a growing body of research supporting the feasibility, cost-efficiency, and benefits of newborn hearing screening, and dozens of large-scale universal newborn hearing screening programs had become operational in various states. Since that time, more and more research has been published, showing the benefits of newborn hearing screening, and the United States Preventive Services Task Force now recommends screening of hearing loss in all newborn infants.

Technological Advances

Technological breakthroughs in hearing screening equipment that occurred in the late 1980s were a major contributor to the growth of newborn hearing screening programs. Without improvements in automated Auditory Brainstem Response (A-ABR) and otoacoustic emissions (OAE), all the policy initiatives, federally funded projects, and clinical screening programs that combined to demonstrate the practicality of universal newborn hearing screening programs would never have happened.

Endorsements by Professional and Advocacy Groups

Successful programs coupled with the results of ongoing research, led to more recommendations for universal newborn hearing screening by other government, professional, and advocacy organizations. For example, in 1999 the AAP endorsed “universal [hearing] screening of all infants.” Other 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 soon followed suit.

Also, in 1998, the federal Maternal and Child Health Bureau (MCHB) 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. 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 established an EHDI program.

Legislation Related to Newborn Hearing Screening

The factors described above were essential in creating an atmosphere where newborn hearing screening programs could be implemented, but legislative and administrative actions have been critical for expanding the reach and sustainability of these programs. The first legislation related to newborn hearing screening was passed in Hawaii in 1990. As more and more newborn hearing screening programs were implemented and policy makers and the public became more aware of the benefits associated with such programs, more and more legislation was passed. As of January 2010 there were 43 states with statutes or other regulatory language related to universal newborn hearing screening, and a recent analysis concluded that states with legislation were much more likely to be screening 95% or more of their infants than those without legislation.

Several important points are worth noting about the legislative mandates related to universal newborn hearing screening.

1. About 80% (34/43 states) were approved after 1998. The increase in legislative activity was probably influenced by the publication of the AAP Position Statement 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.

2. Only 28 of 43 states (65%) require screening of all infants. The fact that some states set the standard as low as 85% of all newborns raises significant issues about accessibility and coverage.

3. Of 43 states, 29 (67%) require hospitals to report data from newborn hearing screening to the state department of health, which is consistent with the view that newborn hearing screening is a public health program.

4. The fact that only 7 states (16%) require parents to provide written informed consent suggests that most states view hearing screening as a routine part of newborn health care.

5. Twenty-one statutes (49%) indicate that newborn hearing screening is a covered benefit of health insurance policies issued in the state. However, because of how insurance reimbursement is done, hospitals in most of these states have not been paid additional money for newborn hearing screening procedures even though the statute states that it is a covered benefit.

It is important to note that legislation specifies the minimum expectations of state policy makers, but does not necessarily
define all that state newborn hearing screening programs are doing. For example, Rhode Island has one of the nation’s best tracking and reporting systems, reports data to the Rhode Island Department of Health, and has an Advisory Committee, even though none of these are required by the Rhode Island legislation.

**Current Status of EHDI Programs in the United States**

With the expansion of newborn hearing screening programs during the mid-1990s, it became clear that screening is only the beginning step in a process necessary to identify infants and toddlers with hearing loss and provide them and their families with timely and appropriate services. Because of work done by JCIH, MCHB, and the Centers for Disease Control and Prevention (CDC)\textsuperscript{10-14} most people stopped using the phrase, “Universal Newborn Hearing Screening” and began referring to “Early Hearing Detection and Intervention (EHDI)” programs. The change in how these programs are described is important, because it underscores that successfully identifying and serving infants and young children with congenital hearing loss, requires going beyond screening to address issues related to audiological diagnosis; appropriate medical, audiologic, and educational intervention; coordination with the child’s primary health care provider (often referred to as the child’s medical home); tracking and surveillance systems; and monitoring/evaluating how the system is functioning. In collaboration with state EHDI program coordinators and representatives from other federal, professional, and advocacy agencies, CDC has developed national EHDI goals, Program objectives, and performance indicators\textsuperscript{32} that are based on EHDI guidelines from various states and the position statements of the JCIH and the AAP. These national goals are summarized in Table 1. How well each of these goals is being achieved is summarized in the remainder of this article.

**Goal 1: All Newborns Will Be Screened for Hearing Loss**

During the past 2 decades screening efforts have increased significantly and by 2007 the CDC was able to document that

<table>
<thead>
<tr>
<th>Goal</th>
<th>National Goals for EHDI Programs\textsuperscript{33}</th>
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<tbody>
<tr>
<td>Goal 1</td>
<td>All newborns will be screened for hearing loss before 1 month of age, preferably before hospital discharge.</td>
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<tr>
<td>Goal 2</td>
<td>All infants who screen positive will have a diagnostic audiological evaluation before 3 months of age.</td>
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<tr>
<td>Goal 3</td>
<td>All infants identified with hearing loss will receive appropriate early intervention services before 6 months of age (medical, audiologic, and early intervention)</td>
</tr>
<tr>
<td>Goal 4</td>
<td>All infants and children with late-onset or progressive hearing loss will be identified at the earliest possible time.</td>
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<tr>
<td>Goal 5</td>
<td>All infants with hearing loss will have a medical home as defined by the AAP.</td>
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<tr>
<td>Goal 6</td>
<td>Every state will have an EHDI Tracking and Surveillance System that minimizes loss to follow-up.</td>
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<tr>
<td>Goal 7</td>
<td>Every state will have a system that monitors and evaluates the progress toward the EHDI Goals and Objectives.</td>
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at least 94.0% of infants were screened for hearing loss. Interestingly, no particular protocol or type of equipment has emerged as the method of choice. As shown in Table 2, a survey conducted by NCHAM in 2004 showed that 50.3% of all screening programs were using OAE in some way, and 62.4% were using A-ABR in some way (percentages sum to more than 100% because some programs use both OAE and A-ABR). Approximately 40% of programs did all of their screening before hospital discharge, while about 60% of programs used a 2-stage protocol in which screening was not completed until an outpatient screening was done after discharge. The fact that so many different screening protocols were used suggests that no single protocol is “best” for all situations. Because the JCIH recently recommended “ABR technology as the only appropriate screening technique for use in the neonatal intensive care unit,” the percentage of programs using A-ABR will probably increase.

Deciding what type of equipment and which protocol to use in a newborn hearing screening program depends on the circumstances of the program and preferences of the people responsible. An important consideration is how difficult it is to make infants come back for a second-stage or outpatient screening. In situations where it is difficult to make infants return for an outpatient screening, A-ABR may have an advantage because refer rates at time of discharge are typically lower (but, the cost of operating the equipment is somewhat higher). It is also important to consider what degree of hearing loss is targeted by the screening program. Depending on the equipment used, OAE has a lower detection threshold, but studies have not yet determined whether infants with mild hearing loss are being missed.

Most state EHDI coordinators leave the decisions about screening equipment and protocol to individual hospitals. In fact, in the 2004 NCHAM survey only 67% of state EHDI coordinators kept track of what equipment and/or protocol was used by various hospital-based screening programs. A small, but important subgroup that is not being well served by current EHDI programs are infants born at home. With 1%-2% of all births occurring outside of a hospital, this represents 40,000-80,000 infants per year. In 2004, only 21 states reported that they had a systematic program in place to screen out-of-hospital births, and those states were only able to screen an estimated 41% of these births. Another subgroup about which little information about newborn hearing screening includes infants born in US military hospitals.

**Goal 2: Referred Infants Will Be Diagnosed Before 3 Months of Age**

When an infant is referred from a screening program, audiological diagnosis should be completed as soon as possible, but all diagnostic testing should be completed before 3 months of age. Figure 2 shows that the average age of diagnosis is 2-4 months of age in states with well-developed EHDI programs, effective follow-up procedures, and appropriate diagnostic systems. This is a dramatic improvement over what was being reported 15-20 years ago.

Unfortunately, according to the latest data from CDC, in 2007 state EHDI programs were not able to document whether diagnostic evaluations were actually completed for 44.8% of the infants who needed them. By 2004, most states (90%) reported that they had developed written guidelines for conducting diagnostic audiological evaluations, and most (78%) had compiled a list of centers or individuals who were qualified and had appropriate equipment and experience to do diagnostic audiological evaluations for infants under 3 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 or certification for pediatric audiologists would be a major step forward. In fact, in the 2004 survey by NCHAM, 79% of state EHDI coordinators said it would be “beneficial if there were a license or certification for pediatric audiologists who specialize in diagnostic assessments and/or hearing aid fitting for infants and toddlers.”

No state currently has such a designation for pediatric audiologists.

In a national evaluation of newborn hearing screening and intervention programs reported by Mathematica Policy Research, Inc., in 2006, the following factors were identified as contributing to poor follow-up rates:

1. Lack of qualified audiologists to do diagnostic evaluations

   ![Figure 2](Author's personal copy)

   **Figure 2** Age in months at which permanent hearing loss was diagnosed.
2. Lack of appropriate equipment
3. Lack of knowledge among health providers about the importance and urgency of follow-up testing
4. Difficulties with transportation, ability to pay and motivation on the part of families
5. Poor communication among primary health care providers, audiologists and the state EHDI program

Goal 3: Provision of Appropriate Medical, Audiologic, and Educational Intervention Before 6 Months of Age

Providing appropriate medical, audiological, and educational services to infants and young children with permanent hearing loss is a complex, multifaceted undertaking. The shortage of experienced and qualified pediatric audiologists noted above, also interferes with fitting appropriate hearing technology as early as desired. But how much do other professionals know about providing services to infants and toddlers with hearing loss? Unfortunately, many primary health care providers (PHCPs) are not up-to-date with current knowledge regarding early identification of hearing loss. For example, JCIH recommends that all infants with confirmed hearing loss be referred to a geneticist, and ophthalmologist, and an otolaryngologist who has knowledge of pediatric hearing loss. However, when 1968 PHCPs who cared for children in 22 different states and territories responded to a question about to whom they would refer a newborn patient who had been “diagnosed with a moderate to profound bilateral hearing loss . . . [when] no other indications are present,” only 0.6% said they would refer to an ophthalmologist, 8.9% to a geneticist, and 75.6% to an otolaryngologist. When asked at what age an infant could be fit with hearing aids, almost half said 6 months or older. Clearly, many PHCPs need better understanding of what is the appropriate treatment for infants and young children with 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 needed. Although Part C of the federal Individuals with Disabilities Education Act requires all states to provide appropriate early intervention programs for all infants and toddlers with disabilities, 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 measurable 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 5 of the 51 state plans for Part C provide an operational definition of how children with hearing loss would qualify for such services. Of greater concern, CDC reports that in 2007 state EHDI coordinators were only able to document that 57.9% of infants and toddlers with permanent hearing loss were enrolled in Part C programs and only 61% of those could be documented as having been enrolled before 6 months of age.

To successfully serve infants and toddlers with hearing loss, the state’s EHDI and Part C programs should be working closely together. Yet, in the 2004 survey by NCHAM only 57% of state EHDI coordinators indicated that they had a “good or excellent coordination and cooperation” with their state Part C program. The perception that EHDI and Part C programs are not working together as closely as they should is reinforced by the following:

- When asked if there was someone on the Part C Interagency Coordinating Council with experience/expertise serving infants and toddlers with hearing loss, five state EHDI coordinators said there was not, and twelve more said they were unsure.
- Fourteen state EHDI programs do not report children identified with hearing loss to the state’s Part C program.
- Twenty-three state EHDI coordinators did not know, and an additional 7 said that children enrolled in the state’s Part C program for reasons other than permanent hearing loss were not regularly checked for hearing.

Goal 4: Infants and Children With Late-Onset or Progressive Hearing Loss Will Be Identified at the Earliest Possible Time

Because the terms “late-onset” and “progressive” are used together frequently, many people seem to think they are different words for the same condition; but they are not. A progressive hearing loss is one that worsens over time, whether the hearing loss is congenital or late-onset. The term “late-onset hearing loss” should only be used when normal hearing was present at birth and a permanent hearing loss occurred later.

The latest statement from JCIH has recommended the following:

- Infants who pass the neonatal screening but have a risk factor should have at least 1 diagnostic audiology assessment by 24-30 months of age. All infants should have an objective standardized screening of global development with a validated assessment tool at 9, 18, and 24-30 months of age. Infants who do not pass The speech-language portion of a medical home global screening or for whom there is a concern regarding hearing or language should be referred for speech-language evaluation and audiology assessment.

Unfortunately, little is known about the costs or benefits of implementing this recommendation. But, implementing such a recommendation will be challenging given the shortage of pediatric audiologists.

In 2004, only 14 states were collecting risk indicator information from “all hospitals” and 17 states were collecting it for “some hospitals.” Eight states reported that they received risk indicator data for ≥85% of all births. In many cases, the state EHDI program reports the presence of the risk indicator to the child’s PHCP and/or parent and takes no further action. States that were collecting risk factor data reported that they
tried to do audiologic monitoring for 57% of the children that had risk indicators. Unfortunately, they were only able to complete “at least one audiologic monitoring during the first year of life” for 40% of those children where an attempt was made.44

Clearly, detection of late-onset hearing losses is an important component of a comprehensive EHDI program. However, more work is needed to determine how this can be done most efficiently.

**Goal 5: All Infants With Hearing Loss Will Have a Medical Home**

The AAP advocates that all children should have access to health care that is accessible, family-centered, comprehensive, continuous, coordinated, compassionate, and culturally effective. More detail on what constitutes a medical home is available elsewhere,1,61 but it is clear that services for infants and toddlers with hearing loss would be much better if families of children with hearing loss were connected soon after birth to a PHCP familiar with their circumstances, knowledgeable about the consequences and treatment of children with hearing loss, and known and trusted by the family.

Unfortunately, according to state EHDI coordinators, this is not the case for many infants and toddlers with hearing loss. In a 2006 national survey, only 73% of coordinators said that hospitals in their state contacted the PHCP when a child did not pass the newborn hearing screening test.57 In the 2004 survey, the name of the PHCP who will care for the infant during the first 3 months of life was only known for about 75% of newborns discharged from the hospital.44 Furthermore, many PHCPs are not well-informed about issues related to early identification of hearing loss.58 This is not surprising given the rapid changes that have occurred in our knowledge about identification and treatment of hearing loss during the last 10 years. It is unrealistic to expect all PHCPs to remain up to date about a condition that affects only about 3 infants per 1000. Thus, states must find ways of providing this information to PHCPs on an “as needed” basis. The AAP is actively working with state EHDI coordinators to develop such informational materials, but much remains to be done.

According to MCHB, State Title V Directors estimated that only 57.5% of all infants were connected with a medical home.62 State EHDI coordinators estimated that results about the hearing screening test were sent to the infant’s medical home for 73% of the births, but it is unclear how frequently these results reached the correct PHCP.57

**Goal 6. Every State Will Have a Tracking and Surveillance System to Minimize Loss to Follow-up**

Making sure that infants who are referred from screening programs receive appropriate and timely diagnostic and intervention services remains a significant challenge. CDC currently awards funding63 to 47 states, 5 territories, and the District of Columbia to assist with the development and enhancement of improved tracking and data management systems that can be linked with other state public health information systems. A recent survey of public health agencies concluded that information from EHDI programs was the child health information most likely to be integrated with other health systems,69 but continued effort and improved coordination among agencies is still needed.

In the meantime, accurate data for follow-up remain one of the biggest challenges to the successful implementation of EHDI programs. As shown in Table 3, results from a 2006 national survey showed that hospitals used various methods to report the results of hearing screenings to the state EHDI program, including paper forms (mailed or faxed), software developed specifically for this purpose, adaptations to the bloodspot screening cards or electronic birth certificates.37 Some state programs required reporting through one method, such as on the metabolic screening card. But, many state programs allowed each hospital to choose which system best suited its needs, which means that only half the EHDI programs received screening results from all hospitals through a single method, the most common being a faxed or mailed paper form.57

Eighty-five percent of EHDI programs received data about the screening outcomes of individual infants,37 which means that most state EHDI programs were in the position to assist in follow-up with individual families. Linkages with other public health data systems are also expanding with 15 states reporting in the 2004 NCHAM survey that they had some type of linkage with newborn dried bloodspot screening programs, 13 with vital statistics, and 4 each with immunization registries and early intervention programs.44 As these linkages are refined and stabilized, it will eliminate duplication and will mean that services to these families can be better coordinated.69

**Goal 7. All States Will Have a System to Monitor and Evaluate Progress Toward the EHDI Goals and Objectives**

Closely related to the development of tracking and data management systems is the implementation of systematic evaluation and quality assurance programs. As visualized in the CDC national goals, an EHDI advisory committee in each state should take the responsibility for developing and maintaining such a system. Almost all states currently have an

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**Table 3 Reporting Methods Used by Hospitals to Convey Information to State EHDI Program**

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<thead>
<tr>
<th>Reporting Method</th>
<th>Used Exclusively</th>
<th>Used in Combination With Other Methods</th>
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<tbody>
<tr>
<td>Paper forms (mailed or faxed)</td>
<td>20%</td>
<td>42%</td>
</tr>
<tr>
<td>Email or other electronic method</td>
<td>12%</td>
<td>26%</td>
</tr>
<tr>
<td>Software</td>
<td>11%</td>
<td>19%</td>
</tr>
<tr>
<td>Bloodspot screening card</td>
<td>4%</td>
<td>21%</td>
</tr>
<tr>
<td>Electronic birth certificate</td>
<td>6%</td>
<td>11%</td>
</tr>
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EHDI advisory committee. Most of these committees meet quarterly or more often and almost all of them have representation from audiologists, parents of children with hearing loss, PHCPs, early intervention providers, and various other stakeholders. These committees have made good progress in overseeing the development of educational materials for PHCPs and parents. In a 2004 survey, coordinators in 78% of the states said they had good to excellent materials for educating parents about the states EHDI program. More work is needed in developing materials to educate PHCPs about EHDI and to educate parents of children with hearing loss about communication options where only 53% and 56%, respectively, of EHDI coordinators said that they had good to excellent materials. Eighty-three percent of the states reported in 2006 that they had developed materials in languages other than English.

Systematic evaluation and monitoring of the state EHDI program is another important area where more work is needed. Although states reported a variety of methods being used to gather information about the EHDI program (31 states used site visits, 36 reviewed archival data, 20 did surveys or focus groups with hospitals, 15 did surveys or focus groups with parents, and 7 did surveys or focus groups with PHCPs); only 18 states reported that a systematic evaluation of their state’s EHDI program had been completed during the last 5 years. Of these 18 evaluations, 10 were internal evaluations conducted by state EHDI program staff and only 8 resulted in a written report. These data suggest that it would be valuable for states to devote more attention to evaluation and monitoring of EHDI programs. An important part of monitoring progress toward the accomplishment of EHDI goals is to ensure that the program has adequate resources to be sustained over time. Unfortunately, most EHDI programs are on somewhat tenuous financial footing. In 2004, almost two-thirds of the resources devoted to state EHDI programs came from the MCHB grants and CDC cooperative agreements that are viewed by Congress as a temporary source of support. Only 17.4% of state EHDI program resources came from state appropriations and only 6 states provided more than half of the resources for their EHDI program from nonfederal sources. The fact that such a high percentage of funding for these programs is from sources that cannot be counted on in the future means that the long-term stability of EHDI programs is somewhat in doubt. In fact, in 2006, 42% of EHDI coordinators were unsure whether the program could be continued if federal funding were to be discontinued.

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 for an infant or toddler with permanent hearing loss to receive timely and appropriate services is better than ever. The substantial accomplishments of the last 15 years provide an excellent foundation for future progress.

According to the National Goals established by CDC, all children with permanent hearing loss should be diagnosed before 3 months of age. But we are still a long ways from achieving the more modest goal set by Dr Koop in 1990 that “no child [would reach] his or her first birthday with an undetected hearing loss.” To effectively identify children with permanent hearing loss and provide them and their families with the services they need, significant improvement must be made 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. In contrast to the early 1990s, there is now a solid research and an 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 PHCPs and audiologists), and parents. The issues that need to be resolved are complex and will require stakeholders to continue working together over a sustained period. Because 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 almost 20 years ago in the Healthy People 2000 report.

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