Evaluation of the Universal Newborn Hearing Screening and Intervention Program

abstract

During the last 20 years, the number of infants evaluated for permanent hearing loss at birth has increased dramatically with universal newborn hearing screening and intervention (UNHSI) programs operating in all US states and many territories. One of the most urgent challenges of UNHSI programs involves loss to follow-up among families whose infants screen positive for hearing loss. We surveyed 55 state and territorial UNHSI programs and conducted site visits with 8 state programs to evaluate progress in reaching program goals and to identify barriers to successful follow-up. We conclude that programs have made great strides in screening infants for hearing loss, but barriers to linking families of infants who do not pass the screening to further follow-up remain. We identified 4 areas in which there were barriers to follow-up (lack of service-system capacity, lack of provider knowledge, challenges to families in obtaining services, and information gaps), as well as successful strategies used by some states to address barriers within each of these areas. We also identified 5 key areas for future program improvements: (1) improving data systems to support surveillance and follow-up activities; (2) ensuring that all infants have a medical home; (3) building capacity beyond identified providers; (4) developing family support services; and (5) promoting the importance of early detection.

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ABBREVIATIONS
UNHSI—universal newborn hearing screening and intervention
EI—early intervention
AAP—American Academy of Pediatrics
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Each year, ~12,000 infants in the United States are born with permanent hearing loss. Newborn hearing screening can help ensure early detection of hearing loss for these infants. The average age of detection of hearing loss without screening is 2½ to 3 years of age, which is far too late. The availability of effective newborn hearing screening and treatment prompted Congress to pass legislation in 1999 that created a universal newborn hearing screening and intervention (UNHSI) program to ensure that (1) all newborns are screened for hearing loss, (2) newborns who do not pass the screening receive an audiologic diagnosis before 3 months of age, (3) infants with hearing loss have a medical home and family support, and (4) infants with hearing loss have a medical home and family support (see Fig 1 for a conceptual framework of the UNHSI program). Research results have revealed that such screening and intervention programs can reduce the time to identification of hearing loss and improve language abilities.

Currently, UNHSI programs are operating in all states and most territories, and nearly every hospital in the United States is currently screening all infants for hearing loss. Despite these advancements, UNHSI programs continue to face barriers to full implementation. One of the most urgent challenges is that many families whose infants screen positive for hearing loss do not return for follow-up evaluations. Recent study results suggest that loss to follow-up is associated with factors such as inadequate communication among various providers, shortages of pediatric audiologists, inadequate health insurance coverage, and various demographic characteristics, but there has not been a systematic analysis of how these and other factors are interfering with successful follow-up and how barriers to follow-up can be addressed. On the basis of a national evaluation, we identify barriers to follow-up for infants who require further evaluation and outline strategies for overcoming these barriers.

**METHODS**

A research team at Mathematica Policy Research conducted a survey of 55 UNHSI program coordinators and made site visits to 8 UNHSI programs to (1) evaluate the progress of the UNHSI program in achieving its goals, (2) identify barriers to follow-up from birth to screening, screening to audiologic evaluation, and audiologic evaluation to EI, and (3) assess how the existence of a medical home and family support programs can help overcome these barriers within UNHSI systems. Respondents to the survey were asked to identify barriers to and successful strategies for implementing each component of an effective UNHSI program. To develop the survey, an open-ended telephone interview guide was constructed on the basis of relevant literature and administered to a diverse set of 7 UNHSI programs. The responses to these interviews were used to develop the survey instrument with discrete options for most survey questions to facilitate cross-program analysis. After approval by the US Office of Management and Budget, in September 2005 the survey was mailed and faxed to UNHSI program coordinators in the 50 states, the District of Columbia, and 8 territories. E-mails and telephone calls were made to nonrespondents in September and October 2005. A 100% response rate from the 50 states was achieved for the survey, and completed surveys were also received from the District of Columbia, Guam, the Northern Mariana Islands, Puerto Rico, and the Virgin Islands.

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**FIGURE 1**
Conceptual framework for the universal newborn hearing screening and intervention program.
all the states and territories responded to every question. Follow-up telephone calls with representatives of UNHSI programs were made to clarify survey responses as needed.

The evaluation also included information about UNHSI programs (such as the number of birthing facilities in a state, the percentage of newborns screened for hearing loss before hospital discharge) that was collected through a survey given by the National Center for Hearing Assessment and Management (NCHAM) in December 2005. The NCHAM survey had a 100% response rate from state programs, and surveys were also received from the District of Columbia, Guam, the Northern Mariana Islands, Puerto Rico, and the Virgin Islands. Additional information was collected through interviews during site visits to 8 UNHSI state programs (Arizona, California, Massachusetts, Minnesota, Nebraska, Pennsylvania, Tennessee, and Wyoming) between January and March 2006. Sites were selected to reflect diversity with regard to geographical distribution, size of the program and state population, mix of program funding, existence of state mandates for newborn hearing screening, rate of audiologic follow-up, relative availability of audiologists in the state who evaluate infants and young children for hearing loss (hereafter referred to as pediatric audiologists), and use and quality of data for program monitoring. During each site visit we interviewed UNHSI program staff, hospital staff responsible for screening and presentation of screening results to families, the state chapter of the American Academy of Pediatrics (AAP) “champion” for hearing screening, and pediatric audiologists.

RESULTS

At the time of the study, virtually all newborns were being screened for hearing loss, but other components of the program (linking infants who do not pass the screening to audiologic evaluation, ensuring they have a medical home, and linking infants diagnosed with hearing loss to EI and family support programs) varied in their implementation across states. Table 1 lists the UNHSI outcome measures reported by programs. The average across programs for each outcome, weighted by the number of live births in each state or territory that responded, is presented as well as the range of program responses. At the time of the survey, most infants (92%) were screened for hearing loss before discharge from the hospital. Of the infants screened, 2% were referred for a diagnostic evaluation. Programs in 46 states and territories reported that ~62% of the infants in need of a diagnostic evaluation received one, and 45 states and territories reported that more than half of those infants (52%) received the evaluation by 3 months of age. These results suggest that there is still substantial loss to follow-up for infants who did not pass the initial hearing screen.

UNHSI programs in 45 states and territories estimated that 80% of infants who did not pass the hearing screening had a medical home. In addition, programs estimated that the majority of infants (68%) with confirmed hearing loss were linked to EI. The least developed area was family-to-family support programs, for which 38 states estimated that only 40% of families with infants with hearing loss were linked to such services.

We identified several barriers within the current UNHSI system that might account for these gaps in follow-up. Many of these barriers are related to the fact that most UNHSI programs are still in the early phases of program implementation. We summarize the barriers to follow-up below, along with strategies that states were developing to reduce them. In general, these barriers can be grouped into 4 broad categories: (1) lack of service-system capacity; (2) lack of provider knowledge; (3) challenges to families in obtaining services; and (4) information gaps.

<table>
<thead>
<tr>
<th>Outcome Measure</th>
<th>Weighted % (Range)</th>
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<tbody>
<tr>
<td>Newborns screened before discharge</td>
<td>92 (25–100)</td>
</tr>
<tr>
<td>Newborns who did not pass screening before discharge</td>
<td>4 (1–34)</td>
</tr>
<tr>
<td>Newborns who were referred for a diagnostic evaluation</td>
<td>2 (1–7)</td>
</tr>
<tr>
<td>Infants who needed a diagnostic evaluation and received one</td>
<td>62 (15–95)</td>
</tr>
<tr>
<td>Infants who needed a diagnostic evaluation and received one by the age of 3 mo</td>
<td>52 (5–83)</td>
</tr>
<tr>
<td>Infants who did not pass the hearing screening who had a medical home</td>
<td>80 (5–100)</td>
</tr>
<tr>
<td>Infants with confirmed hearing loss linked to EI</td>
<td>68 (10–100)</td>
</tr>
<tr>
<td>Infants with confirmed hearing loss linked to family-to-family support</td>
<td>40 (5–100)</td>
</tr>
</tbody>
</table>

*a States and territories reported estimated percentages, which are weighted by the number of live births reported by the state or territory. States did not report estimates for all measures.

*b This measure reflects the percentage of infants referred for diagnostic evaluation as a result of nonpass results in the hospital before discharge or nonpass results at an outpatient rescreening.

*c Some programs reported rates that reflect the percentage of children referred to EI or family-to-family support, whereas others reported rates that reflect the percentage of children who received services through EI or family-to-family programs. When both rates were reported, we recorded the percentage that received services.

Lack of Service-System Capacity

The introduction of the UNHSI programs in most states increased the number of children requiring screening and follow-up services. Building the capacity to provide these services meant introducing new or updated equipment into clinical settings, retraining providers, and developing new service systems. On the basis of survey and interview data, we identi-
fied 4 barriers that states need to address.

**Insufficient Screening Equipment**

The most frequent obstacle to successfully screening all newborns identified by hospital staff was unreliable screening equipment. Some hospitals had back-up equipment, but the lack of back-up equipment in most hospitals meant that infants were often discharged before malfunctioning equipment could be repaired. Families staying in hospitals without back-up equipment were sometimes asked to return to the hospital or to an outpatient rescreening center if their child was not screened during his or her stay, which prompted delays and a higher incidence of missed screenings.

**Shortage of Pediatric Audiologists**

Nearly half of the UNHSI programs cited a lack of pediatric audiologists as a major obstacle to diagnostic evaluation. Shortages in available pediatric audiologists stem from a lack of university training programs that emphasize pediatric audiology. Compounding this problem is the difficulty involved in evaluating infants, because it necessitates specialized equipment and often requires extra time for testing. As noted elsewhere in this supplemental issue, pediatric audiologists are generally reimbursed poorly for diagnostic services, and payment rates by both public and private insurance systems do not reflect the time-intensive nature of pediatric audiology services.

**Inadequate EI Services for Infants With Hearing Problems**

Historically, most children with hearing loss were not identified until 2½ to 3 years of age. Consequently, most EI programs were insufficiently staffed to handle the increased number of younger children who accompanied the implementation of universal newborn hearing screening. One-third of UNHSI programs reported that a lack of EI services was a major problem.

**Lack of Family Support Programs**

Family support programs for children with hearing loss were the least developed component of the UNHSI system. Nine states had no family support programs at all, and half of the UNHSI programs reported that the lack of services was a major problem in their state. In addition, 44% of the programs reported that lack of funding for family-to-family support strongly contributed to the lack of services.

State strategies for reducing or eliminating obstacles to building sufficient capacity included developing partnerships with other resources in the community (eg, sharing screening equipment or providing family support services), establishing training programs to increase the number of pediatric audiologists, and seeking grants to purchase equipment and support family support programs.

**Lack of Provider Knowledge**

The fact that so many additional children are being identified with hearing loss, and that it is occurring at much younger ages, means that key providers (eg, hospital staff, pediatricians, audiologists, etc) need to develop new knowledge and skills related to helping young children with hearing loss. Many UNHSI programs have been working to educate other stakeholders, but at least the following challenges remain.

**Many Screening Hospitals Have No Standardized Protocols for Screening or for Presenting Screening Results**

Most hospital-based hearing screening is performed by nursing and newborn care staff. Although some UNHSI programs provide initial protocols or training materials, most screeners were trained by other screeners or equipment manufacturers without any guidance from the UNHSI program. In addition, only one-third of UNHSI programs reported that screeners in their state had been trained in how to present screening results to parents, which can be important in a family’s decision of whether to follow-up on nonpass results.

**Insufficient Patient Population to Develop Expertise in Some Areas**

Because congenital hearing loss affects only 2 to 3 children per 1000, many pediatricians and EI providers do not see enough children to develop appropriate expertise. We observed a relation between volume and quality of care in 2 areas. First, screening seemed to be of higher quality when it was concentrated in a small group of screeners. Second, there was evidence that the quality of follow-up services was lower in less-populated areas or smaller provider practices. In less-populated states or smaller health care or audiology practices, it has been difficult to “standardize” treatment among providers or to educate them sufficiently to navigate the UNHSI system.

**Many Providers Lack Knowledge of EI or Family-to-Family Support Services**

Many pediatricians have serious gaps in their knowledge about childhood hearing loss because it is often not included as a part of their medical training. Consequently, many pediatricians have not yet integrated follow-up on screening results into their newborn-care protocol. One-third of the UNHSI programs reported that pediatricians in their state did not routinely review screening results for their newborn patients (as reported elsewhere in this supplemental issue, this is sometimes because UNHSI programs do not report the needed information to the pediatrician). One-third of the UNHSI programs reported that pediatricians’ and audiologists’ lack of
knowledge about the availability of EI services was a major problem in their state. A similar percentage reported that providers’ insufficient knowledge about family-to-family support was a major barrier to connecting families to that form of support.

Some Pediatricians Have a “Wait-and-See” Attitude Toward Follow-up
In addition to deficits in their general knowledge of the UNHSI program, our evaluation revealed that some pediatricians took a “wait-and-see” attitude about newborns who did not pass the hearing screening. Such an approach is probably a holdover from the past, when many children were not diagnosed until they were of school age.5 Nearly half of the UNHSI programs reported that such attitudes were a major obstacle to successful follow-up in their states.

Strategies being used by state UNHSI programs to improve the knowledge of pediatricians and other health care providers included training, technical assistance by the UNHSI program, and concentration of some services within a small group of providers (see Table 2).

Challenges to Families in Obtaining Services
Many families have trouble accessing hearing health services because of lack of transportation or they have no health insurance, as well as family characteristics such as repeated moves and the language spoken in the family. We identified 6 barriers related to accessibility of services.

<table>
<thead>
<tr>
<th>TABLE 2</th>
<th>Barriers to Follow-up and Successful State Strategies: Lack of Provider Knowledge</th>
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<tbody>
<tr>
<td><strong>Barrier</strong></td>
<td><strong>State Strategy</strong></td>
</tr>
<tr>
<td>Lack of standardized screening and protocols for presenting results in screening programs</td>
<td>Have UNHSI program assume technical assistance role with screening hospitals</td>
</tr>
<tr>
<td>Low volume of patients decreases quality of screening, follow-up, and evaluation services</td>
<td>Make appointment for further evaluation before hospital discharge</td>
</tr>
<tr>
<td>Lack of provider knowledge about UNHSI and key partners</td>
<td>Concentrate screening in small group of hospital staff</td>
</tr>
<tr>
<td>A “wait-and-see” attitude among health care providers</td>
<td>Provide ongoing training for hospital staff and audiologists</td>
</tr>
<tr>
<td></td>
<td>Ensure UNHSI program support for low-volume areas or practices</td>
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<tr>
<td></td>
<td>Educate providers about EI services through UNHSI outreach</td>
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<tr>
<td></td>
<td>Maintain a single point of contact (such as a toll-free number) for providers to link families to EI</td>
</tr>
<tr>
<td></td>
<td>Educate physicians through AAP-sponsored workshops, grand rounds, online physician access to case studies, and other forms of colleague-to-colleague training</td>
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</table>

Traveling to an Unfamiliar Location for Diagnostic Evaluation
Families may be less likely to follow-up on a referral for an audiological evaluation if they must travel to locations other than the hospital in which their child was born.

Preauthorization Requirements for Further Evaluation
Linking an infant to a pediatric audiologist is often delayed if preauthorization must be obtained to help pay for audiology services. Such delays often occur when the family wants to use Medicaid, the state’s program for children with special health care needs, or their State Children’s Health Insurance Program (SCHIP).

Lack of Transportation to Audiology Services
Lack of transportation can prevent families from keeping appointments with audiologists, particularly if the families must travel long distances. This situation can be especially difficult for low-income families or those who live in rural areas with inadequate public transportation.

Inadequate Health Insurance Coverage for Children’s Hearing Services
Public and private health insurance policies almost never provide adequate coverage for hearing services.14,17 Children with no insurance are less likely to have a usual provider who can act as their medical home. Cost or lack of insurance was also identified as a major barrier to audiology evaluations in one-third of the states.

Challenges to Connecting Mobile Families With EI Services
EI for children with hearing loss usually requires a series of home-based interventions over a 1- to 3-year period. Linking families to EI can be challenging if families of children diagnosed with hearing loss move often and cannot access continuous services.

Language Differences Between Families and Providers
UNHSI program staff noted that if families speak a language other than English, it may be difficult for screening staff and other providers to explain the results of the screening test and to describe the follow-up process.

State strategies for reducing accessibility problems included using services offered through other state assistance programs, such as transportation and interpretation services and educating staff from the UNHSI program, hospitals, and other providers as to how they can help families overcome access barriers by applying for public coverage or initiating preauthorization proceedings on behalf of families (see Table 3).

Information Gaps
An effective data-management and tracking system is critical for a successful UNHSI program. Such systems
provide the information necessary for surveillance and the foundation for managing follow-up visits for families. All UNHSI programs had some type of data system in place, but these systems varied widely in their capacity to support the data needs of the UNHSI program. The evaluation revealed the following problems.

**Poor Communication Among Hospital Staff, Key Providers, and the UNHSI Staff**

Staff from half of the UNHSI programs described the quality of data reported by hospitals in their state as poor or good versus very good or excellent. The most common errors were missing contact information or hearing results or name changes for the infant. During site visits we noted that reporting systems that used handwritten forms were more prone to errors than those that relied on computer-based systems such as electronic birth certificates or metabolic screening systems. Systems to collect follow-up data from audiologists, pediatricians, and other providers are even less well established than those developed to collect screening data from hospitals. These systems generally consist of paper forms for providers to submit via fax or mail and are often difficult for UNHSI staff to collect. To facilitate follow-up, UNHSI staff have to know which audiologists in the state are likely to be evaluating infants and young children to provide them with reporting forms and encourage reporting of results. Similarly, UNHSI staff have to know which pediatricians have a child with a nonpass result in their practice.

**Data Systems That Are Inaccessible to Providers**

For data systems to facilitate follow-up, data have to be collected from providers as children move through the UNHSI sequence of screening, evaluation, and treatment. Informing pediatricians of the infants in their practice who do not pass the hearing screening enables the provider to help families return for follow-up evaluations. However, most current UNHSI data systems are inaccessible to providers.

**Privacy-Sharing Laws**

As reported in more detail elsewhere in this supplemental issue,16 the sharing of education and health information is restricted by federal confidentiality laws such as the Health Insurance Portability and Accountability Act of 1996 (HIPAA), the Federal Educational Rights and Privacy Act (FERPA), and the Privacy Regulations of Part C of the Individuals With Disabilities Education Act.16,18–20 The HIPAA limits the extent to which personal health information can be shared, and the FERPA and the Part C privacy regulations limit the extent to which EI programs can share information about specific children with the UNHSI program without parental consent. During site visits, UNHSI program staff members repeatedly noted that such privacy laws interfered with their ability to facilitate follow-up and linkage to services for children in their programs.

**State strategies for reducing or eliminating barriers to effective surveillance and monitoring included training hospital staff to relay complete information, using more sophisticated data systems, and collaborating with data partners to navigate privacy laws (see Table 4).**

**DISCUSSION**

The results of this evaluation suggest that although universal newborn hearing screening has largely been accomplished, significant loss to follow-up is still occurring at various stages in the UNHSI sequence. As a result, many children who should have further evaluation and/or treatment are not receiving these services. Several factors contribute to this problem, including a lack of service-system capacity, lack of provider knowledge, challenges to families in obtaining services, and data-management and information gaps. These findings are aligned with those from other recent work in the United States and abroad that point to the importance of key factors such as health insurance coverage, availability of audiologists, and appropriate communication of results in linking families to needed services.5,10,11 Our study results add to this literature by conducting the first (to our knowledge) systematic review of the national

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**TABLE 3** Barriers to Follow-up and Successful State Strategies: Family Challenges in Obtaining Services

<table>
<thead>
<tr>
<th>Barrier</th>
<th>State Strategy</th>
</tr>
</thead>
<tbody>
<tr>
<td>Family must go to unfamiliar location for evaluation</td>
<td>Have hospitals establish a relationship with an audiology center(s), preferably within the same hospital system</td>
</tr>
<tr>
<td>Preauthorization requirements delay access to further evaluation</td>
<td>Have hospitals, UNHSI staff, or primary care physicians facilitate preauthorization for services</td>
</tr>
<tr>
<td>Lack of transportation to audiologist</td>
<td>Use existing state programs to assist with transportation (Part C, Title V, public health nurses, Medicaid)</td>
</tr>
<tr>
<td>Lack of health insurance impedes access to medical home and audiologic evaluation</td>
<td>Have UNHSI program staff, audiologists, and EI staff inform families about public health insurance and state assistance programs</td>
</tr>
<tr>
<td>Mobility of families makes linkage to EI services challenging</td>
<td>Have providers of EI services perform targeted outreach to families at risk of being lost to follow-up</td>
</tr>
<tr>
<td>Language spoken by families prevents linkage to services</td>
<td>Have UNHSI program develop educational materials in other languages</td>
</tr>
<tr>
<td></td>
<td>Have UNHSI program, hospitals, and EI programs use translation services and hire bilingual staff</td>
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</table>
UNHSI program and gathering data from multiple perspectives of UNHSI program staff, hospital staff, audiologists, and pediatricians. These results also reveal strategies that UNHSI programs have found to be successful in reducing many of the barriers.

Several limitations to this study should be noted. First, data were collected through self-reported survey instruments, and the UNHSI programs may have used different methods to calculate estimates for outcome measures. For example, the way in which programs calculated the percentage of infants who received an evaluation could have varied because of differing definitions of which infants required follow-up (eg, only those who did not pass a rescreening or all infants who did not pass an initial screening). Similarly, programs varied in whether the rates they reported for linkage to EI and family support programs reflected the percentage of infants referred to services or the percentage that received services. In addition, some programs provided rates on the basis of data for all children in the state, whereas others provided estimates that were based on approximations or on a subset of the population. Because of this, we did not link attributes of program performance to outcome measures in our analyses. Furthermore, because some families may have opted for private EI services because the type of program they wanted was not available through the publicly funded EI program, rates reported for EI may not reflect the entire system of services. These limitations also highlight the fact that many UNHSI programs were still building the infrastructure needed to collect accurate, reliable data about how their system was functioning.

Second, our analyses would have benefited from family perspectives in addition to provider and program staff perspectives, but obtaining this information was beyond the scope of the study. Third, although we attempted to select our case-study sites as representative of the UNHSI program, it is possible that the data from those 8 states do not adequately reflect the situation in all other states. Thus, our conclusions are based on results of the surveys completed by all states, and the site-visit data were only used to provide context and clarification.

Finally, our analyses provide only a single point-in-time snapshot of UNHSI programs. Although the data reflect the status of UNHSI programs in 2006, there have been no national evaluations since that time, and the results of individual studies conducted since then are consistent with the findings of our evaluation. Furthermore, most state UNHSI programs are still developing, and many do not yet have adequate data and tracking systems. Given the time it takes to implement this type of universal, multitype public health initiative, it is not surprising that most programs are still in the process of building a comprehensive system and probably will be for the next several years.

As states continue to address barriers to effective implementation of the UNHSI program, they should consider the following action steps:

**Improve Data Systems to Support Surveillance and Follow-up Activities**

The ability of programs to conduct effective follow-up depends on timely and accurate transmission to the UNHSI program of hospital screening and audiology evaluation results, as well as on accurate contact information for families. Surveillance data are important for evaluating progress toward program goals.

**Ensure That All Infants Have a Medical Home With Adequate Care Coordination**

Because hearing-loss detection is a multistep process that requires the involvement of several entities, children and their families benefit from having a medical home to help them navigate the sequence of detection and treatment. The AAP and the Health Resources and Services Administration’s Maternal and Child Health Bureau have aggressively promoted the concept of the medical home for all children with special health care needs, including children with hearing loss. Recent study results have suggested that it is possible to provide coordinated care

<table>
<thead>
<tr>
<th>TABLE 4 Barriers to Follow-up and Successful State Strategies: Information Gaps Remain</th>
<th>Barrier</th>
<th>State Strategy</th>
</tr>
</thead>
<tbody>
<tr>
<td>Poor communication among hospitals, health care providers, audiologists, and UNHSI program</td>
<td>Train hospital staff on the importance of relaying complete information</td>
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</tr>
<tr>
<td>Data systems are inaccessible to providers</td>
<td>Use existing data sources (metabolic screening, vital records, Medicaid) to complete missing data fields</td>
<td></td>
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<tr>
<td>Privacy laws impede sharing across agencies</td>
<td>Use specialized software, metabolic screening card, or electronic birth certificate to convey results</td>
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<tr>
<td></td>
<td>Use Web-based systems to facilitate real-time transmission of screening and evaluation results, maintain accurate contact information for families, and track follow-up</td>
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<tr>
<td></td>
<td>Collaborate with data partners to establish data-sharing procedures and agreements</td>
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<tr>
<td></td>
<td>Work with EI partners to secure permission from families for data-sharing between the EI and UNHSI program</td>
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in primary care settings, often most efficiently performed by nonphysicians, primarily nurses. For example, care coordination would be improved if all pediatricians provided a standing order to hospitals with whom they work that specified that all of his or her patients should receive newborn hearing screening and that the results should be reported to his or her office. The pediatrician’s office staff then knows to check all infants for screening results, report those that are missing, and refer newborns who require further evaluation for audiology diagnosis. This process works only if the pediatrician is known at the time the infant is discharged from the nursery, which is frequently not the case.

**Build Capacity Beyond Current UNHSI Stakeholders**

To improve UNHSI programs, it is important to appropriately involve other stakeholders who are not now extensively involved. For example, UNHSI programs do not typically reach out to equipment manufacturers, although these businesses often conduct the initial screening training for hospital staff. Similarly, other health care providers (such as otolaryngologists) are important UNHSI providers but are underrepresented in UNHSI program activities.

**Develop Family Support Programs**

At the present time, family support programs are particularly underdeveloped in UNHSI systems. These services often lacked funding or adequate participation from families to make them successful. UNHSI programs may need to reach out to other existing family support services in their states as partners in developing programs for children with hearing loss. Recently, several promising state-based family-to-family support programs were developed, including Hands and Voices in Colorado, BEGINNINGS in North Carolina, and Family Voices in Tennessee. In addition, there are promising national efforts such as the National Initiative for Child Healthcare Quality effort to partner pediatricians and parents as co-leaders in its quality-improvement learning collaborative (described elsewhere in this supplemental issue).

**Promote Understanding of the Importance of Early Detection**

As UNHSI programs mature, they must ensure that all stakeholders are aware of the importance of early detection of hearing loss. Many aspects of the program rely on colleague-to-colleague training. Families often seek advice about whether to pursue further evaluation from hospital staff, pediatricians, audiologists, and other families. Each of these stakeholders should be sending a consistent message about the UNHSI program and its benefits. Similar to other public health initiatives, the UNHSI program may benefit from public awareness campaigns.

**CONCLUSIONS**

Almost all UNHSI programs have implemented universal newborn hearing screening, and most are working to reduce loss to follow-up. As states continue to develop their program components and their ability to track their progress, there will be opportunities for program improvement. The strategies identified through this study will be useful for pediatricians, audiologists, UNHSI staff, and other stakeholders in their work to improve the early identification and treatment of hearing loss. Ongoing evaluation will play an important role in monitoring these activities and help to identify and disseminate effective program strategies.

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