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Foreword: Pursuing Excellence in Early Hearing Detection and Intervention Programs

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Pursuing Excellence in Early Hearing Detection and Intervention Programs

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Surgeon General of the United States, 1981–1989

ABBREVIATION

EHDI—Early Hearing Detection and Intervention

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In 1988, while I was serving as the Surgeon General of the United States, the Congressional Commission on Education of the Deaf issued a report that contained a troubling finding: that the average age at which permanent hearing loss among infants and young children was being identified in the United States was 2½ to 3 years of age. Given the importance of language development and communication during those early years, I found this to be unacceptable. Consequently, I issued a challenge in 1989 to researchers, educators, health care providers, and parents to work together to find better ways of identifying very young children who are deaf or hard of hearing. I set a goal that by the year 2000 all infants with permanent hearing loss would be identified before 12 months of age. Although it was an ambitious goal, and many people thought it was unrealistic, I was optimistic and confident that it could be achieved.

Since that time, we have seen remarkable progress. Universal newborn hearing-screening programs are now functioning throughout the United States. With assistance from the federal government, every state has established an Early Hearing Detection and Intervention (EHDI) program as a part of its public health system. In some areas with the most effective EHDI programs, most infants and young children who are deaf or hard of hearing are being identified at less than 3 months of age. And, research is documenting what we always believed to be the case: deaf or hard-of-hearing children who are identified early and given appropriate educational and health care services develop better language and achieve better in school. I believe it is only a matter of time until we document that such children also grow up to have better jobs and are able to participate more fully and effectively in our communities. The seeds we planted in the 1980s are beginning to bear fruit and will continue to do so.

However, there is still a lot of work to be done before we can reap the full harvest. As exciting as it is to see what happens when EHDI programs function to their full potential, it is clear that most EHDI programs need continued improvement and many children and families are not yet enjoying all of the benefits of early identification and timely and appropriate intervention. As is documented by the articles in this supplemental issue of *Pediatrics*, there are still many challenges and barriers that need to be addressed. Lack of funding, shortages of trained professionals, problems with follow-up, poor coordination of services and programs, inadequately informed families, lack of access to or inadequate use of new technology, and many other challenges continue to interfere with children who are deaf or hard of hearing getting the services they need and making the progress of which they are capable.

In addition to documenting some of the areas most urgently in need of work, the articles in this supplemental issue continue to reinforce my optimism that these problems can be solved in the same way that we implemented newborn hearing screening when many people said it could not be done. These articles show how systematically and thoughtfully collected data can help us focus our quality-improvement efforts. More importantly, they show how such information can be used to develop and implement innovative strategies for achieving systems change, how collaborative efforts can lead to novel and effective solutions, and how creative use of new technology can improve the EHDI system. As these efforts become better known and more widely adopted, more and more children who are deaf or hard of hearing will benefit.

It is exciting to see how far we have come and satisfying to know that continuing work is significantly improving programs for children who are deaf or hard of hearing and their families.

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Preface: Newborn Hearing Screening in the United States: Historical Perspective and Future Directions

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Preface: Newborn Hearing Screening in the United States: Historical Perspective and Future Directions

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Every year, 4000 to 8000 children are born in the United States with permanent hearing losses that pose a risk to their speech and language development.[1–3] If children with milder losses and losses that affect only 1 ear are included, that number is almost doubled. Until just a decade ago, late diagnosis was the norm, with the average age at identification of congenital hearing loss reported as 2½ to 3 years or even later.[1,4] A valuable window of opportunity for early intervention was being lost. Intervention in the first 6 months of life may be particularly important for speech and language development,[5,6] and parents and professionals overwhelmingly prefer early diagnosis.[7,8] Technologic advances in automated newborn hearing-screening technology, followed by a series of successful demonstration projects,[9] resulted in the introduction of universal newborn hearing screening across the United States in the mid-to-late 1990s. More than 95% of newborns are now screened for hearing loss shortly after birth, which represents one of the most successful and rapid examples of research moving into practice in pediatric public health. Newborn hearing screening is 1 of only 7 preventive services for children recommended by the US Preventive Services Task Force.[10]

The success of the screening program depends on far more than the initial screen. The Joint Committee on Infant Hearing has set 3 goals: screening should be completed by 1 month of age, diagnosis should be made by 3 months, and intervention and treatment should commence by 6 months.[11] Although the first goal is close to being met, the other goals are not. Recent data from the Centers for Disease Control and Prevention suggest that up to 60% of newborns who do not pass the hearing screen do not have a documented diagnosis. Of those children confirmed to have a permanent hearing loss, only 77% enroll in intervention by the age of 6 months.[12] In addition, not all children enrolled in intervention have access to the services they need for language and speech development. Pediatricians, through their regular contact with children in the first year of life, could play a pivotal role in guiding families through the follow-up and diagnostic processes. To be effective, they need reliable access to results of screening and audiologic evaluations and knowledge of local services for children who are deaf or hard-of-hearing. Study results suggest that, too often, pediatricians lack these data and knowledge.[13,14] These types of system deficiencies threaten the ability of pediatricians to deliver effective care in the context of the medical home model and threaten the success of the screening program.

In response to these gaps, in January 2008 the Agency for Healthcare Research and Quality and its federal partners convened a workshop

entitled "Accelerating Evidence-Based Recommendations Into Practice for the Benefit of Children With Early Hearing Loss."* A diverse group of more than 50 national experts, including parents of children who are deaf or hard-of-hearing and representatives of the Deaf community, met in Washington to take a practical approach to transforming the system of care. The results of their work, and recommendations for action steps, are reported in the first article in this supplemental issue of *Pediatrics*.[15] The participants used a new framework, "the 3T's Framework to Transform US Health Care,"[16] which considers the types of translational steps needed to move research into practice to guide their discussions. They also used a new tool, a matrix of responsibility,[17] to specify entities that could take action on priority recommendations. The process revealed a need for new types of research and quality-improvement activity, and new approaches to data tracking and measuring system performance were suggested.

One study that informed the workshop deliberations was an evaluation of the universal newborn hearing-screening and intervention program commissioned by the Maternal and Child Health Bureau, Health Resources and Services Administration, and conducted by Mathematica Policy Research. In the second article in this issue, Shulman et al[18] report on quantitative and qualitative findings from their survey of 55 state and territorial screening programs supplemented by 8 site visits. They identified 4 types of barriers to system performance: lack of service-system capacity, especially lack of a sufficient number of audiologists trained to evaluate infants; lack of provider knowledge, including an inappropriate "wait-and-see" attitude among some primary care providers; family challenges in obtaining services, including difficulties with transportation and obtaining insurance authorizations and gaps in information flow, such as poor communication between hospitals and providers; and data systems that are inaccessible to clinicians. Their recommendations for system improvement include improving data systems to support follow-up to ensure that all infants have a medical home and improving family-to-family support services. Shulman et al also identify concerns about federal confidentiality laws as an important factor that limits the sharing of information on children across government agencies and private groups. In the next article, Houston et al[19] explore this theme further. They conclude that providers can find ways to work efficiently within the regulations by obtaining parental consent using coordinated consent forms that incorporate the elements required by the Health Insurance Portability and Accountability Act of 1996, the Family Educational Rights and Privacy Act, and Part C privacy regulations, by including an option on the child's individual family service plan for parents to give permission for a copy to be shared with the child's pediatrician and other health care providers, and by ensuring that families always have copies of diagnostic evaluation results, treatment plans, and individual family service plans that they can share with providers as they wish.

The next 2 articles tackle the important issue of finance. McManus et al[20] investigated Medicaid reimbursements of hearing services for children. They found that state Medicaid fees for these services are significantly lower than equivalent Medicare and commercial fees and that fees for some services had actually declined since 2000. They also found considerable variation in fee levels across states. They go on to discuss the implications of their findings for provider recruitment and make suggestions for improving financial incentives. For their second article, McManus and colleagues[21] investigated financing arrangements for hearing aids for infants and young children and report on recommendations made by the Audiology Financing Work Group. Their findings reveal cause for concern. Many children lack coverage for hearing aids through private insurers. Although Medicaid and the Children's Health Insurance Program do cover hearing aids, reimbursement rates are low, and in some states there are medical-necessity restrictions. Pediatricians may not be familiar with the challenges that families face in obtaining financing for hearing aids, and data such as these can help inform pediatric advocacy efforts. The authors consider policy options to address this important barrier to care.

Early diagnosis has led to increased demand for intervention services at early ages. Families, especially those in rural locations, report transportation difficulties and other challenges to accessing services. One innovative solution to this problem has been piloted in Australia. McCarthy et al[22] report on their experience with teleintervention. More than 140 children currently receive all of their intervention services via 2-way videoconferencing. The authors discuss further research needed on the teleschool model and its potential applicability to the United States. Their article may be of particular interest to pediatricians who are practicing in rural areas and

*The term "early hearing loss," as used throughout this supplemental issue, refers to permanent hearing losses that are either congenital or acquired shortly after birth. Most of these losses are sensorineural, but some are conductive or mixed. Although transient conductive hearing losses may warrant detection and management, they are not the focus of these supplemental articles.

whose patients have limited access to specialized interventions.

The authors of the final article of this supplement issue report on experience with a large national learning collaborative focused on minimizing loss to follow-up after newborn hearing screening.[23] Using quality-improvement techniques, teams from 8 states worked with the National Initiative for Children's Healthcare Quality to improve their systems of care for children with hearing loss. Pediatricians worked alongside audiologists, hearing screeners, interventionists, otorhinolaryngologists, and families to suggest and try improvement strategies. The teams found that infants who did not pass their hearing screens frequently lacked correct documentation of the primary care provider who would be responsible for future follow-up. This system deficit resulted in a barrier to effective communication of screen results and case tracking. The collaborative identified simple, yet effective, change strategies that affected the care process (eg, verifying the primary care provider's identity and obtaining a second contact number for families before hospital discharge). Correct documentation of the primary care provider before discharge from the birthing hospital could have a large impact on broader systems of care for young children. The collaborative also found that more work was needed on defining indicators of system performance. This collaborative experience revealed that it was possible to apply quality-improvement techniques to systems of care that involve hospitals, pediatric offices, and intervention services. Pediatricians who are embarking on quality-improvement initiatives that tackle the continuum of care between primary care and community-based services may find this report of interest.

As states continue to work toward improving their systems of care for children with permanent hearing loss, we hope that the information in this supplemental issue will prove useful in both recommending action steps and describing new tools and techniques to use when implementing them. The multidisciplinary and collaborative nature of much of this work reflects the high degree of cooperation and communication between the responsible federal agencies, pediatricians, audiologists, and other providers together with a strong partnership with parents and family advocates. This ongoing partnership between parents and professionals will continue to drive system improvements for the deaf and hard-of-hearing and may serve as a model for broader improvements to developmental services.

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Accelerating Evidence Into Practice for the Benefit of Children With Early Hearing Loss

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Accelerating Evidence Into Practice for the Benefit of Children With Early Hearing Loss

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KEY WORDS
deaf, hard-of-hearing, early intervention, newborn hearing screening

ABBREVIATIONS
DHH—deaf/hard-of-hearing
CDC—Centers for Disease Control and Prevention
EI—early intervention
EHL—early hearing loss
AHRQ—Agency for Healthcare Research and Quality
HRSA—Health Resources and Services Administration
MCHB—Maternal and Child Health Bureau
PCP—primary care provider
AAP—American Academy of Pediatrics
CHIP—Children's Health Insurance Program

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abstract

Over the years, multiple groups have issued recommendations for newborn hearing screening, diagnosis, and intervention. In January 2008, the US Department of Health and Human Services held an invitational workshop at which more than 50 national experts met for 2 days to consider ways to accelerate the movement of evidence-based recommendations into practice. Participants set priorities among existing recommendations, identified areas with the most promise and created a national blueprint to accelerate evidence into practice. Workshop participants adopted the "3T's Roadmap to Transform US Health Care" as the conceptual model for this work and used a modified Delphi process to identify high-priority recommendations in 5 areas (diagnosis, treatment, parental and public awareness, continuous quality improvement, and stewardship). A matrix of responsibility was developed to specify entities that could take action to implement these recommendations. Participants placed a high priority on measurement and recommended improved data-tracking of newborns after screening and creation of a limited set of national indicators to monitor progress toward evidence-based system goals. They also identified a greater role for parents and families in contributing to system transformation and a need for more culturally and linguistically appropriate resources. Targeting infants in the NICU for early testing and creating guidelines and resources for early intervention were additional priorities. Finally, the workgroup noted the need to create a stewardship function to monitor the progress of the entire system of care, disseminate reports, consider future research directions, and continue to develop critical cross-agency and public-private coordination of activities. *Pediatrics* 2010;126:S7–S18

Many different organizations and entities have issued recommendations concerning newborn screening. The US Preventive Services Task Force recently reviewed the evidence for the benefits and possible harms of universal newborn hearing screening.[1] On the basis of new research published since its last statement in 2001,[2] the task force concluded that there is now sufficient evidence to recommend screening of all newborns.[3] However, the reviewers recognized that improved outcomes depend not just on screening but also on effective methods of referral, follow-up, and treatment.[1]

The United States has been successful in implementing newborn hearing-screening programs. After pilot studies in Rhode Island in the early 1990s,[4,5] screening rates rose from a baseline of <5% to 92% in 2006 and to a rate now likely exceeding 95% and continuing to rise. Only 2% of newborns do not pass their final hearing screen,[6] which allays fears that high proportions of screen "referrals" could overwhelm the system. However, the subsequent steps of referral, diagnosis, and treatment have been more problematic. As discussed in other articles in this supplemental issue of *Pediatrics*,[7,8] pediatricians in the United States have reported that they frequently lack access to screening and diagnostic test results and to information about relevant local services that limits their ability to coordinate care for infants who are deaf/hard-of-hearing (DHH) as intended in the medical home model.[9,10] National data collected by the Centers for Disease Control and Prevention (CDC) suggest that more than half of the infants who do not pass their hearing screens have "no documented diagnosis." Of those with confirmed hearing loss, one-third could not be confirmed as receiving early intervention (EI).[6] Lack of agreed-on definitions for key system measures adds to the problem.[11] The absence of a standard method to monitor children as they proceed through the system and to document outcomes such as language development was also cited by the US Preventive Services Task Force as contributing to the lack of good-quality US evidence to guide clinical recommendations.[1]

Although the task force confined its evidence review to high-quality published studies, the Joint Committee on Infant Hearing based its 2007 position statement on "best available" evidence,[12] including lower categories of evidence such as expert opinion, when published studies were lacking. Clinicians who seek to improve delivery of evidence-based care to children with early hearing loss (EHL) need both stronger evidence to guide creation of clinical recommendations and a more efficient process for moving those recommendations into practice. Although the first aim can be achieved through traditional basic and clinical translational research, the second aim requires a combination of translational research, health services research, policy development, and quality improvement.

To address this gap in knowledge of how to move evidence into practice, in January 2008 the Agency for Healthcare Research and Quality (AHRQ), along with its federal partners (the CDC, the Health Resources and Services Administration–Maternal and Child Health Bureau [HRSA-MCHB], the National Institute on Deafness and Other Communication Disorders, and the Office on Disability), invited more than 50 national experts including parents and representatives of the DHH community to a 2-day workshop entitled "Accelerating Evidence-Based Recommendations Into Practice for the Benefit of Children With Early Hearing Loss." In this article we report the conclusions and recommendations from that meeting.

APPROACH

The group adopted the "3T's roadmap to transform US health care"[13,14] as the conceptual model for this work (see Fig 1). The term "3T's" refers to the 3 types of translational steps involved in moving research into practice: T1, the translation of basic science to clinical research; T2, clinical outcomes research coupled with the creation of practice guidelines and tools; and T3, quality-improvement strategies coupled with measurement and reporting of health care quality and costs. For successful transfer of evidence to practice, all 3 steps are important, especially T3, which has traditionally received the least attention.

To illustrate this approach, Table 1 applies the 3T's model to the process of moving cochlear implantation from research into practice. T1 and T2, the steps of basic science, clinical trials, and preliminary outcomes research, have been largely accomplished, but significant gaps remain in T3, including ensuring that the appropriate children are offered cochlear implants and that outcome measures are reported and monitored. Similar T1, T2, and T3 steps can be identified for other aspects of the system of care for children with EHL.

The workshop planning group, comprising representatives of each of the federal partners, identified sources of expert recommendations relevant to the system of care for children with EHL.[7,12,24–26] The group concluded that, apart from certain special populations such as infants in the NICU and those birthed at home, the initial step of hearing screening had been largely successfully implemented, so the workshop focused on later steps in the process, such as rescreening, diagnosis, and intervention. The planning

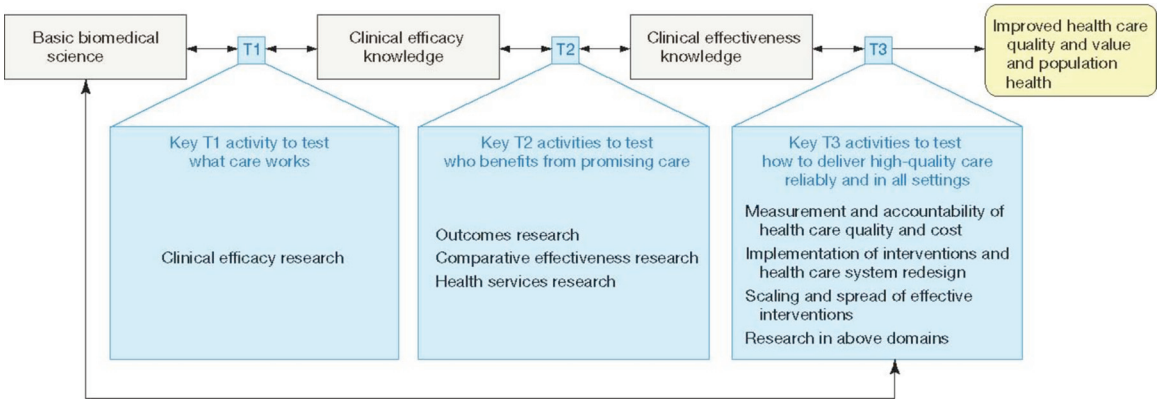

FIGURE 1

The 3T's roadmap. T indicates translation. T1, T2, and T3 represent the 3 major translational steps in the proposed framework to transform the health care system. The activities in each translational step test the discoveries of previous research activities in progressively broader settings to advance discoveries originating in basic science research through clinical research and eventually to widespread implementation through transformation of health care delivery. Double-headed arrows represent the essential need for feedback loops between and across the parts of the transformation framework. (Source: Dougherty D, Conway PH. *JAMA*. 2008;299[19]:2320. Reproduced with permission.)

TABLE 1 Moving Cochlear Implantation From Research to Practice

Translation 1 (T1): from basic science to clinical trials
The idea of stimulating hearing with electricity begsn with experiments by the Italian physicist Volta as early as 1800.[15]
The journey from bench to bedside took almost 200 years and included pioneering work by William House and Blair Simmons in the United States and Graeme Clark in Australia.[15]
Clark successfully developed a multiple-channel cochlear implant[16] and piloted it successfully on the first patient in 1974.
Scientists continue to improve cochlear implants and test refinements.[17]
Translation 2 (T2): outcomes research
Early outcomes studies compared the language abilities of children who received earlier versus later implants.[18,19]
Clinical guidelines and protocols for implantation and follow-up care were developed.
Translation 3 (T3): reliably delivering high-quality cochlear implant programs
Strategies are needed to ensure that all appropriate children are identified promptly, offered referral to cochlear implant centers, and given postimplant educational and health support services.
Quality measures are needed to address the 6 Institute of Medicine quality domains (safety, timeliness, effectiveness, efficiency, equity, and patient-centeredness) as applied to cochlear implant programs.[20,21] Examples include the following:
The proportion of children correctly identified as eligible for implantation in a timely way
The proportion of families given sufficient information about implants to make an informed choice
Measures of coordination of care among providers such as the care-coordination measure from the 2005–2006 National Survey of Children With Special Health Care Needs[22]
Measures of language development and quality-of-life outcomes after implantation
Measures of cost-effectiveness[23]
Measures of equity (eg, stratify quality measures according to race, ethnicity, income, or other possible sources of disparities and develop measures of particular importance to vulnerable subgroups of children)[23]

group identified 160 recommendations from existing reports.

Duplicate recommendations and recommendations that had already been implemented were eliminated, and the remainder were divided into 4 domains: (1) diagnosis and evaluation; (2) treatment and intervention; (3) parent resources and public awareness; and (4) program evaluation and continuous quality improvement. This final list of 130 recommendations was distributed to workshop attendees before the meeting. Participants used a modified Delphi process to identify no more than 5 recommendations in each of the 4 domains as priorities for discussion during the workshop. Each recommendation was rated on the basis of the strength of the underlying evidence and its potential impact. Participants also considered options for establishing a "stewardship" group to help guide implementation of priority recommendations and monitor progress toward improvement of the system of care for children with EHL.

Workshop participants divided into 4 groups that corresponded to the 4 system domains and used a matrix-of-responsibility tool[27] to guide discussion of roles and responsibilities of stakeholders in implementing the highest-priority recommendations. The matrix-of-responsibility tool has been used in defining roles and responsibilities of service sectors in the provision of developmental services to

TABLE 2 Matrix-of-Responsibility Framework

Modified Recommendation	Action Step	Potentially Responsible Actors, by Type of Group					
		Professional Organizations	Advocacy Groups	State or local education/ EI agencies	State or local public health agencies (e.g., Title V)	State/local Medicaid/ CHIP agencies	Federal Agencies

young children.[28] Table 2 presents the matrix outline as used by the workshop participants. Each breakout group focused on the 2 highest-priority recommendations for their domain (Table 3). The groups then completed matrices of responsibility for implementation of each recommendation.

The workshop adopted a broad definition of health for children with EHL, "the extent to which individual children or groups of children are (*a*) able or enabled to develop and realize their potential, (*b*) satisfy their needs, and (*c*) develop the capacities that allow them to interact successfully with their biological, physical, and social environments."[28] Consequently, our organizing framework included educational and social interventions in addition to traditional medical treatments and management.

TABLE 3 Initial List of Priority Recommendations for Implementation

Diagnosis and evaluation
1. Targeted outreach to at-risk families to prevent loss to follow-up
2. Comprehensive assessment of both ears by 3 mo of age by an audiologist who has been well-trained in infant assessment
3. Comprehensive coordinated workup by core team: PCP, ENT, EI specialist, and SLP
4. EI assesses language, cognitive skills, social-emotional, auditory
5. Innovative models for rural and underserved populations

Treatment and intervention
1. Treatment with hearing aids within 1 mo of diagnosis
2. EI and ancillary services by 6 mo of age (maximum)
3. Provide resources and financial assistance for parents to acquire effective skills for communicating with their children
4. Recruit adults who are DHH to serve on coordinated service team
5. Establish programs to ensure the development of communication for infants and children with all degrees and types of loss, allowing them access to all educational, social, and vocational opportunities throughout their life span

Parent resources and public awareness
1. Special resources for parents from minority and non–English-speaking cultures
2. Ensure transition from Part C (EI) to Part B education services in ways that encourage family participation and ensure minimal disruption of child and family services
3. Access to deaf mentors/role models for children and their families
4. Widespread, comprehensive public awareness campaign that addresses the screening program, potential benefits of early identification and intervention, choices in communication/education, and positive role models
5. Resources to support families in carrying out professional recommendations

Program evaluation, CQI, practice to research
1. Expand/improve state data-management and -tracking systems for all states and territories
2. Measure educational outcomes by using universally designed instruments that do not discriminate against DHH children (assess both sign and oral language)
3. Test utility of a limited national data set and develop nationally accepted indicators of EI system performance
4. Initiate prospective population-based studies to determine the prevalence and natural history of auditory neural conduction disorders
5. Improve data-management systems of tracking and surveillance to minimize loss to follow-up

Stewardship options
1. Public-private oversight body funded and organized by the federal government
2. Public-private oversight body funded and organized privately
3. Public oversight body only
4. Private oversight body only

ENT indicates ear, nose, and throat specialist; SLP, sign language pathologist; CQI, continuous quality improvement.
Source: priority recommendations identified through prework for the "Accelerating Evidence Into Practice for the Benefit of Children With Early Hearing Loss" workshop, January 24, 2008.

RESULTS

Prework: Selection of Priorities From Previously Recommended Steps

Table 3 shows the results of the modified Delphi process to identify the top 5 recommendations in each domain. For example, in the diagnosis-and-evaluation domain, the highest-priority recommendation was "targeted outreach to at-risk families to prevent loss to follow-up." In the treatment-and-intervention domain, "treatment with hearing aids within 1 month of diagnosis" was selected as the top priority. Participants also ranked 4 options for the constitution of a stewardship group, and the public-private oversight body funded by the federal government ranked first.

Workshop Recommendations and Matrices of Responsibility

Results of the 4 breakout groups' discussions are shown in Tables 4 through 7. Each table shows the highest-priority recommendations identified by each breakout group, the action steps to be taken to implement the recommendations, and the actor(s) believed by the breakout group to be responsible. The following are summaries of each of the breakout groups' discussions, together with the "stewardship" discussion, for which the 3T's framework was applied with an emphasis on T3.

Diagnosis and Evaluation Group

The diagnosis and evaluation group focused on 2 areas related to the need for hearing screening, diagnosis, and

TABLE 4 Recommended Action Steps and Proposed Responsible Actors in Diagnosis and Evaluation: Reduce Loss to Follow-up by Targeting Infants in the NICU for Earlier Diagnosis

Action Steps Recommended by Breakout Groups	Responsible Actors
Develop screening protocol for NICU infants who transfer hospitals	State EHDI programs, hospitals, NACHRI, AAP, AAA
Develop protocol for diagnostic testing of infants in NICU	AAP, AAA
Parent-to-parent support during diagnostic testing	EHL advocacy organizations
Work with audiology diagnostic centers to facilitate referrals to EI	State or local education/EI agencies, audiology diagnostic centers
Create Web-based resource lists	State or local public health agencies (eg, Title V)
Create Web-based resource list of diagnostic testing sites	
Create Web-based list of PCPs grouped according to geographic area with contact numbers (telephone and fax)	
Streamline authorizations for diagnostic audiologic testing, including testing in the NICU when possible	State/local Medicaid/SCHIP agencies, AAA, AAP, ASHA
Create centers or networks of expertise/excellence in newborn diagnostic testing	AAA, ASHA, state or local public health agencies (eg, Title V)
Develop intervention protocols for use in the NICU with infants identified with hearing loss	AAP, ASHA, EI agencies
Survey centers that perform diagnostic testing and aid fitting before discharge	NCHAM, state EHDI coordinators
Monitor EI process and outcome indicators separately for NICU graduates	CDC
Create a protocol to ensure correct identification of newborn's PCP for follow-up before discharge from birth hospital	AAP, AAFP, NACHRI, AHA, Joint Commission
Perform a nationally representative survey of current communication methods between birthing hospitals and PCPs	CDC (AUCD), AHRQ, AAP
Ongoing developmental surveillance by PCP	AAP, EI Agencies

NACHRI indicates National Association of Children's Hospitals and Related Institutions; AAA, American Academy of Audiology; SCHIP, State Children's Health Insurance Program; ASHA, American Speech-Language-Hearing Association; NCHAM, National Center for Hearing Assessment and Management; EHDI, early hearing detection and intervention program; AAFP, American Academy of Family Physicians; AHA, American Hospital Association; AUCD, Association of University Centers on Disabilities. Source: diagnosis and evaluation breakout group, "Accelerating Evidence Into Practice for the Benefit of Children With Early Hearing Loss" workshop, January 24, 2008.

referral to EI of infants in NICUs (Table 4), a specific subgroup that is at risk of late diagnosis.

Improve Screening Protocols and Diagnostic Testing Before Discharge

Infants in the NICU are at a higher risk of hearing loss, yet diagnosis and management are often delayed.[3] Contributors to this problem include postponing screening because of immaturity or fragile medical status, a greater likelihood of missed screening because of hospital transfers, and a low priority for audiologic follow-up when other medical conditions require attention. Solutions lie with exploring options for earlier screening (eg, as soon as the infant's condition is stable) and improving communication between hospitals to ensure that screening is not missed in infants who transfer. Certain infants, such as very premature infants or term infants with complex medical problems who may be hospitalized for 2 to 5 months before discharge, could benefit from diagnostic audiologic testing performed in the NICU to speed diagnosis and timely treatment.[3]

There are specific recommendations for screening newborns who have been in the NICU longer than 5 days[13] because they are at higher risk of auditory neuropathy spectrum disorder. Such infants may pass screening with otoacoustic emissions, so it is recommended that all infants cared for in the NICU for longer than 5 days be screened with automated auditory brainstem responses (AABRs). All infants who do not pass the AABRs must be referred to an audiologist for rescreening with AABRs or comprehensive diagnostic testing.

Workshop attendees concluded that work was needed to create widely accepted screening and diagnostic protocols for infants in the NICU. The group acknowledged that future technologic advances (T1) could facilitate bedside diagnostic testing in the NICU but focused their discussions on accelerating the use of existing technology. The group identified a need for the creation of clinical practice guidelines (T2) for the testing and management of infants in the NICU coupled with the creation, implementation, and validation of quality indicators (T3) (Table 4). Additional actions the group recommended were creating resources for parent-to-parent support during diagnostic testing; performing diagnostic testing in the NICU; working with audiology diagnostic centers to facilitate referrals of infants in the NICU with diagnosed hearing loss to EI while they are still inpatients; and creating Internet-based resource lists of diagnostic testing sites and primary care providers (PCPs) for use by NICU staff and parents (T3 activities).

To take responsibility for these actions, the group identified professional organizations including the American Academy of Pediatrics (AAP), the American Academy of Audiology, and the American Speech-Language-Hearing Association (Table 4). Advocacy groups could facilitate parent-to-parent support during diagnostic testing, whether performed in the NICU

TABLE 5 Recommended Action Steps and Proposed Responsible Actors in Treatment and Intervention: Increase Timely Access to Effective EI Services Delivered by Qualified Providers

Action Steps Recommended by Breakout Group	Responsible Actors
Increase support for training and innovative delivery models	Advocacy groups (CEC–Division of Early Childhood, Infant Toddler Coordinators Association, NAD, NCHAM, Hands and Voices, ASDC, AG Bell) State and local education agencies (schools for the deaf, Department of Education, Part C coordinators, Commission for the Deaf and Hard of Hearing) Federal, state, and local health programs (Department of Health and Human Services, Title V; 2)
Collaborate on training modules	Department of Education, MCHB
Create best-practice guidelines for EI	All, with leadership from a working group of all professional organizations
Disseminate practice guidelines and provide technical assistance for implementation	NECTAC, NCHAM, Marion Downs National Center, Boys Town National Research Hospital, Department of Education, others
Develop valid tools for monitoring and reporting developmental outcomes	NIDCD, NICHD, CEC, AAP
Request increased support for interventions	Professional alliance of Hands and Voices, AG Bell, NAD, ASHA, CEC, Easter Seals, AAP, Infant Toddler Coordinators Association
Expand loaner hearing aid banks	National collaboration of all hearing aid providers; local philanthropic organizations, state EI programs

CEC indicates Council for Exceptional Children; NAD, National Association for the Deaf; NCHAM, National Center for Hearing Assessment and Management; ASDC, American Society for Deaf Children; AG Bell, Alexander Graham Bell Association for the Deaf and Hard of Hearing; CSHCN, children with special health care needs; NECTAC, National Early Childhood Technical Assistance Center; NIDCD, National Institute on Deafness and Other Communication Disorders; NICHD, Eunice Kennedy Shriver National Institute of Child Health and Human Development; ASHA, American Speech-Language-Hearing Association.
Source: treatment and intervention breakout group, "Accelerating Evidence Into Practice for the Benefit of Children With Early Hearing Loss" workshop, January 24, 2008.

TABLE 6 Parent Support and Public Awareness: Support Culturally and Linguistically Appropriate Family Resources (eg, Parent-to-Parent Supports): DHH Mentors

Action Steps Recommended by Breakout Group	Responsible Actors
Proactive, formal support mechanisms at state, national, and local levels	
Collaborate to support a forum for key stakeholders	Advocacy groups (Hands and Voices, AG Bell, ASDC)
Support DHH family-to-family resources	Federal, state, and local Medicaid/SCHIP programs
Create proactive mechanisms for offering to families (eg, add to HIPAA/FERPA release form)	Federal, state, and local Medicaid/SCHIP programs
Track data nationally on family resources/mentoring	Federal, state, and local Medicaid/SCHIP programs
Study use of existing programs	Federal, state, and local Medicaid/SCHIP programs
Identify resources and expertise to ensure programs are culturally and linguistically competent	National Center for Cultural Competence, CDC, HRSA-MCHB, advocacy groups
Create local lists of diverse DHH mentors/role models	Advocacy groups, state EI programs
Facilitate respectful partnerships with providers	All stakeholders
Support capacity of family resource centers to address hearing loss	HRSA-MCHB, advocacy groups, both DHH and national parent-to-parent
Public awareness campaign on EI	CDC, advocacy groups, public relations, social marketing groups

AG Bell indicates Alexander Graham Bell Association for the Deaf and Hard of Hearing; ASDC, American Society for Deaf Children; SCHIP, State Children's Health Insurance Program; HIPAA, Health Insurance Portability and Accountability Act; FERPA, Family Educational Rights and Privacy Act.
Source: parental support and public awareness breakout group, "Accelerating Evidence Into Practice for the Benefit of Children With Early Hearing Loss" workshop, January 24, 2008.

or after discharge. EI agencies could develop evidence-based intervention protocols for infants diagnosed with hearing loss while they are still in the NICU.

Other recommendations included having Title V agencies compile lists of centers of excellence/expertise in diagnostic testing for infants who are referred from the NICU. State programs could work with insurers (private insurers, Medicaid, Children's Health Insurance Program [CHIP]) to streamline authorizations for diagnostic testing. In addition, the CDC could monitor and report both process and outcome indicators separately for NICU graduates and infants cared for in the well-infant nursery to evaluate the impact of system improvements.

The group noted that a few hospitals currently perform diagnostic testing in the NICU and fit hearing aids before hospital discharge. They recommended that the National Center for Hearing Assessment and Management convene a workgroup of representatives from such hospitals to summarize and disseminate evidence-based best practices and provide technical assistance to other hospitals to replicate this model.

Link Infants Who Do Not Pass Screening in the NICU With a Medical Home Provider

Correct documentation of the child's main health care professional by the hospital before discharge is critical for reducing loss to follow-up and ensuring quality care. The group proposed that the AAP, the American

TABLE 7 Program Evaluation, Continuous Quality Improvement, and Practice to Research: Expand and Improve Information Systems on the Care of Children With EHL

Action Steps Recommended by Breakout Group	Responsible Actors
Track/report individual and aggregate data across all states	
Agree on locus of responsibility for monitoring and tracking care and outcomes data, including improvement data	CDC EHDI system; all stakeholders
Increase ability to share information across health/education agencies and jurisdictions	
Implement consent for data-sharing at time of diagnosis	Departments of health and education, family advocacy groups
Support IT infrastructure that includes both health and educational systems	Departments of health and education, family advocacy groups
Identify the medical home as responsible/accountable for monitoring care of DHH	Health care professional associations
Partner with families on information systems	
Encourage family ownership of health/education records	Advocacy organizations and state and local public health agencies
Advocate for personal health records	Advocacy organizations and state and local public health agencies
Design IT systems with families in mind	
Be proactive in identification of needs and linkage of data with existing systems (eg, public health metabolic screening and immunization registries, birth certificates)	National, state, and local public health agencies
Upgrade and improve information systems (via federal transformation grants)	State and local
Create and enforce uniform standards of care and Medicaid services across states	Federal agencies
Create and use common client identifier	State and local public health agencies
Agree on structure and standards for measuring key aspects of care and outcomes	
Base care process and outcomes measures on professional organization recommendations	Professional societies, advocacy groups
Identify program characteristics associated with high-quality care and use to create relevant structural measures of quality	CDC, state EI programs
Collect and submit measures for endorsement by the National Quality Forum	JCIH with CMS, National Quality Forum
Performance improvement in health and EI services	
Use consensus-based indicators to simulate improvement in care quality and outcomes	All stakeholders
Develop standards for identified data elements	CDC works with all stakeholders
Use health IT to increase ability to track children through life span	CDC, DHHS, and ED, all stakeholders

EHDI indicates Early Hearing Detection & Intervention Program; IT, information technology; JCIH, Joint Committee on Infant Hearing; CMS, Centers for Medicare & Medicaid Services; DHHS, Department of Health and Human Services; ED, Department of Education.

Source: Program evaluation, continuous quality improvement, and practice to research breakout group, "Accelerating Evidence Into Practice for the Benefit of Children With Early Hearing Loss" workshop, January 24, 2008.

Academy of Family Physicians, the National Association of Children's Hospitals and Research Institutions, the American Hospital Association, and the Joint Commission (formerly the Joint Commission on Accreditation of Healthcare Organizations [JCAHO][29]) work together to create a protocol to ensure correct identification of the PCP before discharge. The group recommended conducting a nationally representative assessment of how often the PCP is known at the time of discharge and ascertaining how frequently the PCP has the results of hearing screening when seeing the newborn for follow-up. The group also recommended ongoing developmental surveillance of all infants by their PCPs to monitor for both the progress of infants diagnosed with hearing loss and late-onset losses in those infants who pass their newborn screenings.

Treatment and EI Group

The treatment and EI group focused its deliberations on 3 sets of action steps (Table 5).

Increase Timely Access to Effective EI Services

Evidence-based practice guidelines for EI programs (including traditional center- and home-based interventions as well as innovative delivery models such as teleintervention, described elsewhere in this supplemental issue[30]), should be developed and disseminated. Provision of unbiased information to families on choices of interventions available is also needed, as are continuous efforts to measure and improve the quality of services.

Recent evaluations of EI services, largely based on family assessments, have revealed that services are valued by families, yet there is an urgent need for experimental research to identify factors in EI that are most likely to lead to successful outcomes.[31,32] The growth of neurodevelopmental and behavioral science research now presents tremendous opportunities to design innovative intervention approaches and assess their effects. More evidence of what works in EI could motivate more health care providers to screen and refer to such services.[33–35] For example, a working group of professional associations

and other interested stakeholders could create and disseminate evidence-based best-practice guidelines for intervention with young children from birth to the age of 5. These guidelines could be modeled on the National Association of State Directors of Special Education document on school-aged children who are DHH.[36,37] In addition, the US Department of Education Office of Special Education and Rehabilitative Services and the MCHB could develop evidence-based training modules for preservice and in-service programs for interventionists. The National Center for Hearing Assessment and Management could collaborate with the National Early Childhood Technical Assistance Center and other organizations (eg, Marion Downs National Center, Boys Town National Research Hospital, etc) on an ongoing technical-assistance effort focused on EI services for children who are DHH. The group also recommended advocacy for increased resources for interventions by a professional alliance of all interested groups (eg, Hands and Voices, the Alexander Graham Bell Association for the Deaf and Hard of Hearing, National Association of the Deaf, American Speech-Language-Hearing Association).

Develop Initiatives to Improve Access to Loaner Hearing Aids

Infants who are newly diagnosed with DHH frequently experience delays in fitting of hearing aids while sources of funding for permanent aids are identified. Some groups have organized "loaner banks" that provide a temporary aid until a permanent aid can be obtained (see also the Limb et al[38] article in this supplemental issue). Only a few states mandate coverage for hearing aids,[39] and reimbursement rates vary considerably.[40]

Create a Systematic Process for Monitoring Developmental Outcomes

There was widespread agreement on the need for better documentation of language and communication abilities of children who are DHH (T1). Intervention providers need tools for valid assessments of early progress both in signing and oral communication skills. Providers also need tools that measure quality of life and family functioning alongside family knowledge and satisfaction with services. Measures of individual developmental progress need to be translated into local, state, and national indicators of system performance (T3). Funding is available from the National Institute on Deafness and Other Communication Disorders for such work.[41–43]

Parent Support and Public Awareness

Consumers are important contributors in shaping the health care system and as participants in their own care,[44] yet they have been an underutilized resource in facilitating translation of research into practice. Families of children with EHL need formal support mechanisms at the national, state, and local levels (Table 6) that are embedded in the system and proactively offered to parents (eg, parents could request contact with other families through a checkbox added to a Health Insurance Portability and Accountability Act of 1996 [HIPAA] or Family Educational Rights and Privacy Act [FERPA] release form).

Workshop attendees recommended that advocacy groups collaborate to support a forum for key stakeholders to develop these support mechanisms and that Medicaid and CHIP programs support family-to-family resources and track data nationally on their availability, use, and functioning. Families need culturally and linguistically appropriate resources in multiple modalities, in the language of their choice, including written information, available as handouts, Web downloads, and visual media (eg, video, DVD). The group recommended that all visual media be made available in sign language and/or with captioning. Families should be offered contact with DHH role models and/or mentors that reflect the diversity of the DHH population. They should include individuals with unilateral and bilateral hearing loss from a range of cultural backgrounds who use a range of communication options. Families should decide which of these resources they wish to access to best address their individual needs.

The workgroup recommended that advocacy groups partner with the National Center for Cultural Competence[45] to hold a forum on appropriate resources. In addition, the breakout group recommended that each state's Title V program identify existing resources and work with the CDC and HRSA-MCHB to distribute written and media resources via the Internet and in other family-friendly ways. State programs for children with EHL also could work with local advocacy groups to compile a comprehensive list of DHH mentors and role models and to ensure that family resource centers[46,47] are equipped to provide appropriate services to families of children who are DHH.

The breakout group suggested that parents contribute to a comprehensive public awareness campaign coordinated through the HRSA-MCHB, CDC, and AHRQ to increase awareness of newborn-screening programs and the need for prompt follow-up and management. The campaign must be designed to reach all cultural and linguistic groups and draw on the expertise of established public relations and social marketing groups.

Program Evaluation, Continuous Quality Improvement, and Practice to Research

The program evaluation, continuous quality improvement, and practice to research group focused on 4 action areas.

Expand and Improve EHL Information Systems

Improving data quality and integrating information should be a high priority. Currently, the CDC is responsible for tracking and reporting aggregate data on systems related to EHL.[48] In addition, the Individuals With Disabilities Education Act (IDEA) program requires reports from states on performance goals, including goals for children who are DHH.[49,50] However, these data-collection efforts are not linked. Specific action steps recommended by the group (Table 7) include expansion of state data-tracking systems to allow for reporting and appropriate sharing of data. Future linkage of screening and diagnosis data with language outcomes could inform program development and facilitate the long-term follow-up that is recommended for individuals with disorders diagnosed through newborn screening.[51]

States could use other data-tracking systems as models such as existing state immunization registries[52] or Australia's database on all individuals (including children) with hearing aids.[53] The US Department of Health and Human Services Office of the National Coordinator for Health Information Technology is developing guidelines that could assist in the development of data-collection and -tracking mechanisms for newborn hearing screening and follow-up.[54] Medicaid transformation grants could be a source of funding for database development.[55] As reported elsewhere in this supplemental issue,[56] privacy regulations such as those contained in the Health Insurance Portability and Accountability Act of 1996 and the Family Educational Rights and Privacy Act are a significant challenge that will need to be addressed in such initiatives.

Stakeholders Agree on a Locus of Responsibility for Monitoring and Tracking Care and Outcomes Data, Including Improvement Data

Currently, there is a lack of clarity on who is responsible for clinical case-tracking for Early Hearing Detection and Intervention programs. Individual states will need to determine who is responsible for this function, who will have access to the data, and how they will access the data. States will also need to determine who is responsible for reporting aggregate data, using data for quality improvement, and sharing data with other entities. Evaluation of different approaches will inform the most efficient arrangements for data-sharing.

Develop and Use a Limited Set of Agreed-on Indicators for EHL Program Structure, Process, and Outcome Indicators

An agreed-on set of structure, process, and outcome indicators[57] is needed to monitor services for children with EHL for purposes of accountability and quality improvement.[58,59] Some of the quality measures already available for children with special health care needs could be used to measure processes of care (eg, parent-provider communication, timeliness of care),[60] but additional measures specific to children with EHL must be identified and agreed on by a consortium of advocates, providers, purchasers, policy makers, and measurement and health information technology experts.[61]

The breakout group recommended that the Joint Committee on Infant Hearing (JCIH) act as a coordinating entity to identify and review possible measures. Endorsement by the JCIH and other groups such the National Quality Forum[62] would increase the chances of their use by important payers and service providers (eg, the Centers for Medicare & Medicaid Services).

Involve Families and Children

To ensure that children with EHL and their families benefit, families must be involved in the design, testing, and governance of information systems.[63] Families also should be encouraged to take ownership of their health and information records through such new developments as personal health records.[64] Optimally, personal health records should be connected to the many settings in which care is provided to children with EHL (eg, birth hospital, pediatrician's office, audiologist's office, EI services, other therapists).[65,66]

Stewardship

Numerous entities are keenly interested in working to improve care and outcomes for children with EHL.[7,12,24–26] Workshop attendees recognized the need for a locus of responsibility to monitor progress and stimulate needed action and recommended the creation of a public-private oversight body funded and organized by the federal government. However, any formal public-private advisory group would need to comply with the Federal Advisory Committee Act of 1972 (FACA), as amended, which requires approval by the White House.

Should a stewardship group be created in either the public or private sectors, the breakout group recognized the need to build on existing collaborative efforts. The stewardship group could review information derived from system monitoring to stimulate targeted studies and spur action on the basis of evidence. A workgroup comprising representatives of the federal

agencies with responsibility for services for children with EHL, family advocacy groups, and other stakeholders could assist in "closing the circle" between basic science research and clinical practice. The group could consider use of the 3T's model as a framework to guide future discussion of how to accelerate evidence into practice. The group also could receive advice from the US Secretary of Health and Human Services' Advisory Committee on Heritable Disorders and Genetic Diseases in Newborns and Children.[51]

DISCUSSION

Building on previous work,[7,12,24–26] this workshop focused on prioritizing recommendations to improve the system of care for children with EHL, specifying clear action steps to move evidence into practice and specifically identifying those who are responsible for action. The methodology adopted at the workshop provided a useful, practical approach to moving evidence into practice. Identifying evidence-based recommendations through literature review, prioritizing recommendations with a modified Delphi process, and then identifying action steps for implementation by using a matrix of responsibility provided a practical mechanism through which to address the important question of how to improve practice.

Workshop processes were inclusive, with input from a variety of stakeholders. The varied practical experience of the participants facilitated clarification of the steps needed to transform written recommendations into actual practice. Identifying specific action steps and entities that could move implementation plans forward was frequently difficult. Many existing recommendations required further clarification. The matrix-of-responsibility exercise highlighted gaps in participant understanding of the roles of the various government agencies (eg, the CDC, MCHB, National Institutes of Health, Department of Education, and AHRQ). Even simple recommendations often required complex implementation plans that involved multiple agencies working together at the local, state, and national levels.

During this process, it was clear that the 4 facilitators of translation identified by the 3T's model (shared leadership, teamwork, tools, and resources) are all important considerations for moving recommendations into practice. Although implementation is ultimately a local activity, participants acknowledged the important role of national leadership in driving innovation. Moving any of the recommendations into practice requires teamwork across disciplines and service sectors; no single group or agency acting alone can achieve the necessary practice change.

Although participants expressed the need for increased resources for continued system improvement, policy changes that would direct resources to the system were outside the scope of this workshop. Similarly, broader policy issues influencing, for example, the proportion of young children who are uninsured were not the focus of this workshop but undoubtedly would influence the likely success of T3 efforts. Attendees identified both opportunity and openness to public-private partnerships (including families) that could drive system improvements.

CONCLUSIONS

More infants are being screened early for hearing loss, but the extent of essential diagnostic follow-up and treatment is variable, and there is concern that not all children are receiving the best available, evidence-based care. The outcomes of infants identified with EHL and their families can be improved by efforts to accelerate evidence into practice and to continuously monitor access, quality, and outcomes of services. Fifty participants with varying roles in improving services for children with EHL strongly endorsed a more systematic and comprehensive approach to data collection and sharing, as well as enhanced stewardship to ensure accountability and continuous quality improvement. Specific contributions of workshop participants included identification of responsible stakeholders to develop protocols for screening, diagnosis, and timely referral of infants in NICUs, develop evidence-informed guidelines and innovative approaches to EI, mount a public awareness campaign, and involve families in all aspects of early hearing detection and intervention.

The best basic research and evidence-based guidelines will not affect population health or meet the needs of families unless the final stage of translating research into practice—ensuring that the health care delivery system gets the right care to the right children at the right time—is addressed. The system of care for children with EHL has benefited from a high degree of cross-disciplinary collaboration at national, state, and local levels and is open to innovations. The transformation of health care delivery for this group of children, using approaches recommended by the workgroup, could serve as a model for broader developmental systems transformation and inform future efforts to improve delivery of all child health services.

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KEY WORDS

deaf, hard-of-hearing, early intervention, newborn hearing screening

ABBREVIATIONS

UNHSI—universal newborn hearing screening and intervention
EI—early intervention
AAP—American Academy of Pediatrics

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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. *Pediatrics* 2010;126:S19–S27

Each year, ~12 000 infants in the United States are born with permanent hearing loss.[1] Newborn hearing screening can help ensure early detection of hearing loss for these infants.[2] The average age of detection of hearing loss without screening is 2½ to 3 years[3,4] of age, which is far too late.[5]

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 are enrolled in early intervention (EI) programs before 6 months of age, 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.[6–9]

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.[9] 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,[10–13] 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. Not

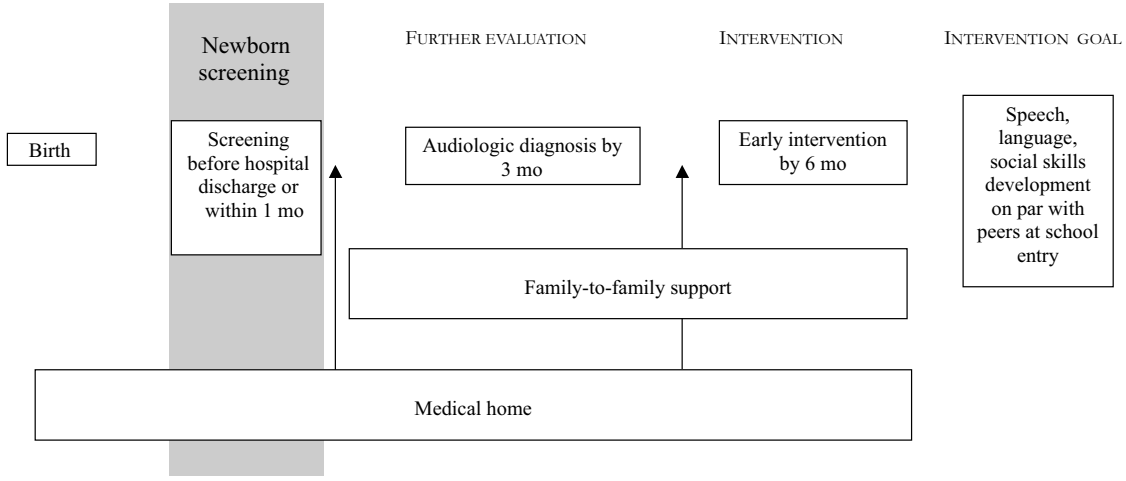

FIGURE 1
Conceptual framework for the universal newborn hearing screening and intervention program.

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.

TABLE 1 Summary of Outcome Measures Reported by UNHSI Programs

Outcome Measure	Weighted % (Range)[a]
Newborns screened before discharge	92 (25–100)
Newborns who did not pass screening before discharge	4 (1–34)
Newborns who were referred for a diagnostic evaluation[b]	2 (1–7)
Infants who needed a diagnostic evaluation and received one	62 (15–95)
Infants who needed a diagnostic evaluation and received one by the age of 3 mo	52 (5–93)
Infants who did not pass the hearing screening who had a medical home	80 (5–100)
Infants with confirmed hearing loss linked to EI[b]	68 (10–100)
Infants with confirmed hearing loss linked to family-to-family support[c]	40 (5–100)

[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.

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.

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,[14] 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.[5] 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.[15] 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.[15] 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,[16] 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.

Traveling to an Unfamiliar Location for Diagnostic Evaluation

Families may be less likely to follow-up on a referral for an audiologic 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

TABLE 2 Barriers to Follow-up and Successful State Strategies: Lack of Provider Knowledge

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

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

Barrier	State Strategy
Family must go to unfamiliar location for evaluation	Have hospitals establish a relationship with an audiology center(s), preferably within the same hospital system
Preauthorization requirements delay access to further evaluation	Have hospitals, UNHSI staff, or primary care physicians facilitate preauthorization for services
Lack of transportation to audiologist	Use existing state programs to assist with transportation (Part C, Title V, public health nurses, Medicaid)
Lack of health insurance impedes access to medical home and audiologic evaluation	Have UNHSI program staff, audiologists, and EI staff inform families about public health insurance and state assistance programs
Mobility of families makes linkage to EI services challenging	Have providers of EI services perform targeted outreach to families at risk of being lost to follow-up
Language spoken by families prevents linkage to services	Have UNHSI program develop educational materials in other languages
	Have UNHSI program, hospitals, and EI programs use translation services and hire bilingual staff

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.[6,10,11] Our study results add to this literature by conducting the first (to our knowledge) systematic review of the national

TABLE 4 Barriers to Follow-up and Successful State Strategies: Information Gaps Remain

Barrier	State Strategy
Poor communication among hospitals, health care providers, audiologists, and UNHSI program	Train hospital staff on the importance of relaying complete information
	Use existing data sources (metabolic screening, vital records, Medicaid) to complete missing data fields
	Use specialized software, metabolic screening card, or electronic birth certificate to convey results
Data systems are inaccessible to providers	Use Web-based systems to facilitate real-time transmission of screening and evaluation results, maintain accurate contact information for families, and track follow-up
Privacy laws impede sharing across agencies	Collaborate with data partners to establish data-sharing procedures and agreements
	Work with EI partners to secure permission from families for data-sharing between the EI and UNHSI program

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, multientity 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.[21] Recent study results have suggested that it is possible to provide coordinated care

in primary care settings, often most efficiently performed by nonphysicians, primarily nurses.[22] 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).[23]

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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Federal Privacy Regulations and the Provision of Early Hearing Detection and Intervention Programs

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Federal Privacy Regulations and the Provision of Early Hearing Detection and Intervention Programs

abstract

To be successful, Early Hearing Detection and Intervention (EHDI) programs require individually identifiable information about children to be shared among people who are responsible for screening, diagnosis, early intervention, family support, and medical home services. Pediatricians and other stakeholders in the EHDI process often point to federal laws that were passed to ensure privacy and confidentiality in health care and educational programs as major obstacles to achieving efficient and effective EHDI programs. In this article we summarize the provisions of 3 federal laws (the Health Insurance Portability and Accountability Act [HIPAA], the Family Education Rights and Privacy Act [FERPA], and Part C privacy regulations of the Individuals With Disabilities Education Act [IDEA]) that most directly affect information-sharing in EHDI programs. We suggest strategies for sharing the information needed to operate successful EHDI programs while remaining in compliance with these laws, including obtaining signed parental consent to share information between providers, including an option on the individual family services plan for parents to permit sharing of the plan with pediatricians and other providers, and giving copies of all relevant test results to parents to share with providers as they wish. *Pediatrics* 2010;126:S28–S33

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KEY WORDS

deaf, hard-of-hearing, early intervention, newborn hearing screening

ABBREVIATIONS

DHH—deaf/hard-of-hearing
EHDI—Early Hearing Detection and Intervention
HIPAA—Health Insurance Portability and Accountability Act
FERPA—Family Education Rights and Privacy Act
IDEA—Individuals With Disabilities Education Act
IFSP—individualized family service plan

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More than 95% of newborns are now being screened for hearing loss.[1] However, progress in diagnosing children who are deaf or hard-of-hearing (DHH) before 3 months of age and enrolling them in appropriate intervention services before 6 months of age has been more problematic. According to the Centers for Disease Control and Prevention,[2] only 57% of infants who did not pass a newborn hearing-screening test in 2007 could be documented as completing a diagnostic evaluation, and only 58% of those who were diagnosed as DHH could be documented as being enrolled in an early-intervention program. These percentages have changed little since the beginning of the decade.[3]

Although every state has now established an Early Hearing Detection and Intervention (EHDI) program, it is clear that efficient communication among the various stakeholders (eg, screeners in the birthing hospital, pediatricians, audiologists, early-intervention providers, parents, and others) is perceived to be a major obstacle to achieving the goals referred to above.[3–6] For example, in 2007 the National Center for Hearing Assessment and Management conducted a survey of state EHDI program coordinators to determine the extent to which they thought that the Health Insurance Portability and Accountability Act (HIPAA)[7] and the Family Education Rights and Privacy Act (FERPA)[8] interfered with their ability to create and operate an effective EHDI system. EHDI program coordinators in the 50 states and territories responded,[9] and 51% of them said that HIPAA created problems in completing audiological diagnoses of infants who failed the hearing screening, whereas 62% said that the HIPAA interfered with enrolling children who are DHH in early-intervention programs. With respect to the FERPA, 32% of the respondents said that it caused problems in communicating important information to early-intervention providers, and 70% said it caused problems in getting information back from early-intervention providers. Similar findings were reported after a nationwide evaluation of EHDI programs funded by the Maternal and Child Health Bureau, which is reported elsewhere in this supplemental issue.[10]

Some of the problems noted by state EHDI coordinators are based on misunderstandings of what these laws require. As pointed out by Mark Rothstein, JD, chair of the National Committee on Vital and Health Statistics Subcommittee on Privacy and Confidentiality, "misunderstanding of the HIPAA requirements, and concern about sanctions, [are] leading to defensive practices by those in possession of protected health information. Among these practices was a reported decline in public health reporting . . . [that is] permissible under HIPAA."[11]

The purpose of this article is to summarize the requirements of the federal laws that most directly affect sharing of information among pediatricians and other stakeholders in EHDI programs and suggest ways in which such programs can be efficiently operated and still be in compliance with these laws. Particular emphasis will be placed on issues that affect pediatricians and other health care providers.

DEFINING PRIVACY LAWS AND REGULATIONS RELATED TO EHDI PROGRAMS

Federal laws that most directly affect how EHDI stakeholders are able to share information include the HIPAA,[7] the FERPA,[8] and Part C privacy regulations of the Individuals With Disabilities Education Act (IDEA).[12] It should be noted that a state law cannot take away any of the rights or protections that are guaranteed by these federal laws. This was noted with respect to the HIPAA (but is equally applicable to the other laws) by Joy Pritts, JD, of Georgetown University in her testimony before the National Committee on Vital and Health Statistics Subcommittee on Privacy and Confidentiality:

> "In general, the HIPAA Privacy Rule preempts contrary provisions of state law, ie, those where a covered entity would find it impossible to comply with both the state and Federal law or where the provision of state law stands as an obstacle to the accomplishment and execution of the goals of the Privacy Rule. However, contrary state laws that are 'more stringent' than the HIPAA Privacy Rule are not preempted . . . the Federal rule defines the term 'more stringent' generally as meaning that the state provision provides a person with greater rights of access to his own health information."[13]

The relevant aspects of the HIPAA, the FERPA, and Part C privacy regulations as they apply to EHDI programs are summarized in Table 1 and are discussed below.

The HIPAA

Passed in 1996, the HIPAA was designed to ensure health insurance coverage for workers and their families if they change or lose jobs. Title II of the HIPAA includes the "privacy rule," which was designed to protect the privacy of individually identifiable health information, which is referred to in the law as "protected health information." The HIPAA establishes conditions for protected health information use and disclosure by those who are required to abide by the HIPAA provisions (known as "covered entities"). According to HIPAA regulations, a health care provider who conducts any medical business electronically, including billing, is covered by the law and required to abide by its requirements.[14] In practice, this means that practicing pediatricians as well as anyone who is paid to provide screening, diagnosis, or any type of early-intervention services for children with hearing

TABLE 1 Summary of Privacy Regulations for the HIPAA, the FERPA, and Part C Privacy Regulations of the IDEA

	HIPAA (45 CFR Part 164)	FERPA (34 CFR Part 99)	Part C (34 CFR Part 303)
Signed consent	Must be obtained to use personal information for marketing or research purposes	Must be obtained to share any personal information from a child's educational record	Must be obtained for any Part C provider to disclose personal information to a third party
Exemptions to the need for signed consent	When health care providers exchange information with other health care providers for the purpose of providing health care	When only "directory information" is shared (eg, enrollment status, dates of attendance, honors and awards) and the educational program has given public notice at least annually that such information will be shared	When information is only being shared with a "participating agency" for purposes of providing early intervention services
	When health care providers share personal information for public health purposes	When personal information is shared only when there is a legitimate educational interest	When it is necessary to protect the health or safety of the child or other person
		When it is necessary to protect the health or safety of the student or other person	
Who must comply	Any health plan, clearinghouse, or health care provider who conducts financial and administrative transactions electronically (in other words, anyone who bills for the provision of health care services)	Any agency or program that receives federal funds from the Department of Education	Lead agencies, Part C programs, and participating agencies

loss would be considered "covered entities."

According to the HIPAA privacy rule:

1. "Signed consent" must be obtained to use personal information for marketing or research.
2. Signed consent is not required for
   - health care providers to exchange information with other health care providers for health care or medical service delivery purposes; or
   - sharing personal information for public health purposes (such as surveillance of newborn hearing screening and follow-up intervention).
3. Patients must be informed of the intention of the health care provider to share personal information with other health care providers, and providers must keep a record of any personal information that is shared.

The FERPA

The FERPA of 1974 is a federal law that protects the privacy of students' education records. Any educational program that receives funds from the US Department of Education must abide by the provisions of this law. School nurse or other health information records on children served under the IDEA are also considered educational records and are covered by the FERPA.

According to the FERPA:

1. Except as noted below, signed consent is needed for education program staff to share any personally identifiable information from a child's educational records, including student identification number, race, ethnicity, gender, and nationality.
2. Signed consent is not needed
   - to share general contact information about a child (ie, name, address, enrollment status, dates of attendance at school, honors and awards, etc) if the educational agency informs parents at least annually of their intent to share such information and gives individual parents the opportunity to object to such information being shared;
   - when personal information is shared directly with the student or other school officials within the same institution when there is a legitimate educational interest (eg, enrollment or transfer matters or financial aid issues); or
   - when it is necessary to protect the health or safety of the student or other person, such as in circumstances of abuse or neglect.

IDEA Part C Privacy Regulations

Under Part C of the IDEA, the US Department of Education provides funds to each state to assist in establishing a comprehensive system of early-intervention services for children with disabilities who are 0 to 3 years old.[12]

Once a child is referred to the Part C program, a "participating agency" (which includes the lead agency, early-intervention service providers, and any other individual agency or institution that "collects, maintains, or uses personally identifiable information" as part of the Part C service system) must obtain previous written parental consent before disclosing personal information about the child or his or her family to any person or entity outside the Part C system. Because Part C programs receive money from the US Department of Education, they must comply with the FERPA, but the Part C privacy regulations go beyond what is

required by the FERPA. Part C privacy regulations have the following stipulations related to sharing personal information.

1. Previous written parental consent is needed for anyone in a Part C participating agency to share personal information with any individuals or entities that are not a part of the Part C system. The FERPA provision that allows agencies to share general contact information about students if annual notice is given is not allowed under Part C.
2. The Part C confidentiality provisions do not apply until a child is referred to Part C; thus, signed consent provisions do not apply when an EHDI program refers a child to the Part C program. Part C regulations expressly provide that anyone who suspects that a child under the age of 3 has or is at risk of having a disability is obligated to refer the child to Part C. If the referral source is an educational agency that is subject to the FERPA, Part C expressly permits the disclosure of information under the FERPA for purposes of "child find."
3. When obtaining parental consent, the early-intervention service provider must ensure that the consent (*a*) describes the activity for which consent is sought, (*b*) specifically identifies the information that will be released, and (*c*) identifies to whom information will be disclosed.
4. Signed consent is not needed for Part C agencies to share a child's information if
   - information is being shared with a "participating agency" within the Part C system (to be considered a "participating agency," the entity must have a significant role in multiple components of the Part C system [eg, child find, multidisciplinary evaluation, public awareness, comprehensive system of personnel development, etc]); or
   - disclosure of personally identifiable information is necessary to protect the health or safety of a child or other individual.

HOW DO THE HIPAA, THE FERPA, AND PART C PRIVACY REGULATIONS AFFECT PARTICIPANTS IN THE EHDI SYSTEM?

EHDI programs must comply with all of the privacy regulations described above. However, many of the perceptions that state EHDI coordinators have about restrictions and problems caused by these privacy laws are simply not correct. For example, because the HIPAA expressly allows for sharing of information among health care providers to facilitate health care services and for reporting personally identifiable information requested by public health programs, there is nothing in the HIPAA that prevents screening-program personnel from reporting screening results to other hospitals, state EHDI programs, pediatricians, or Part C early-intervention programs. All of this can be done without obtaining informed consent from the patients. However, because well-informed patients are better patients[15,16] and because it is important for patients or clients to know what is being done with their data, it makes sense to inform parents before their data are shared with anyone. Although it is not legally required under the HIPAA, one of the best ways to ensure that patients are informed is to have a signed consent form.

The Part C privacy regulations (which incorporate but go beyond the requirements of the FERPA) are much more restrictive than those of the HIPAA. It is important to remember, however, that Part C privacy regulations are not in force until the child has been referred to or received services from an agency that is receiving Part C funds. Thus, in most cases, the screening and diagnosis of hearing loss and the referral to an early-intervention program will be completed before Part C privacy regulations become a concern. Once a child has been referred to Part C, though, information about that individual child, including whether he or she is participating in the Part C program, cannot be given by the Part C program staff to the screening program, the audiologist who performed the diagnostic evaluation, or a pediatrician unless the parent provides informed consent.

In most cases, both the HIPAA and Part C regulations would prohibit giving information about the child (including name, contact information, or status in the program) to a family support group unless permission to do so is obtained from the family. The exception would be if the family support group is considered a participating provider in the state's Part C early-intervention system.

IMPROVING INFORMATION-SHARING IN EHDI PROGRAMS AND COMPLYING WITH FEDERAL PRIVACY REGULATIONS

Although a significant number of state EHDI program coordinators see federal privacy laws as a major stumbling block when ensuring access to and coordination of services in EHDI programs,[9] many of these concerns are based on misinformation. For example, the HIPAA does not restrict sharing of information among health providers for purposes of providing health care, even when parents have not given informed consent. Thus, virtually all information-sharing among health care providers related to screening, diagnosis, and referral to the early-intervention system is not restricted by the HIPAA. Although Part C privacy

regulations require signed consent to share information with nonparticipating providers, the following strategies can be implemented to ensure that appropriate information gets to those who need it. Examples of the forms and documents that can be and are being used by state EHDI programs to support many of these strategies are available at www.infanthearing.org/privacy.

1. Obtaining signed parental consent to exchange any personally identifiable information is an important method for ensuring that families are full partners and participants in screening, diagnosis, and intervention activities.
2. Coordinated consent forms that comply with the requirements of the HIPAA and Part C privacy regulations can be used to streamline the referral process and relieve parents of the burden of completing similar forms for essentially the same purpose.
3. Memoranda of agreements that designate EHDI programs as participating agencies of the Part C system can be useful for those cases in which EHDI is serving functions beyond being a primary referral source for child-find activities (eg, diagnostic procedures as part of the multidisciplinary evaluations, public awareness, provision of direct services, etc). This is particularly appropriate for those cases in which the EHDI and Part C programs are housed in the same state agency.
4. Parents should always be given copies of diagnostic evaluation results, treatment plans, individualized family service plans (IFSPs), and signed consent forms, which enables the parent to provide information at will and provide back-up documentation for services the child is receiving.
5. Although not required under the HIPAA, the FERPA, or Part C privacy regulations, state laws that mandate the reporting of screening, diagnostic, and early-intervention service information to EHDI programs and to the child's pediatrician are a useful tool to use to encourage sharing of appropriate information. Standard reporting forms and procedures and periodic training help reporting to be more efficient.
6. The IFSP should include an option for parents to give permission for the document to be shared with EHDI staff, the child's pediatrician, and other health care providers, which enables EHDI program staff to better monitor and improve services and the pediatrician to serve a supporting role in the child's intervention care. Including a place for parents to give permission on the IFSP also reminds parents on a regular basis of how information about their child is being shared and gives them a chance to adjust the plan so that it is consistent with their desires.

The procedures and forms outlined above cannot be effectively implemented without a concerted effort to develop strong interagency and interpersonal relationships among key stakeholders including EHDI programs, Part C early-intervention programs, the child's pediatrician, and family support groups. Consistent training is needed at the community level to ensure that all stakeholders understand the importance of consistently and accurately sharing information and helping families to be full participants in that process. In addition, families, pediatricians, and other providers should provide regular feedback to EHDI programs to guide quality improvement in ensuring that all children are receiving timely and effective hearing screening, diagnostic evaluations, and interventions.

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Medicaid Reimbursement of Hearing Services for Infants and Young Children

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Medicaid Reimbursement of Hearing Services for Infants and Young Children

abstract

As newborn hearing-screening programs have expanded, more and more infants and young children need hearing services. Medicaid is one of the primary sources of funding for such services and, by law, must establish payment rates that are sufficient to enlist enough providers to provide services. In this study we compared 2005 Medicaid reimbursement rates for hearing services for infants and young children in 15 states with the payment rates for the same services by Medicare and commercially available health insurance. On average, Medicaid rates for the same services were only 67% as high as Medicare and only 38% as high as commercial fees. Furthermore, most Medicaid rates declined from 2000 to 2005, and many states did not have billing codes for a significant number of the hearing services needed by infants and young children. These factors likely contribute to infants and young children with hearing loss not being able to get the hearing services they need to benefit from early identification of hearing loss. These data also raise questions about the extent to which states are meeting the federal requirement that Medicaid payments be sufficient to enlist enough providers so that care and services are adequately available to the general population in the geographic area. *Pediatrics* 2010;126:S34–S42

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KEY WORDS

deaf, hard-of-hearing, early intervention, newborn hearing screening

ABBREVIATIONS

EHDI—Early Hearing Detection and Intervention
EPSDT—Early and Periodic Screening, Diagnosis, and Treatment
CPT—*Current Procedural Terminology*
HCPCS—Healthcare Common Procedure Coding System

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Approximately 95% of newborns are screened for hearing loss before leaving the hospital, and all states have established Early Hearing Detection and Intervention (EHDI) programs.[1] Consequently, substantially more infants and young children are being identified with hearing loss, and there is a significantly increased need for early audiological, medical, and educational services for these infants and young children. Not surprisingly, concerns about how to pay for such services have been raised.[2,3]

Because Medicaid is the largest single insurer of children in the United States, its reimbursement policies significantly affect access to care for millions of children. National data show that approximately one-third of all children in the United States are enrolled in Medicaid.[4]One of the primary mechanisms by which Medicaid services are provided to children is the Early and Periodic Screening, Diagnosis, and Treatment (EPSDT) program, which is a mandatory benefit that focuses on the prevention and early treatment of children's health problems.[5]

Under Medicaid law,[6] states have considerable discretion in developing their own payment methods and rates as long as 3 requirements are met:

1. Payment methods and procedures must be consistent with efficiency, economy, and quality of care.
2. Payments must be sufficient to enlist enough providers so that care and services are available to at least the extent they are available to the general population in the geographic area.
3. Except for some special circumstances that are not relevant for this article, providers must accept Medicaid reimbursement as payment in full.

Whether the second statutory requirement is met is particularly important for families of infants and young children with hearing loss. As discussed in other articles in this supplemental issue,[7,8] the lack of qualified pediatric audiologists is one of the biggest obstacles to providing high-quality services to infants and young children with hearing loss and their families.[2] In addition, ensuring that payments are sufficient to enlist enough providers has been the subject of extensive debate and even lawsuits in several states regarding the provision of health care services.[9]

State Medicaid officials recognize that reimbursement rates are often well below the actual cost incurred to provide care to Medicaid-insured children. However, faced with serious fiscal difficulties, most states have elected not to increase provider payments but, rather, to extend coverage to the growing number of children who are eligible for Medicaid. Between 2003 and 2004, one-third of states actually froze or reduced fee-for-service provider payments.[6,10] Research has also revealed that pediatricians cite low reimbursement as the key factor that limits their participation in Medicaid, and nearly one-third of pediatricians have reported that they would accept more Medicaid patients if reimbursement rates were increased.[4,9,10]

Until recently, little attention has been directed at the adequacy of Medicaid reimbursement for audiology and speech-language pathology services despite the fact that significant hearing loss is the most frequent birth defect in the United States; ~3 in 1000 newborns have a permanent hearing loss.[11,12] By the time children reach school age, the prevalence triples to at least 10 in 1000.[13]

In addition to the fact that permanent hearing loss has significant negative impact for a relatively large number of children if it is not identified and treated at a very young age,[11] 3 other factors underscore the need for an objective analysis of Medicaid reimbursement rates of hearing services for children. First, new medical standards and technology for infants and children with hearing loss have been adopted in the last 10 years but may not yet be incorporated into states' EPSDT policies and procedures.[14] Second, a serious shortage of qualified pediatric audiologists is adversely affecting timely access to care for all children, but especially low-income children.[2,7,8] Third, progress in evaluating and intervening early with children suspected of having hearing loss has not kept pace with our national Healthy People 2010 goals,[15] which call for an increase in the proportion of newborns who are screened for hearing loss by the age of 1 month, have an audiologic evaluation before the age of 3 months, and are enrolled in appropriate intervention before the age of 6 months.

Our study addressed the following questions:

1. Do state Medicaid agencies have reimbursable codes for a comprehensive set of hearing services for children?
2. What are states' payment policies for children's hearing services?
3. Did the amount of reimbursement for children's hearing services change between 2000 and 2005?
4. How do state Medicaid fees for children's hearing services compare to Medicare and commercial fees?

The goal of the study was to assess whether Medicaid is providing payment for children's hearing services in ways that are likely to support or interfere with the provision of timely and appropriate services for children identified with permanent hearing loss.

METHODOLOGY

Information for this study was obtained from a survey of 15 states (Idaho, Illinois, Iowa, Kentucky, Maine,

Maryland, Massachusetts, New Mexico, North Dakota, Ohio, Oklahoma, Texas, Vermont, Washington, and Wyoming) conducted by the Maternal and Child Health Policy Research Center between January and March 2005 and compared with a previous survey conducted between November 2000 and February 2001.[16] Six states (Arizona, Connecticut, Delaware, Minnesota, Oregon, and Tennessee) that relied exclusively on capitated managed care organizations were excluded. Therefore, the fees presented in this article are direct provider payments for services provided to children in fee-for-service arrangements, primary care case management systems, or in managed care organizations that carve out audiology services from a managed care contract.

Sixty-five codes for children's hearing services were examined, including codes for audiologic diagnostic evaluation and treatment services, hearing, speech, and language function tests, hearing aid services, cochlear implant services, and assistive communication services. For each service, we determined whether states had a billable *Current Procedural Terminology* (CPT) code or a Healthcare Common Procedure Coding System (HCPCS) code. We then examined the average, range, and distribution of payments for 2005 and compared them to fees paid in 2000 on the basis of a previous study.[17] To assess payment adequacy, we analyzed differences in 2005 Medicaid and Medicare fees on the basis of Medicare fee schedules for audiologists published by the Centers for Medicare & Medicaid Services.[18] We also analyzed differences in Medicaid and commercial fees on the basis of actuarial data from Milliman, Inc, which conducted an evaluation for the American Speech-Language-Hearing Association of the fees paid for certain hearing assessment and treatment services, supplies, and devices in a typical employer-sponsored health insurance plan. Milliman calculated the prevalence of the procedures and the unit cost of providing the procedures from a large database of commercial claim encounters. The report also used the Milliman health care guidelines, which reflect a level of utilization and charges per service associated with typical employer-sponsored health care coverage in the United States.[19]

RESULTS

Data were analyzed with respect to fees paid for various services related to children's health services, how those fees changed from 2000 to 2005, and how the fees compared to fees paid for the same services by Medicare and commercial providers.

Billable Codes, Current Fees, and Payment Trends for Specific Hearing Services

Results are presented for children's hearing services in 5 areas: (1) audiologic, diagnostic, evaluation, and treatment services; (2) audiologic function tests; (3) hearing aid services; (4) cochlear implant services; and (5) assistive communication services.

Audiologic Diagnostic, Evaluation, and Treatment Services

This category included services related to (1) evaluation of speech, language, voice, communication, auditory processing, and aural rehabilitation status and (2) treatment of these disorders. In 2005, 13 of the 15 states in our study had a billable code for diagnostic evaluation services. The average payment rate for this service was $59.98 (range: $12.10–$127.42) as shown in Table 1. The vast majority of states paid rates for these services that were in the lowest to middle fee distribution level (in other words, most states paid between $12.10 and $50.54). Medicaid fees for diagnostic and evaluation services were, on average, 32% higher than fees paid in these same states in 2000, as shown in Table 2.

For audiologic treatment services, 2 states did not have a billable code. For the remaining states, Medicaid agencies reimbursed less for audiologic treatment than for evaluation services and paid, on average, $39.16 (range: $10.38–$69.03). The most likely factor accounting for the wide range in Medicaid payment rates for these 2 services is the length of the visit (15, 30, or 60 minutes), which is not distinguished in CPT codes. Compared with evaluation services, almost one-third of the states had fees for audiologic treatment in the highest fee distribution. Over the 5-year study period, Medicaid fees for this service increased by 21%.

Audiologic Function Tests

To detect permanent hearing loss at an early age, a variety of audiologic function tests are used with infants and young children. Almost all states had billable codes for each of the 15 audiologic function tests analyzed in this study; the exceptions were for select picture audiometry, auditory evoked potentials for evoked response audiometry, and/or testing of the central nervous system (limited), which were not used by 1 to 4 of the 15 states.

Medicaid fees for audiologic tests varied significantly; payment for comprehensive auditory evoked potentials was at the highest average rate ($90.76), and payment for acoustic reflex testing was at the lowest ($11.21). There were a number of noteworthy payment patterns. For example, the average payment for CPT code 92587 (evoked otoacoustic emissions: limited) was $45.05 (range: $16.00–$59.01). This test typically requires ~15 minutes by a technician who has had a few hours of training and uses a

TABLE 1 Average Medicaid Fee-For-Service Payment Amounts for Hearing Services in 15 States, 2005

CPT or HCPCS Code	Audiology Services	Average Payment		Range of Payments (Low to High), $	Lowest Third, %	Middle Third, %	Highest Third, %
		$	No. of States Reporting				
Audiologic diagnostic, evaluation, and treatment services							
92506	Evaluation of speech, language, voice communication, auditory processing, and/or aural rehabilitation status	59.98	13	12.10–127.42	38.46	53.85	7.69
92507	Treatment of speech, language, voice communication, and/or auditory processing disorder (includes aural rehabilitation), individual	39.16	13	10.38–69.03	38.46	30.77	30.77
Audiologic function tests							
92551	Pure tone screening test	11.97	14	4.00–17.58	21.43	28.57	50.00
92552	Pure tone audiometry, air only	12.62	15	6.00–17.38	13.33	53.33	33.33
92553	Pure tone audiometry, air and bone	19.29	14	13.97–26.06	35.71	42.86	21.43
92555	Speech audiometry threshold	11.37	14	8.99–15.20	50.00	28.57	21.43
92556	Speech audiometry with speech recognition	18.09	15	9.00–40.00	86.67	6.67	6.67
92557	Comprehensive audiometry threshold	36.86	15	28.10–47.42	33.33	53.33	13.33
92567	Tympanometry	15.68	15	5.50–21.00	6.67	33.33	60.00
92568	Acoustic reflex testing	11.21	15	4.50–15.00	13.33	33.33	53.33
92579	Visual reinforcement audiometry	19.66	14	4.50–28.60	7.14	42.86	50.00
92582	Conditioning play	20.82	13	11.88–28.60	23.08	46.15	30.77
92583	Select picture	22.72	11	4.50–35.11	18.18	27.27	54.55
92585	Auditory evoked potentials for evoked response audiometry and/or testing of central nervous system, comprehensive	90.76	15	45.11–140.00	26.67	53.33	20.00
92586	Auditory evoked potentials for evoked response audiometry and/or testing of central nervous system, limited	56.59	11	43.21–72.40	36.36	36.36	27.27
92587	EOEs, limited	45.05	15	16.00–59.01	6.67	33.33	60.00
92588	EOEs, comprehensive or diagnostic	61.48	15	26.00–77.47	6.67	26.67	66.67
Hearing aid services							
92590	Hearing aid exam and selection, monaural	42.86	10	16.92–65.00	20.00	50.00	30.00
92591	Hearing aid exam and selection, binaural	62.84	10	36.24–165.00	80.00	10.00	10.00
92592	Hearing aid check, monaural	18.80	9	10.61–35.00	66.67	22.22	11.11
92593	Hearing aid check, binaural	26.01	10	13.07–45.00	50.00	20.00	30.00
92594	Electroacoustic evaluation for hearing aid, monaural	16.78	8	11.48–16.25	12.50	12.50	75.00
92595	Electroacoustic evaluation for hearing aid, binaural	49.03	7	8.71–200.00	85.71	0.00	14.29
92596	Ear protector evaluation	17.79	7	13.93–23.53	57.14	28.57	14.29
V5010	Assessment for hearing aid	36.00	4	12.56–62.12	50.00	25.00	25.00
V5011	Fitting orientation/checking of hearing aid	24.64	4	5.00–40.00	25.00	25.00	50.00
V5014	Repair, modification of hearing aid	136.37	4	80.48–250.00	75.00	0.00	25.00
V5090	Dispensing fee, unspecified hearing aid	237.38	5	75.00–350.00	20.00	40.00	40.00
V5110	Dispensing fee, bilateral, in the ear	500.00	2	300.00–700.00	50.00	0.00	50.00
V5160	Dispensing fee, binaural, BTE	346.28	8	100.00–700.00	25.00	62.50	12.50
V5241	Dispensing fee, monaural hearing aid, any type	240.94	6	120.00–350.00	16.67	50.00	33.33
V5050	Hearing aid monaural, in the ear	411.69	10	350.00–467.00	20.00	50.00	30.00
V5060	Hearing aid monaural (BTE)	409.39	10	350.00–465.07	20.00	50.00	30.00
V5130	Hearing aid binaural, in the ear	779.28	9	400.00–950.00	11.11	22.22	66.67
V5140	Hearing aid binaural, BTE	775.89	9	400.00–960.68	11.11	22.22	66.67
V5247	Hearing aid, digitally programmable analog, monaural, BTE	529.25	5	350.00–1070.25	80.00	0.00	20.00
V5253	Hearing aid, digitally programmable, binaural, BTE	1022.85	5	400.00–1987.24	60.00	20.00	20.00
V5257	Hearing aid, digital, monaural, BTE	394.00	4	350.00–450.00	50.00	25.00	25.00
V5261	Hearing aid, digital, binaural, BTE	688.00	4	400.00–900.00	25.00	25.00	50.00
V5264	Ear mold/insert, not disposable, any type	30.83	9	15.00–45.00	22.22	33.33	44.44
V5265	Ear mold/insert, disposable, any type	34.43	3	19.80–45.00	33.33	0.00	66.67
V5266	Battery for use in hearing device	3.98	11	1.00–20.00	90.91	0.00	9.09
V5267	Hearing aid supplies/accessories		[a]	21.50–21.50	[a]	[a]	[a]
V5275	Ear impression, each		[a]	[a]	[a]	[a]	[a]

TABLE 1 Continued

CPT or HCPCS Code	Audiology Services	Average Payment		Range of Payments (Low to High), $	Lowest Third, %	Middle Third, %	Highest Third, %
		$	No. of States Reporting				
V5299	Hearing service miscellaneous	151.50	4	25.00–401.00	75.00	0.00	25.00
Cochlear implant services							
L8614	Cochlear device/system	15 247.53	4	14 074.16–17 127.00	50.00	25.00	25.00
L8616	Microphone for use with cochlear implant device, replacement	84.36	3	82.70–85.19	33.33	0.00	66.67
L8617	Transmitting coil for use with cochlear implant device, replacement	73.68	3	72.23–74.40	33.33	0.00	66.67
L8618	Transmitter cable for use with cochlear implant device, replacement	20.95	2	20.64–21.25	50.00	0.00	50.00
L8619	Cochlear implant external speech processor, replacement	5366.23	5	41.95–7352.00	20.00	0.00	80.00
L8620	Lithium ion battery for use with cochlear implant device, replacement, each	51.94	3	50.93–52.45	33.33	0.00	66.67
L8621	Zinc air battery for use with cochlear implant device, replacement, each	0.85	3	0.50–1.56	66.67	0.00	33.33
L8622	Alkaline battery for use with cochlear implant device, any size, replacement	0.59	4	0.26–1.56	75.00	0.00	25.00
92510	Aural rehabilitation, following cochlear implant with or without speech processor programming	81.63	12	20.99–132.13	25.00	41.67	33.33
92601	Cochlear implant follow-up exam, <7 y of age	84.82	11	49.00–125.98	27.27	45.45	27.27
92602	Reprogram cochlear implant, <7 y	60.58	11	37.80–87.97	36.36	36.36	27.27
92603	Cochlear implant follow-up exam, >7 y	57.79	11	36.12–83.26	36.36	36.36	27.27
92604	Reprogram cochlear implant, >7 y	40.40	11	24.78–55.75	36.36	27.27	36.36

EOEs indicates evoked otoacoustic emissions; BTE, behind the ear.

[a] Data for this service were not reported by any state, or values in the table could not be calculated because there was no range in reported values.

piece of handheld equipment that costs approximately $4000. Visual reinforcement audiometry (CPT code 92579), on the other hand, had an average reimbursement rate of $19.66 (range: $4.50–$28.60) but requires a specially designed sound booth with an adjoining observation room (which costs at least $35 000) and an additional $25 000 worth of equipment. A licensed audiologist with extensive specialized training and an assistant are needed for 1 to 2 hours to complete the test. The Medicaid fee schedules for almost all of the audiologic function tests declined from 2000 to 2005.

Hearing Aid Services

The 29 hearing aid services examined in this study included CPT codes for hearing aid examinations and HCPCS codes for hearing aid fitting and repairs as well as for different types of hearing aids. Twelve of the 29 hearing aid codes are new since 2000. State Medicaid reimbursement policies for hearing aid services are much more varied than for either diagnostic and treatment services or audiologic function tests. Several states set their fees on the basis of manual pricing or bundled multiple services into a single fee. The hearing aid services least likely to have allowable billing codes were dispensing fees (bilateral, in the ear) and ear impressions. The hearing aid services most likely to be paid on the basis of billed charges are hearing aid repair, hearing aid supplies, and miscellaneous hearing aid services. Five of the 15 states in our sample had no billable codes for digitally programmable hearing aids, and 1 of these 5 states had no billable codes for any hearing aid service. The range of Medicaid payments for hearing aid services is dramatic. For example, a provider in the state with the highest rate would be reimbursed 20 times as much for performing an electroacoustic evaluation for a binaural hearing aid as a provider in the state with the lowest rate. Other significant payment differences can be seen with digitally programmable hearing aids, the payment for which ranged from $350 to $1070 (monaural) and $400 to $1987 (binaural).

Fees for half of the hearing aid codes that existed in both 2000 and 2005 declined over the 5-year period. For example, the average rates for electroacoustic evaluation for hearing aid (binaural) decreased 35%, whereas most other fees declined by ~5%.

Cochlear Implant Services

Of the 13 cochlear implant services analyzed, 10 had been added since 2000.

TABLE 2 Trends in State Medicaid Fee-For-Service Payment Amounts for Hearing Services in 15 States, 2000 and 2005

CPT or HCPCS Code	Audiology Services	Average Payments, $		Percentage Change
		2000	2005	
Audiologic diagnostic evaluation and treatment services				
92506	Evaluation of speech, language, voice communication, auditory processing, and/or aural rehabilitation status	45.40	59.98	32
92507	Treatment of speech, language, voice communication, and/or auditory processing disorder (includes aural rehabilitation), individual	32.49	39.16	21
Audiologic function tests				
92551	Pure tone screening test	11.67	11.97	3
92552	Pure tone audiometry, air only	13.91	12.62	−9
92553	Pure tone audiometry, air and bone	21.10	19.29	−9
92555	Speech audiometry threshold	11.15	11.37	2
92556	Speech audiometry with speech recognition	NC	18.09	—
92557	Comprehensive audiometry threshold	37.54	36.86	−2
92567	Tympanometry	15.96	15.68	−2
92568	Acoustic reflex testing	11.34	11.21	−1
92579	Visual reinforcement audiometry	20.79	19.66	−5
92582	Conditioning play	25.26	20.82	−18
92583	Select picture	25.86	22.72	−12
92585	Auditory evoked potentials for evoked response audiometry and/or testing of central nervous system, comprehensive	105.82	90.76	−14
92586	Auditory evoked potentials for evoked response audiometry and/or testing of central nervous system, limited	60.14	56.59	−6
92587	EOEs, limited	45.63	45.05	−1
92588	EOEs, comprehensive or diagnostic	62.87	61.48	−2
Hearing aid services				
92590	Hearing aid exam and selection, monaural	63.21	42.86	−32
92591	Hearing aid exam and selection, binaural	65.60	62.84	−4
92592	Hearing aid check, monaural	19.16	18.80	−2
92593	Hearing aid check, binaural	27.03	26.01	−4
92594	Electroacoustic evaluation for hearing aid, monaural	16.87	16.78	−1
92595	Electroacoustic evaluation for hearing aid, binaural	75.52	49.03	−35
92596	Ear protector evaluation	17.02	17.79	5
V5010	Assessment for hearing aid	30.14	36.10	20
V5011	Fitting orientation/checking of hearing aid	21.43	24.64	15
V5014	Repair, modification of hearing aid	87.16	136.37	57
V5090	Dispensing fee, unspecified hearing aid	198.77	237.38	19
V5110	Dispensing fee, bilateral, in the ear	377.25	500.00	33
V5160	Dispensing fee, binaural, BTE	NC	346.28	—
V5241	Dispensing fee, monaural hearing aid, any type	NC	240.94	—
V5050	Hearing aid monaural, in the ear	416.50	411.67	1
V5060	Hearing aid monaural, BTE	416.50	411.69	−1.20
V5130	Hearing aid binaural, in the ear	760.64	779.28	2.50
V5140	Hearing aid binaural, BTE	755.10	755.89	2.80
V5247	Hearing aid, digitally programmable analog, monaural, BTE	NC	529.25	—
V5253	Hearing aid, digitally programmable, binaural, BTE	NC	1022.85	—
V5257	Hearing aid, digital, monaural, BTE	NC	394.00	—
V5261	Hearing aid, digital, binaural, BTE	NC	688.00	—
V5264	Ear mold/insert, not disposable, any type	NC	30.83	—
V5265	Ear mold/insert, disposable, any type	NC	34.43	—
V5266	Battery for use in hearing device	NC	3.98	—
V5267	Hearing aid supplies/accessories	NC	21.50	—
V5275	Ear impression, each	NC	0.00	—
V5299	Hearing service miscellaneous	NC	151.50	—
Cochlear implant services				
L8614	Cochlear device/system	14 101.76	15 247.53	8
L8616	Microphone for use with cochlear implant device, replacement	NC	84.36	—
L8617	Transmitting coil for use with cochlear implant device, replacement	NC	73.68	—
L8618	Transmitter cable for use with cochlear implant device, replacement	NC	20.95	—

TABLE 2 Continued

CPT or HCPCS Code	Audiology Services	Average Payments, $		Percentage Change
		2000	2005	
L8619	Cochlear implant external speech processor, replacement	5753.61	5366.23	−6.70
L8620	Lithium ion battery for use with cochlear implant device, replacement, each	NC	51.94	—
L8621	Zinc air battery for use with cochlear implant device, replacement, each	NC	0.85	—
L8622	Alkaline battery for use with cochlear implant device, any size, replacement	NC	0.59	—
92510	Aural rehabilitation, following cochlear implant with or without speech processor programming	73.32	81.63	11.30
92601	Cochlear implant follow-up exam, <7 y of age	NC	84.82	—
92602	Reprogram cochlear implant, <7 y of age	NC	60.58	—
92603	Cochlear implant follow-up exam, >7 y of age	NC	57.79	—
92604	Reprogram cochlear implant, >7 y of age	NC	40.40	—

NC indicates no code; EOEs, evoked otoacoustic emissions; BTE, behind the ear; —, not applicable.

States in our sample commonly established manual pricing policies for cochlear implant services, and a few states included the cochlear implant device and its replacement in the hospital payment for cochlear implant surgery. Three states included no codes for cochlear implants, and 4 states had no billable code for cochlear implant replacements.

In 2005, state Medicaid payments for the cochlear implant device in the 4 states that covered this code averaged $15 248 and ranged from a low of $14 074 to a high of $17 127. Cochlear implant replacement fees in the 5 states that covered that code paid, on average, $5366 (range: $41.95–$7352). On the basis of reported fee data, cochlear implant replacements were reimbursed at only 22% of the initial implant. Between 2000 and 2005, fees for initial cochlear implants increased by 8%, and fees for replacements decreased by almost 7%.

Assistive Communication Services

Only 3 of the 15 states allowed providers to bill for this service. Of the remaining states, 3 did not provide information about their payment policies, and 9 had no billable code. Although we found no change overall in the pattern of coverage and payment for assistive communication devices services since 2000, 3 states shifted their policies, mostly to be more restrictive.

Comparison of Medicaid to Medicare and Commercial Fees

Average Medicaid fees in 2005 were compared with Medicare and commercial fees to examine the adequacy of Medicaid payment for 21 selected children's hearing services. Overall, Medicaid's fees were only 67% of Medicare's fees and only 38% of commercial fees. Table 3 shows that Medicare fees were consistently higher than Medicaid fees for the audiology services examined. As a proportion of Medicare fees, Medicaid fees ranged from a low of 45% to a high of 88%. As a proportion of commercial fees, Medicaid fees ranged from a low of 37% to a high of 112%. For all but 1 service, commercial fees were considerably higher than Medicaid fees.

State Medicaid agencies allow fee-for-service coverage for a broad range of diagnostic and evaluation tests and treatment services for children related to hearing loss but sometimes restrict reimbursement for specific hearing aid services, cochlear implant services, and assistive communication services. The extent to which these services were covered under EPSDT was not examined as a part of this study. However, federal EPSDT law obligates states to pay for medically necessary services to correct or ameliorate physical conditions identified by a screen regardless of whether the service or item is otherwise included in the state Medicaid plan.[20] Therefore, it may be possible that, on an individual case basis, states approve and cover audiology services for which they do not have billable codes.

CONCLUSIONS

Although a relatively broad array of hearing services for children are covered by state Medicaid programs, fees are low: only 67% as much as Medicare fees and 38% as much as commercial fees for the same services. The impact of such low fees is that providers are less likely to see Medicaid patients, which contributes to the difficulty that children with hearing loss have in getting the services they need. Since 2000, Medicaid fees for more than half of all hearing services for children examined actually declined in our 15-state sample. Thus, it is not surprising that state EHDI coordinators report difficulty in getting audiological evaluations completed for infants who are referred from the newborn hearing-screening programs. There was also significant variation among states in the level of Medicaid reimbursement for most hearing services for children. This variation is not accounted for by whether a state is rural or urban or whether a state has a low or high average per-capita income. It does suggest that the quality of services for hearing

TABLE 3 Comparison of Average Medicaid to Average Medicare and Commercial Fees for Selected Audiology Services, 2005

Selected CPT Code	Audiology Services	Medicaid Average 2005		Medicare Average 2005 Fees, $	Medicaid Fees as Percentage of Medicare Fees	Commercial Average 2005 Fees, $	Medicaid Fees as Percentage of Commercial Fees
		$	No. of Reporting States				
92506	Evaluation of speech, language, voice communication, auditory processing, and/or aural rehabilitation status	59.98	13	131.88	45	114.66	52
92507	Treatment of speech, language, voice communication, and/or auditory processing disorder (includes aural rehabilitation), individual	39.16	13	62.53	63	81.42	48
92552	Pure tone audiometry, air only	12.62	15	118.19	69	19.59	64
92553	Pure tone audiometry, air and bone	19.29	14	27.29	71	27.55	70
92555	Speech audiometry threshold	11.37	14	15.92	71	18.04	63
92556	Speech audiometry with speech recognition	18.09	15	23.88	76	24.94	73
92557	Comprehensive audiometry threshold	36.86	15	49.65	74	51.10	72
92567	Tympanometry	15.68	15	21.98	71	22.78	69
92568	Acoustic reflex testing	11.21	15	15.92	70	15.91	70
92579	Visual reinforcement audiometry	19.66	14	29.94	66	39.96	49
92582	Conditioning play	20.82	13	29.94	70	39.48	53
92583	Select picture	22.72	11	36.76	62	38.75	59
92585	Auditory evoked potentials for evoked response audiometry and/or testing of central nervous system, comprehensive	90.76	15	103.46	88	150.40	60
92586	Auditory evoked potentials for evoked response audiometry and/or testing of central nervous system, limited	56.59	11	75.42	75	87.71	68
92587	EOEs, limited	45.05	15	61.39	73	82.01	55
92588	EOEs, comprehensive or diagnostic	61.48	15	80.72	76	82.46	75
92510	Aural rehabilitation following cochlear implant	81.63	12	138.33	59	112.45	73
92601	Cochlear implant follow-up exam, <7 y of age	84.82	11	135.29	63	75.96	112
92602	Reprogram cochlear implant, <7 y of age	60.58	11	92.85	65	113.56	53
92603	Cochlear implant follow-up exam, >7 y of age	57.79	11	83.75	69	154.13	37
92604	Reprogram cochlear implant, >7 y of age	40.40	11	53.81	75	87.74	46

EOEs indicates evoked otoacoustic emissions.

loss that a child receives depends, in part, on where he or she lives.

Data from this study reveal a consistent pattern of inadequate Medicaid payment levels for a broad set of services related to hearing loss among infants and young children. Such low rates likely have negative consequences for access to audiology services by children from low-income families. At issue, therefore, is the extent to which states are meeting the federal requirement that payments be sufficient to enlist enough providers so that care and services are available to the general population in the geographic area.

Although the study was based on data from 2000 and 2005 in only 15 states, it still provides important information that can be used to improve services for infants and young children with hearing loss across the country. Participating states were from all regions of the country and were diverse with respect to population density, per-capita income, health care delivery systems, and cultural characteristics of the population. The findings and trends in these data are particularly important given that more current data have not been reported.

Given the benefits that accrue to infants and young children with hearing loss when they receive timely and appropriate hearing services,[14] there is a need to find ways to increase Medicaid reimbursement rates for hearing services to young children. Making Medicaid fees comparable to Medicare and commercial fees would be an ideal solution, and it would require closer collaboration between state and federal governmental agencies, state legislatures, state EHDI programs, and consumer groups.

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Ensuring Financial Access to Hearing Aids for Infants and Young Children

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Ensuring Financial Access to Hearing Aids for Infants and Young Children

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KEY WORDS

deaf, hearing aids, assistive technology, early intervention, newborn hearing screening, reimbursement, health insurance

ABBREVIATIONS

EHDI—Early Hearing Detection and Intervention
CHIP—Children's Health Insurance Program
IDEA—Individuals With Disabilities Education Act
VA—Department of Veterans Affairs
EPSDT—Early and Periodic Screening, Diagnosis, and Treatment

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abstract

Many young children with permanent hearing loss do not receive hearing aids and related professional services, in part because of public and private financing limitations. In 2006 the Children's Audiology Financing Workgroup was convened by the National Center for Hearing Assessment and Management to evaluate and make recommendations about public and private financing of hearing aids and related professional services for 0- to 3-year-old children. The workgroup recommended 4 possible strategies for ensuring that all infants and young children with hearing loss have access to appropriate hearing aids and professional services: (1) clarify that the definition of assistive technology, which is a required service under Part C of the Individuals With Disabilities Education Act (IDEA), includes not only analog hearing aids but also digital hearing aids with appropriate features as needed by young children with hearing loss; (2) clarify for both state Medicaid and Children's Health Insurance Programs that digital hearing aids are almost always the medically necessary type of hearing aid required for infants and young children and should be covered under the Early and Periodic Screening, Diagnosis, and Treatment (EPSDT) program; (3) encourage the passage of private health insurance legislative mandates to require coverage of appropriate digital hearing aids and related professional services for infants and young children; and (4) establish hearing-aid loaner programs in every state. The costs of providing hearing aids to all 0- to 3-year old children in the United States are estimated here. *Pediatrics* 2010;126:S43–S51

The US Public Health Service's Healthy People 2010 goals[1] call for increased access to hearing technology and rehabilitative services, including hearing aids, cochlear implants, and assistive or augmentative devices. Although >95% of newborns in the United States are now screened for hearing loss, many of those who do not pass newborn hearing screening do not receive the follow-up services they need, including timely access to hearing aids.[2–4] In a 2003 survey to which coordinators of all state Early Hearing Detection and Intervention (EHDI) programs responded, 88% cited financing problems for hearing aids as a significant problem for young children with hearing loss.[3]

In this article we summarize the findings and recommendations of the Children's Audiology Financing Workgroup, which was convened in 2006 by the National Center for Hearing Assessment and Management (NCHAM) to consider what is known about public and private financing for hearing aids and related professional services and to develop recommendations for improving access to these services for infants and young children with permanent hearing loss. Pediatricians need to be aware of this information, because parents of children who are newly identified with hearing loss depend on them as a primary source of guidance about how to obtain the services their child needs.[4]

HEARING LOSS IN INFANTS AND YOUNG CHILDREN: PREVALENCE, CONSEQUENCES, AND COSTS

Significant hearing loss is one of the most common birth defects in the United States: ~3 newborns per 1000 are deaf or hard-of-hearing,[5] and approximately twice that many more acquire permanent hearing loss by school age.[6] The configurations of hearing loss are more varied in children than in adults, and children are more likely to have asymmetric losses than adults.[7] Consequently, children's hearing aids should have different characteristics than those used by adults. Optimally, children's hearing aids should make all speech sounds audible and comfortable and ensure that high input intensities are limited to a safe level. Relatively recently developed digital hearing aids with features such as automatic feedback cancellation, multiple channels, expansion to reduce low-level noise, and wide dynamic range compression can achieve these goals, whereas analog hearing aids cannot.[8–11]

If permanent hearing loss of any severity is not identified early and treated correctly, there are serious negative consequences for children, their families, and society. Without appropriate access to language, hearing technology, and early intervention, children with hearing loss almost always fall behind their peers in language, cognition, and social-emotional development.[12,13] Even unilateral loss has substantial negative consequences for academic achievement.[14,15] The costs to society are also significant in terms of direct medical costs, special education expenditures, and lost productivity. In 2000, the annual average education expenditure per student for a child with hearing loss was more than twice that for a child without a disability ($15 992 vs $6556),[16] and the estimated lifetime economic cost of hearing loss in children is more than $2 billion (an average of $417 000 per child).[17] For most children with permanent hearing loss, many of the negative outcomes can be minimized or avoided completely with early identification and intervention, including the use of appropriate hearing technology.[18–20]

FINANCIAL BARRIERS TO ACCESSING HEARING AIDS FOR INFANTS AND YOUNG CHILDREN

Despite the demonstrated advantages of early intervention, only ~64% of infants diagnosed with permanent hearing loss are reported to be enrolled in early intervention before 6 months of age.[4] As discussed in other articles in this supplemental issue,[21,22] there are many reasons why infants who do not pass the newborn hearing-screening test are lost to follow-up, including poor communication with parents, insufficient numbers of audiologists with pediatric expertise, and lack of knowledge among health professionals about the consequences of hearing loss.[23,24] Pediatricians who understand these issues can help parents obtain the resources and services their child needs.[4] In this article we summarize the range of audiology financing problems, present a new national cost estimate for audiology and related health services, and outline a series of recommendations from the Children's Audiology Financing Work Group with respect to Medicaid, the Children's Health Insurance Program (CHIP), private health insurance, and hearing-aid loaner programs.

Medicaid and the CHIP

More than half of all infants and young children in the United States are enrolled in the Medicaid and CHIP programs,[25] and unlike private health insurance, all Medicaid programs and nearly all CHIP programs cover hearing aids for children.[26] As discussed in detail elsewhere in this supplemental issue,[27] access to appropriate hearing aids and related professional services is nonetheless limited for children covered by Medicaid because of low reimbursement rates in many states, coverage restrictions and limits, limited availability of pediatric audiologists, restrictions caused by definitions of medi-

cal necessity, and difficulties experienced by providers in obtaining timely authorization and reimbursement.

Low Reimbursement Rates

Average Medicaid fees for digital hearing aids are only 38% of those paid by private health insurers.[27] The workgroup noted that many audiologists with pediatric expertise are not participating or are limiting their participation in public programs because of low reimbursement rates. The difficulties caused by low reimbursement rates are exacerbated because current Medicaid reimbursement rates do not adequately take into account the additional time required to provide services to young children compared with providing the same service to adults. Audiologists have also reported delays in receiving payment and burdensome paperwork requirements that further reduce their interest in participating in Medicaid or the CHIP.

Medical-Necessity Restrictions

In all states, Medicaid programs use medical-necessity guidelines when deciding what services will be covered. Such guidelines often require the least costly acceptable alternative to be chosen, according to workgroup members. This can cause problems, because those who write Medicaid policies often do not realize that most young children with hearing loss need features that are only available on digital hearing aids, which are usually more costly.

Coverage Restrictions and Limits

Given that more than half of all young children are covered by Medicaid or the CHIP,[25] the workgroup was concerned that these children frequently do not receive the most appropriate hearing aids: digital hearing aids with specific features. Also, when states contract with managed care organizations to provide hearing-aid services, it seems that Medicaid coverage policy is often not well understood, and hearing aids are sometimes not covered. Although only 3 of the 36 states that operated separate CHIP programs in 2005 did not cover hearing aids at all, 6 other states imposed dollar limits. In addition, 5 states limited the number of hearing aids for which they will pay during a given time period.[27]

Limited Access to Audiologists With Pediatric Expertise

Audiologist workforce shortages exist throughout much of the United States, in part because of increased demand for audiology services that resulted from the expansion of universal newborn hearing screening. The Bureau of Labor Statistics has projected the need for 1000 more audiologists by 2014 to meet the growing demand for services.[28] Workforce needs are particularly acute for audiologists who have the training, expertise, and equipment to work with young children.

Timely Access to Amplification

Many families and audiologists have reported frequent delays in getting timely access to hearing aids because of lengthy approval procedures.

Private Health Insurance

Approximately 40% of all infants and young children in the United States are privately insured,[29] and these private plans generally do not cover children's hearing aids.[30,31] In addition to the pervasive lack of hearing-aid coverage, the workgroup identified the following problems with private health insurance as a source of funding for hearing aids for children.

Lack of Employer Awareness

Insurers and employers are not well informed about the importance of hearing aids for young children and the consequences of hearing loss and delayed identification among children.

Hearing-Aid Riders Seldom Taken by Employers

Insurers may offer hearing-aid coverage riders on their policies, but employers seldom take the rider options because of the increased costs required.

Mandated Benefits Do Not Cover Full Cost

In the 7 states with mandated coverage of hearing aids as of January 1, 2006, there are typically dollar limits that range from $400 to $1400 per ear per 36 months, which results in high out-of-pocket expenditures for families.

Plan Network Provider Restrictions

Families sometimes have to pay higher fees for audiologists with pediatric expertise because they are often not in-network, preferred providers.

Part C Early-Intervention Program

In 1997, Congress passed Pub L. No. 99–457 (the Individuals With Disabilities Education Act [IDEA]), which gives resources and guidelines for all states to provide early-intervention services to 0- to 3-year-old children with disabilities. Better coordination between this federal program and the activities of state EHDI programs would help ensure that young children with hearing loss have access to hearing aids and related professional services. The following factors limit the degree to which Part C is helping children with hearing loss gain access to hearing aids.

Variability in States' Early-Intervention Program Eligibility Criteria Related to Hearing Loss

Federal regulations that accompany the law (34 CFR Part 303.16) require states to provide appropriate early-

intervention services to any infant or toddler who "is experiencing developmental delays as measured by appropriate diagnostic instruments and procedures in one or more of the areas of cognitive development, physical development, communication development, and adaptive development" or who has "a diagnosed physical or mental condition that has a high probability of resulting in developmental delay." Infants and toddlers with permanent hearing loss will almost always exhibit developmental delays in 1 or more of the specified developmental areas if appropriate early-intervention services are not provided.[12] However, existing development assessments are not sensitive enough to measure these delays until children are at least 1 year old, which is far too late for early-intervention programs to begin.[18–20,32] Most states stipulate that infants and young children with "hearing loss" are eligible for services. However, the type and degree of hearing loss that must be present to be eligible is different from state to state,[33] and some states only provide services to children with more severe degrees of hearing loss, although there is clear evidence that children with mild and moderate hearing loss would also benefit from hearing aids.[18,34]

Part C Statute/Regulations Are Silent on Whether Hearing Aids Are an Assistive Technology

It seems that Part C programs in most states consider hearing aids to be a noncovered medical device. Neither the statute nor the regulations explicitly address hearing aids, and at the time that the workgroup met, there had been no policy letters from the Department of Education or pertinent legal cases to clarify this issue. Moreover, even among states that do cover them, digital hearing aids with the most appropriate features may not be fully covered because of funding limitations.

Limited Funding

Unlike Part B of the IDEA, for which funding has steadily increased over the last decade, Part C funding has increased an average of only 1% per year since 2002.[35] Limited funding has led to delays in timely evaluations and eligibility determinations.

Hearing-Aid Loaner and Other Programs

Other publicly and privately supported programs that could pay for hearing aids and related services are hearing-aid loaner programs, state Title V programs for children with special health care needs, and Assistive Technology Act programs. Hearing-aid loaner programs currently operate in 28 states but serve relatively few children.[36] These programs are administered by multiple sources, including Part C, state agencies, service organizations (such as Lions and Sertoma Clubs), schools, audiology clinics, hospitals, and EHDI programs. Programs in 7 states (Oregon, Vermont, Pennsylvania, Texas, Arizona, Ohio, and Indiana) accounted for 70% of the hearing aids loaned in 2005, with most of the existing programs loaning very few. Most of the loans are for short periods of time while repairs are being made or a hearing aid is being evaluated for purchase.

Every state has a Title V Program for Children with Special Health Care Needs that is funded in part through the federal Title V block grant.[37] All states also have an Assistive Technology Act program, which is funded in part with federal grants, to operate a comprehensive statewide program of technology-related assistance for individuals of all ages with disabilities.[38] Unfortunately, little information is available about the extent to which such programs are providing hearing aids to young children with permanent hearing loss. Although hearing-aid loaner banks are frequently mentioned as a way of helping to increase access to hearing aids for infants and young children, there are a number of problems with this approach, including the following.

Lack of Funding

Most hearing-aid loaner programs have reported that they have insufficient funding to purchase and maintain hearing aids and accessories and to staff loaner programs.

Lack of Appropriate Hearing Aids

Hearing-aid loaner programs often rely on recycled hearing aids with older technology that are not optimal for infants and young children.

Lack of Awareness

Parents, Part C coordinators, educators, and providers are often unaware of the existence of hearing-aid loaner programs in their state.

NATIONAL COST ESTIMATES FOR HEARING AIDS AND RELATED PROFESSIONAL SERVICES

Understanding how to improve accessibility to hearing aids for 0- to 3-year-old infants and young children requires information about the number and cost of hearing aids that are needed. On the basis of the assumptions outlined below, the workgroup estimated that providing hearing aids to all infants and young children in the United States in a 0- to 3-year-old cohort would require 44 800 digital hearing aids and related professional services at a per-aid cost of $3000, for a total of $134 640 000. As explained below, a significant amount of this total is already being spent (see Table 1).

Prevalence

On the basis of results from successful universal newborn hearing-screening

TABLE 1 Estimated Annual Number and Cost of Hearing Aids Needed for Infants and Young Children Aged 0 to 3 Years in the United States

No. and Cost of Hearing Aids	Age				
	Newborn	1–12 mo	12–24 mo	24–36 mo	Total
Prevalence, per 1000	3	1.2	1.2	1.2	—
No. with bilateral hearing loss who need hearing aids (No. of hearing aids required)	9600 (19 200)	3840 (7680)	3840 (7680)	3840 (7680)	21 120 (42 240)
No. with unilateral loss who need hearing aids (No. of hearing aids required)	1200 (1200)	480 (480)	480 (480)	480 (480)	2640 (2640)
Total No. with unilateral and bilateral hearing loss who need hearing aids (No. of hearing aids required)	10 800 (20 400)	4320 (8160)	4320 (8160)	4320 (8160)	23 760 (44 880)
Total cost (at $3000 per aid), $	61 200 000	24 480 000	24 480 000	24 480 000	134 640 000

programs, ~3 per 1000 (or 12 000) newborns per year have permanent hearing loss (which includes mild bilateral and unilateral hearing loss).[39–41] By school age, the prevalence of hearing loss increases by threefold because of acquired and late-onset hearing loss resulting from trauma, noise exposure, infections such as meningitis and cytomegalovirus, and other hereditary and environmental causes.[6] Thus, there would be an additional 1.2 cases of hearing loss per 1000 children for each age cohort from 0 to 12, 13 to 24, and 25 to 36 months.

Bilateral and Unilateral Hearing Loss

The cost model assumes that 80% of infants and young children with hearing loss have bilateral loss and that each such child will receive 2 hearing aids. The remaining 20% have unilateral hearing loss and only half of them will require 1 hearing aid.[3,4]

Take-up Rate

It was assumed that all infants and young children with hearing loss are identified early and that all those who require hearing aids receive them. In other words, the model assumes that there will be no financing or distribution problems and that no families will decide not to use hearing aids for personal reasons. In addition, although many children with profound hearing loss will receive a cochlear implant, it was assumed that almost all children will use hearing aids until they are given the implant at 12 months of age and will continue to use a hearing aid on the nonimplanted side.

Type of Hearing Aids, Accessories, and Related Professional Services

The most appropriate hearing aids for infants and young children are behind-the-ear models with automatic feedback cancellation, multiple channels, expansion to reduce low-level noise, and wide dynamic range compression.[7–10,42] Accessories (eg, ear molds, pediatric earhooks, batteries, and cords) and related professional services (eg, assessment and evaluation, fitting and programming, and repairs) are also needed. The model assumes that infants and young children require more frequent professional services than adults because of the complexity and variation in their hearing loss.[7]

Cost of Hearing Aids, Accessories, and Related Services

The per-aid cost for the hearing aid, accessories, and related professional services was estimated at $3000 on the basis of fiscal impact statements from 2 states that assessed the cost of mandating private health insurance coverage for hearing aids.[43] The hearing aid and accessories account for 60% ($1800) of this total cost, and the related professional services account for the balance.[44]

FINANCING RECOMMENDATIONS FOR INCREASING ACCESS TO HEARING AIDS

Financial barriers should not prevent any infant or young child with permanent hearing loss from obtaining hearing aids with appropriate features and related professional services. Four possible solutions are described below, including (1) Part C early-intervention programs, (2) Medicaid and the CHIP, (3) private health insurance mandates, and (4) expansion of hearing-aid loaner programs (which could be used as a supplement to any of the others).

Part C Early-Intervention Program

The federal Part C regulations should clarify that the definition of children with a diagnosed physical condition that has a high probability of resulting in developmental delay includes all children with a permanent hearing loss. It is also important to clarify that the definition of assistive technology[45] includes digital hearing aids with appropriate features needed by infants and young children with hearing loss. Part C may be able to reduce the costs of purchasing hearing aids by accessing the national contracts for hearing aids established by the Department of Veterans Affairs (VA). The VA negotiates discounts of up to 85% on the basis of volume purchasing.[46]

Pros

- Under this option, all infants and young children with permanent

hearing loss will have access to appropriate hearing aids and related services.

- Coverage of hearing aids and related professional services is consistent with the congressional intent for Part C "to enhance the development of infants and toddlers with disabilities, to minimize their potential for developmental delay. . .and to reduce the educational costs to our society, including our Nation's schools, by minimizing the need for special education and related services after infants and toddlers with disabilities reach school age."
- Coverage under Part C can significantly reduce the costs of future special education services needed by these children under Part B of the IDEA.[17]
- Timely and appropriate provision of hearing aids will facilitate and enhance the delivery of effective early-intervention services.[18–20]
- Programs can require family contribution toward the cost of hearing aids and related professional services on the basis of income but cannot deny services if payment is not made.
- As a payer of last resort, Part C can draw on private and public insurance.
- The VA hearing-aid purchasing program is efficient and uniform across states, and bulk purchasing would yield huge cost savings to families and taxpayers.[46] Part C has an existing nationwide infrastructure to support bulk purchasing.

Cons

- Full implementation will require additional funding.
- The Part C system is not consistently integrated with the medical service system.
- Accessing the VA national hearing-aid contracts will require approval by the VA and additional provisions to ensure that the hearing aids offered under the contract are appropriate for infants and young children.

Medicaid and CHIP Programs

This option would require clarification that for nearly all infants and young children with hearing loss, digital hearing aids with appropriate features, not analog aids, are the medically necessary type of hearing aid required and are a mandatory benefit under Early and Periodic Screening, Diagnosis, and Treatment (EPSDT). Furthermore, reimbursement rates for digital hearing aids and related professional services should be increased to ensure full payment of the $3000 bundled fee, and the timeliness of approving and paying for digital hearing aids for infants and young children needs to improve.

Pros

- More than half of all infants and young children with permanent hearing loss can benefit under this option.[25]
- Medicaid already mandates coverage of hearing aids and related professional services for infants and young children through EPSDT.

Cons

- The potential exists for slow and variable implementation by states.
- States have discretion to establish their own medical-necessity definitions and payment rates.
- Cooperation with Part C is required, and the level of collaboration among Part C, Medicaid, and managed care organizations is variable in states.
- In a small number of states, the CHIP either excludes coverage of hearing aids or imposes coverage limitations or cost-sharing requirements.

Private Health Insurance

Under this option, legislative mandates could be passed in every state to require coverage of digital hearing aids and related professional services for infants and young children with permanent hearing loss.

Pros

- Approximately 20% of infants and young children with permanent hearing loss can benefit from this option.
- The increase in premiums from adding a hearing-aid mandate for children is likely to be $<1\%$.[43]

Cons

- This option would not cover all privately insured infants and young children, because self-insured plans are excluded from these types of mandates under the Employee Retirement Income Security Act of 1974 (ERISA).[47]
- State legislatures are becoming increasingly reluctant to require insurance mandates, and insurers and employers are likely to oppose mandates.
- Mandated benefits are not likely to cover the full cost of hearing aids, and cost-sharing requirements may make the cost of purchasing hearing aids prohibitive.
- This option requires separate implementation by each state.

Hearing-Aid Loaner Programs

Hearing-aid loaner programs could be established in each state and operated by the Part C early-intervention program, Assistive Technology Act program, EHDI program, or other program with statewide capacity to provide for quick, short-term access to digital hearing aids.

Pros

- All infants and young children who need access to hearing aids while awaiting coverage under Part C, Medicaid, the CHIP, or private health insurance can benefit.
- The legal authority already exists to administer hearing-aid loaner programs through Part C, Assistive Technology Act, or EHDI programs.
- The costs of administering a statewide hearing-aid loaner program are relatively low.

Cons

- New funding would be required, because few existing loaner programs currently operate statewide.
- The program would be most effective if it were enacted in conjunction with another option.

CONCLUSIONS

Hearing loss is one of the most common birth defects in the United States. Although impressive strides have been made in screening all newborns for hearing loss, more progress is needed to ensure that infants and young children with hearing loss receive timely evaluation and treatment, including hearing aids. Delays in treatment are especially problematic for infants and young children who are at a critical stage in developing communication and social skills. Even brief delays can result in significant problems with language acquisition, cognition, academic achievement, and social-emotional development and can lead to substantial societal costs.

Current financing arrangements for hearing aids are not adequate for 0- to 3-year-old children with hearing loss. Lack of coverage through private health insurance plans, restrictive eligibility and coverage under states' early-intervention programs, medical-necessity restrictions and low reimbursement rates in many Medicaid and CHIP programs, and limited availability of hearing-aid loaner programs are the main financial barriers that impede access to hearing aids for infants and young children.

The Children's Audiology Financing Work Group estimated that in a given year, ~24 000 0- to 3-year-old children in the United States need a hearing aid. The total cost of providing appropriate hearing aids and related services to these infants and young children would be approximately $134.6 million per year, much of which is already being spent through EPSDT, Part C programs, and private insurance. The total cost estimate is based on several key assumptions: (1) that the prevalence of permanent congenital hearing loss among newborns is 3 per 1000 and that an additional 1.2 per 1000 acquire late-onset hearing loss for each year between 0 and 36 months of age; (2) that 1 pair of hearing aids is required up to the age of 3 years for children with bilateral loss and 1 aid is required for those with unilateral loss; and (3) that the per-aid cost for a digital hearing aid with features needed by children, accessories, and related professional services is $3000.

Providing hearing aids and related professional services to this young population will likely yield significant future cost savings, most particularly for the special education system. The lifetime economic cost of permanent hearing loss in children in terms of special education expenditures, direct medical costs, and lost productivity is estimated to be more than $400 000 per child.[17]

The Children's Audiology Financing Workgroup concluded that the option with the most potential to eliminate financial access barriers for all infants and young children with hearing loss is to clarify that under the Part C regulations, all infants and young children with permanent hearing loss are eligible for services and also clarify that the definition of assistive technology includes digital hearing aids with appropriate features as needed by infants and young children with hearing loss. The workgroup also recommended that Part C programs explore the possibility of accessing national purchasing contracts that have been established by the VA to reduce the cost of purchasing hearing aids. It is important to note that although new funding would be required to implement this option, Part C would not have to bear the full financial burden of this program expansion because it could draw on public and private insurance sources. Establishing loaner programs in every state in tandem with the Part C policy option would further increase access to hearing aids by providing short-term availability for infants and young children who are awaiting coverage from a public or private source. Other policy options for improving private insurance, Medicaid, and the CHIP, although useful, would not benefit as many infants and young children.

Remarkable progress has been made in the last decade in identifying infants with hearing loss; comparable efforts will be needed in the next decade to ensure that they receive the necessary intervention and treatment services, including high-quality hearing aids and related professional services.

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Teleintervention for Infants and Young Children Who Are Deaf or Hard-of-Hearing

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Teleintervention for Infants and Young Children Who Are Deaf or Hard-of-Hearing

abstract

Advancements in videoconferencing equipment and Internet-based tools for sharing information have resulted in widespread use of telemedicine for providing health care to people who live in remote areas. Given the limited supply of people trained to provide early-intervention services to infants and young children who are deaf or hard-of-hearing, and the fact that many families who need such services live significant distances from each other and from metropolitan areas, such "teleintervention" strategies hold promise for providing early-intervention services to children who are deaf or hard-of-hearing. Unfortunately, little is known about the cost-effectiveness of such teleintervention services. In this article we outline the rationale for using teleintervention services for children who are deaf or hard-of-hearing, describe a teleintervention program that has been serving relatively large numbers of children in Australia since 2002, and summarize what we know about the cost-effectiveness of such an approach. We conclude by summarizing the type of research needed to decide whether teleintervention should be used more frequently with children who are deaf or hard-of-hearing and the potential relevance of the teleintervention approach for the development of intervention systems in the United States. *Pediatrics* 2010;126:S52–S58

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KEY WORDS

deaf, hard-of-hearing, early intervention, newborn hearing screening

ABBREVIATIONS

DHH—deaf/hard-of-hearing

RIDBC—Royal Institute for Deaf and Blind Children

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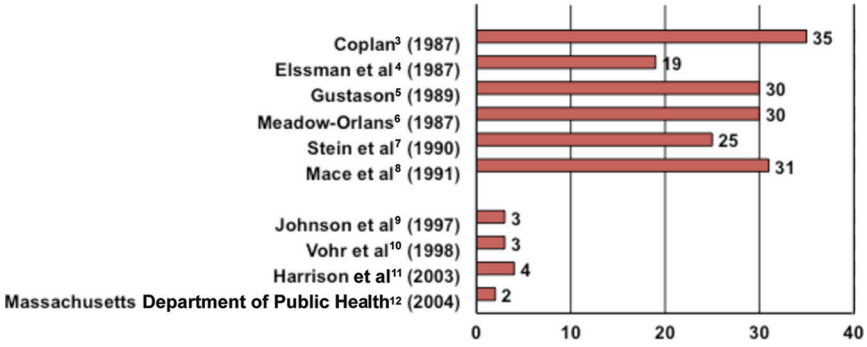

FIGURE 1
Age (in months) of identification of permanent hearing loss.[3–12]

Approximately 3 newborns per 1000 are born deaf or hard-of-hearing (DHH), which makes it the most frequent birth defect in the United States.[1] Fifteen years ago, children who were DHH were typically not identified until they were 2 to 3 years of age.[2] In those states in which newborn-screening programs have been effectively implemented, the average age at which DHH children are identified has been reduced from ~30 months to 2 to 3 months of age (see Fig 1). Consequently, over the past 2 decades there has been a large increase in demand for early-intervention services for young children who are DHH. Most DHH children who are identified early and provided with appropriate early intervention are able to progress at age-appropriate rates.[13–15] As a result, there are substantial cost savings, mostly in reduced need for special education services,[16,17] and 43 states have passed legislation that requires newborn hearing screening.[18]

Still, there are many DHH children and their families who do not receive appropriate services.[19] In fact, a recent letter sent to all state early-intervention programs from federal officials at the Department of Education and the Department of Health and Human Services noted that there is a "growing national crises in the provision of essential early intervention and health care services for infants and toddlers with hearing loss."[20] That letter went on to state:

> "Although efforts to identify and evaluate hearing loss in young children have improved, there is still anecdotal evidence to suggest that many young children with hearing loss may not be receiving the early intervention or other services they need in a timely manner that will enable them to enter preschool and school ready to succeed."

One of the reasons that many young children who are DHH do not receive the early-intervention services they need is that although deafness is more frequent than any other birth defect, it is still a relatively low-incidence condition. Consequently, many children who are DHH live a great distance from the specialized services they need and there are often few DHH children living in the same area, which makes it difficult for many educational systems to find appropriately trained people to deliver services.[21]

THE POTENTIAL FOR "TELEMEDICINE" TYPES OF SOLUTIONS

A potential solution for this problem is to use 2-way videoconferencing to provide early-intervention services to children who are DHH who do not live in heavily populated areas. As telecommunication technologies have improved and costs have declined, many people have become convinced that telemedicine enables us to provide high-quality health care in situations in which it is difficult or unnecessarily expensive to have the health care provider and the patient in the same room at the same time. The rationale for the expanded use of such telemedicine solutions is that it can be used to provide high-quality care, save money through improved care management and coordination, and reduce patient costs.

A typical application of telemedicine involves a patient at a health care facility in a rural or medically underserved area, which is similar to the situation faced by many infants and young DHH children and their families. Telemedicine uses videoconferencing to link an expert located at a "hub site" with a patient located at a "spoke site." Widespread conceptual support for telemedicine has lead to hundreds of applications. As pointed out by Wootton, most of these have

> ". . . been in the form of feasibility studies and pilot trials. As a result there is little convincing evidence of the cost-effectiveness of many applications. . . . Various feasibility studies . . . have been driven by the hope that care of chronically ill patients can either be provided more cheaply or be of a higher quality. . . . Although these studies indicate that patient satisfaction is not a problem, little hard evidence on cost-effectiveness has been obtained"[22] (see also refs 23–25 for similar assessments).

Others have been more optimistic. For example, McConnochie et al compared:

> ". . . two groups of children that were almost identical, but one had access to their doctor's office, the emergency department and telemedicine technology for care, while the second had only the first two options. . . . [T]he first group of families, which had access to telemedicine for their children, did in fact access care for illness overall nearly 23% more often than the second group. But since the children with telemedicine access had 24% fewer Emergency department visits, which cost about seven times the cost of a doctor office or telemedicine visit, the telemedicine group ultimately still cost insurers less per child over a year."[26]

Although more studies are needed, there is growing support for using

telemedicine types of solutions to provide early-intervention services to children who are DHH. For example:

> "It is the position of the American Speech-Language-Hearing Association (ASHA) that telepractice (telehealth) is an appropriate model of service delivery for the profession of speech-language pathology. Telepractice may be used to overcome barriers of access to services caused by distance, unavailability of specialists and/or subspecialists, and impaired mobility. Telepractice offers the potential to extend clinical services to remote, rural and underserved populations."[27]

The following are some examples of how teleinterventions have been implemented to address issues similar to those experienced by children who are DHH.

- Sicotte et al[28] implemented a teleintervention program to treat stuttering in children and concluded that (1) it was feasible to provide services to families in remote areas, (2) families participated frequently and consistently, and (3) there was high rate of client and provider satisfaction.
- Hill et al[29] explored the feasibility of using teleintervention for assessing motor speech disorders with acquired neurologic impairment and determined that although it was feasible, additional refinement of the technology and assessment tools was needed.
- Jessiman[30] compared speech and language assessments via a telehealth system to an in-person system and also evaluated the progress that school-aged children made in articulation and language treatment when it was provided via telehealth. He concluded that children "progressed in their speech and language goals quickly over the 12 sessions."
- Forducey[31] used 2-way interactive teleconferencing to deliver speech treatments to students throughout the state of Oklahoma and concluded that the program was successful.
- Carpenedo[32] used real-time interactive video technology to provide speech services as an adjunct to traditional in-home speech-treatment visits and concluded that it improved patient services.
- Xu et al[33] evaluated the costs of providing pediatric otolaryngology services using videoconferencing compared with conventional outpatient services and found that it was more economical to provide services via videoconferencing; however, they did not assess patient outcomes.

Studies such as these are used to suggest that teleintervention might be used to address the barriers created by the shortage of trained early-intervention providers and the high costs of providing services to geographically dispersed families of DHH children. However, it is important to note that there is not enough systematic, rigorously collected evidence to demonstrate that such services would really be less costly or equally effective as the face-to-face services that are typically provided currently. Before teleintervention should be considered a viable tool for addressing the problems noted above for infants and young children who are DHH, better data are needed about the costs and effects of such services compared with currently available alternatives.

The largest and most comprehensive teleintervention effort yet undertaken to deliver early-intervention services to children who are DHH has been operational in Australia for a number of years. As a first step in deciding whether teleintervention should be used more broadly for providing services to US children who are DHH, it would be useful to consider what can be learned from the Australian experience.

AUSTRALIA'S TELESCHOOL PROGRAM

Since 2002, the Royal Institute for Deaf and Blind Children (RIDBC) in Australia has been using 2-way videoconferencing to provide early-intervention services to more than 100 children per year who are DHH, deaf-blind, or visually impaired. These children are receiving all of their educational services via the RIDBC Teleschool (www.ridbc.org.au/services/teleschool.asp). According to a recent evaluation study (K. Dally and R. Conway, Invest to Grow Local Evaluation Report for RIDBC Remote Early Learning Program, unpublished report from the University of Newcastle, Callaghan, Australia, 2008), most professionals and parents participating in this program have agreed that it provides high-quality services with which parents are very satisfied and that children seem to be progressing as well as they would if they were enrolled in a traditional program in which providers visit the family in their homes. Unfortunately, the authors did not collect data to compare the developmental outcomes of children participating in the RIDBC Teleschool with those of similar children who are receiving face-to-face services. On the basis of the limited cost data that were collected, the report concluded:

> "At present the cost of the remote delivery of services appears to be slightly higher than the cost of face-to-face service delivery. However, the costs of the telephony and remote technology connections are likely to decrease in the future . . . [and] the motor vehicle costs for the local service delivery are likely to rise if fuel prices continue to escalate. Thus, at present, the remote program appears to be cost comparative with face-to-face service delivery and, over time, may become even more cost efficient than local delivery options."

The goal of the RIDBC Teleschool is to provide families who live in rural areas of Australia with the same level and quality of service they would receive if they lived in a metropolitan area.

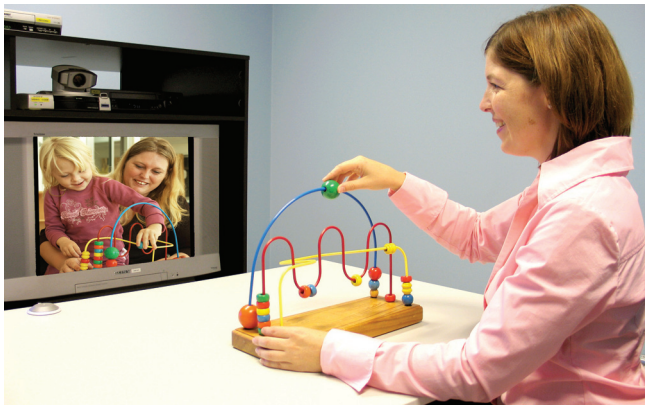

FIGURE 2
Early-intervention services being provided via teleschool.

Videoconferencing equipment is used so that a specially trained early-intervention specialist can work with the child and teach the parent how to deliver effective early-intervention services in between these virtual home visits. Participating families live all over Australia (an area roughly the size of the continental United States but with less than one-tenth as many inhabitants). Videoconferencing sessions are typically held 1 hour/week or 2 half-hours/week depending on the family's schedule and the child's needs.

Videoconferencing equipment is set up in the family's home so that the child and caregiver can view the specialist in real time on a television screen or computer monitor (and vice versa). An example of this setup is shown in Fig 2. Materials necessary for the instruction are sent to the families via the postal service or over the Internet. Examples include educational resources such as books, toys and puzzles, lesson plans that outline specific goals for the child, information sheets about hearing and vision loss, and regular progress reports.

Before beginning the RIDBC Teleschool program, families are strongly encouraged to schedule a visit to the RIDBC central campus in Sydney. Financial assistance for travel expenses and free on-site accommodation are provided to families to make it easier to complete this visit. Families are able to access a wide range of services during this initial visit:

- diagnostic assessment of the child's developmental status;
- meeting with the specialist who will be providing the RIDBC Teleschool services for their child and participating in several face-to-face intervention sessions;
- meeting with other professionals who will assist with their child's educational program, including audiologists, speech-language pathologists, occupational therapists, psychologists, etc;
- learning about and using educational resources from the RIDBC library; and
- participating in a practice videoconference session so that they can experience and discuss the differences between face-to-face and videoconference sessions.

Typically, videoconferencing equipment is placed in the family's home to reduce travel time, allow flexibility in scheduling, and provide the opportunity for other family members to participate in the weekly sessions. In-home videoconferencing also allows RIDBC Teleschool staff to observe activities in the home and teach parents how to enhance their child's natural learning environment by encouraging interactions with the people and resources to which they have access. Weekly videoconferencing sessions enable the specialist to observe the family's interactions with the child, monitor the child's progress, and offer suggestions for further expanding the child's skills.

A typical videoconference includes:

- parent feedback on previous activities;
- specialist modeling of new activities and skills;
- specialist coaching of the parent during parent/child interactions;
- review of video footage from previous videoconferences;
- suggestions for generalizing the goals to the home environment; and
- discussion of test results and reports from other professionals.

Other family members such as grandparents or siblings or local professionals such as specialists or speech-language pathologist may also attend the session. Videoconferencing sessions are also recorded and made available to families so that they can review or share previous sessions with other family members or professionals. In addition, specialists may use this video footage to help parents reflect on their own skills and to better understand their child's abilities. Such sessions help parents improve their observational skills so that they are able to watch their child's responses and accurately report on the child's abilities and progress.

Before each RIDBC Teleschool session, the specialist sends an educational package to the family. This package consists of a lesson plan that outlines specific goals from the program, a description of activities for achieving the

goals, and relevant resources for completing the activities such as books, toys, puzzles, DVDs, and craft material. Many families also use videoconferencing to access courses in specific skills that are not available in their local area, such as sign language instruction. Also, parents are introduced to other families via videoconference and are often able to establish support networks.

Since 2002, RIDBC Teleschool services have been provided to more than 170 families. Although a comprehensive evaluation of the children's developmental outcomes and the cost-effectiveness of the service has not been performed, participants have reported that teleintervention has provided an effective method of delivering a personal, immediate, and specialized service to them and their child. According to Dally and Conway (K. Dally and R. Conway, Invest to Grow Local Evaluation Report for RIDBC Remote Early Learning Program, unpublished report from the University of Newcastle, Callaghan, Australia, 2008), families value the immediacy of teleintervention services, which are less susceptible to waiting lists, travel arrangements, and unforeseen obstacles such as weather or illness. Participants also reported better satisfaction with teleintervention services compared with telephone and correspondence services, because the early-intervention specialist is able to directly observe the parent-child interactions and provide responsive feedback that can be applied immediately. Early-intervention providers in the teleschool program have also noted that parents seem to acquire skills more rapidly than in a traditional face-to-face model. In a face-to-face session, the early-intervention specialist may regard the child as the primary participant and engage more often in modeling activities and strategies directly with the child and involving the parents only occasionally. In a teleintervention setting, the roles shift because the early-intervention specialist has limited physical access to the child and must now regard the parents as the primary participants. This shift seems to change the focus of the session from teaching the child to coaching the parent(s) in implementing appropriate educational activities with their child.

In addition, feelings of isolation and anxiety are often quite strong for families who live in remote areas. Participants have reported that teleschool offers emotional support and reassurance by providing a weekly face-to-face contact with a specialist who can provide information and guidance about how to enhance their child's development.

Anecdotal evidence has also suggested increased participation by fathers and other family members as well as fewer cancellations by families. This increased level of engagement is probably attributable to greater ease of attendance and flexibility of scheduling. Teleschool sessions are offered from 8 AM to 8 PM and on Saturday mornings. Furthermore, the effort of bringing a child to a center-based activity or of hosting early-intervention staff in their own homes is often a cause for city-based families to cancel scheduled visits. For remote families, the in-home videoconferencing approach seems to reduce both the effort and the cost of accessing appropriate services.

DISCUSSION

Evidence about the cost-effectiveness of using teleintervention to provide services to children who are DHH is similar to the conclusions regarding telemedicine made in 2004 by Hailey et al,[34] who noted that "good-quality studies are still scarce." Because of critical needs for services and the shortage of trained and qualified providers, it is easy to assume that teleintervention services are as good as face-to-face services and can be delivered at lower cost. The feasibility of using 2-way real-time videoconferencing to deliver the types of services needed by infants and young children who are DHH has been demonstrated a number of times,[28–33] including in large-scale implementations such as the RIDBC Teleschool program in Australia (K. Dally and R. Conway, Invest to Grow Local Evaluation Report for RIDBC Remote Early Learning Program, unpublished report from the University of Newcastle, Callaghan, Australia, 2008). Nonetheless, we do not yet have good evidence that the outcomes for children or the costs of delivery are comparable to those with face-to-face services.

As telemedicine was first gaining popularity, Hersh et al[35] made an observation that should be kept in mind as the use of teleintervention to serve DHH children and their families is considered:

> "Despite the widespread use of telemedicine in virtually all areas of health care delivery, there is only a small amount of evidence that interventions provided by telemedicine result in clinical outcomes that are comparable to or better than face-to-face care. . . . Large-scale RCTs [randomized, controlled trials] must be done to identify the health outcomes whose benefit appears most promising. If the goal is to show comparability to usual care, then studies must provide adequate statistical power to show that the lack of a difference truly exists."

What is needed are randomized comparisons of teleintervention services and face-to-face services for relatively large numbers of infants and young children who are DHH. To have adequate statistical power, such studies should include at least 100 children in each group and at least 2 years of service so that longitudinal data about the children's language, cognitive, social, and functional development can be col-

lected. Data collection should be performed by people who do not have a vested interest in the outcome of the study (and preferably would not even know that the children are participating in a randomized, controlled trial). To control for the effects of teacher experience and skill, it would be best if all teachers participating in the study provided early-intervention services to an equal number of children in both the teleintervention and the face-to-face conditions.

In addition to collecting data about children's outcomes, the study should examine the actual costs of delivering both types of services, including equipment, materials, staff time, travel, and administrative support. Such an analysis should also include information about parent time and opportunity costs as well as the impact of each kind of service on parent employment and access to health care and other social services. Economic-analysis techniques such as discounting, sensitivity analyses, amortization of costs over time, and alternative cost allocations should be included in the cost-effectiveness analyses.

Parent and staff satisfaction with the program should be assessed, as should the scalability of the teleintervention program. In addition, effects of the program on other parts of the system should be considered. For example, does the use of teleintervention improve or hinder the family's relationship with other providers and/or families, and does it lead to greater or less understanding of what other services are available for their child?

CONCLUSIONS

Using 2-way videoconferencing to deliver services in rural and remote areas to children who are DHH is a potential solution to one of the biggest obstacles to effective services identified in the US national evaluation of newborn-screening and intervention programs described elsewhere in this supplemental issue[36]: the severe shortage of appropriately trained teachers and clinicians in many parts of the country. However, although the potential benefits are great, much more systematic data are needed to determine the costs and effects of such services compared with face-to-face services for DHH infants and young children and their families. The US could consider introduction of a pilot program to test the feasibility of the teleintervention approach for this population. The United States could also be an ideal site at which to carry out a randomized, controlled trial of teleintervention versus traditional face-to-face services.

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Improving Follow-up to Newborn Hearing Screening: A Learning-Collaborative Experience

Shirley A. Russ, Doris Hanna, Janet DesGeorges and Irene Forsman

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Improving Follow-up to Newborn Hearing Screening: A Learning-Collaborative Experience

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KEY WORDS
deaf, hard-of-hearing, early intervention, newborn hearing screening

ABBREVIATIONS
EHDI—Early Hearing Detection and Intervention
NICHQ—National Initiative for Children's Healthcare Quality
PCP—primary care provider
QI—quality improvement
PDSA—plan-do-study-act
ENT—ear, nose, and throat

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abstract

Although ~95% of US newborns are now screened for hearing loss at birth, more than half of those who do not pass the screen lack a documented diagnosis. In an effort to improve the quality of the follow-up process, teams from 8 states participated in a breakthrough-series learning collaborative. Teams were trained in the Model for Improvement, a quality-improvement approach that entails setting clear aims, tracking results, identifying proven or promising change strategies, and the use of small-scale, rapid-cycle plan-do-study-act tests of these changes. Parents acted as equal partners with professionals in guiding system improvement. Teams identified promising change strategies including ensuring the correct identification of the primary care provider before discharge from the birthing hospital; obtaining a second contact number for each family before discharge; "scripting" the message given to families when an infant does not pass the initial screening test; and using a "roadmap for families" as a joint communication tool between parents and professionals to demonstrate each family's location on the "diagnostic journey." A learning-collaborative approach to quality improvement can be applied at a state-system level. Participants reported that the collaborative experience allowed them to move beyond a focus on improving their own service to improving connections between services and viewing themselves as part of a larger system of care. Ongoing quality-improvement efforts will require refinement of measures used to assess improvement, development of valid indicators of system performance, and an active role for families at all levels of system improvement. *Pediatrics* 2010;126:S59–S69

Screening newborns for hearing loss is now a standard of care across the United States. All states have established Early Hearing Detection and Intervention (EHDI) programs, and 43 states have enacted legislation related to hearing screening.[1,2] The US Preventive Services Task Force has endorsed universal newborn hearing screening,[3] and the Joint Committee on Infant Hearing has set national targets for EHDI system performance: screening of all infants by 1 month of age; diagnostic testing of infants who do not pass screening before 3 months of age; and entry into early intervention for children who are deaf or hard-of-hearing as soon as possible, but no later than 6 months of age.[4] Approximately 95% of the infants born in the United States are now screened for hearing loss at birth. Of these, ~2% (76 000) have a positive screening test that requires follow-up (either rescreening or diagnostic audiologic evaluation) to determine if they have permanent hearing loss.[2] National data for 2007 suggest that nearly half of these infants have "no documented diagnosis," the majority of whom are classed as "lost to follow-up" or "lost to documentation." Of those infants found to have a permanent hearing loss, just more than one-third were not documented to receive early-intervention services.[5] There is understandable concern that these high attrition rates will limit the effectiveness of the EHDI program.

Although the EHDI process itself seems conceptually straightforward (screening, diagnostic testing, and referral for early intervention), the "system of care" for infants and young children in which the program operates is surprisingly complex. The initial screen is usually performed in a hospital during the birth admission; rescreening is frequently performed after discharge, necessitating either a return to the birthing hospital or referral to another facility. Because experienced pediatric audiologists needed to perform diagnostic testing are in short supply, families, especially those in rural areas, frequently need to travel long distances to access definitive audiologic testing, which often requires several sessions.[6] Children identified with permanent losses are referred to an otorhinolaryngologist for "medical clearance" before amplification and for etiology investigations. Hearing-aid fitting by a pediatric audiologist often involves an appointment at yet another facility. Accessing intervention services involves a transition from health to education systems and often involves audiologists, the child's pediatrician, teachers of the deaf, speech therapists, and early childhood educators. It is not surprising that many families experience significant challenges to navigating this complex system.

Although most pediatricians believe that they have primary responsibility for follow-up planning for children who do not pass their hearing screens, they frequently do not have the access they need to screening-test results or to the results of any subsequent diagnostic audiologic evaluations.[7] Primary care providers (PCPs) also lack information about local services needed to guide parents to appropriate family-centered interventions.[8] Fewer than half have reported that they actually coordinate care for these infants,[9] although care coordination is a core component of the medical home.

In response to these issues, the Health Resources and Services Administration Maternal and Child Health Bureau, which oversees EHDI program implementation, and the National Center for Hearing Assessment and Management collaborated with the National Initiative for Children's Healthcare Quality (NICHQ) to use a quality-improvement (QI) approach to reduce loss to follow-up after newborn hearing screening. QI activities are intended to close the gap between desired processes and outcomes of care and what is actually delivered.[10,11] To date, most child health QI initiatives have focused on improving care in groups of practices[12] or hospitals.[13] However, the learning-collaborative approach has been applied successfully to public health issues such as emergency preparedness.[14] Our initiative focused on statewide systems of care for children with hearing loss, including care delivered in newborn nurseries, NICUs, pediatric practices, audiology practices, and early-intervention programs. In addition to improving the services within individual programs, which is the typical focus of QI initiatives, this effort emphasized improving links and connections between services both within the health sector and between health and education sectors. Consequently, each team that participated in this collaborative had broad representation from multiple disciplines and service-delivery sites. In this article we describe how the principles and activities contained in the Model for Improvement,[15] the Breakthrough Series,[16] and the care model for child health[17] were used to implement a successful learning collaborative to improve the EHDI systems in 8 states.

THE EHDI LEARNING COLLABORATIVE

In a learning collaborative, teams from different organizations and geographic areas work together toward an agreed set of goals, track and report common improvement measures over time, and learn together how to improve care by sharing strategies for change and their experiences with trialing those strategies (Fig 1). Teams used the Model for Improvement[15] as the specific approach to making changes. The Model for Improvement (Fig 2) incorporates 4 key elements: (1) setting specific, measurable aims; (2) tracking measures of improvement over time; (3) identifying key changes that result in desired im-

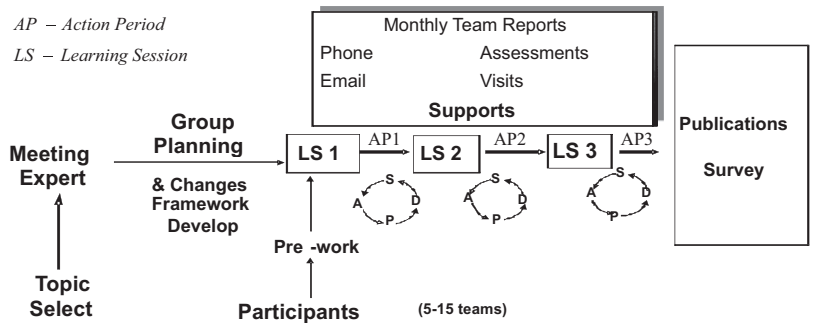


FIGURE 1
Breakthrough-series learning-collaborative model. (Reproduced with permission from Institute for Healthcare Improvement. The Breakthrough Series: IHI's Collaborative Model for Achieving Breakthrough Improvement. IHI Innovation Series White Paper. Boston: Institute for Healthcare Improvement; 2003:5.)

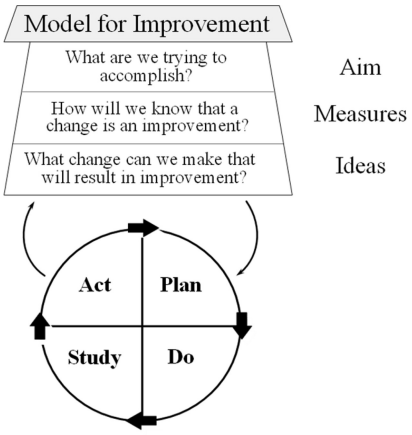


FIGURE 2
Model for Improvement: PDSA cycles. (Reproduced with permission from Langley G, Nolan K, Norman C, et al. *The Improvement Guide: A Practical Approach to Enhancing Organizational Performance*. New York, NY: Jossey-Bass; 1996:10.)

provement; and (4) using continuous, rapid-cycle tests of change (called plan-do-study-act [PDSA] cycles).

For this collaborative, 8 teams were recruited from statewide EHDI systems. Each state agreed to form a team to address the goals of the collaborative. Teams had to commit to sending at least 4 to 6 members to each learning session, whereas a larger team worked on the local QI effort. The core team for each state that attended learning sessions usually included a senior leader from the state's Title V program, a pediatrician, a "day-to-day" team leader (usually the state's EHDI coordinator), a data coordinator, and a parent. The larger extended state team included representatives from other components of the EHDI system including hospital screeners, PCPs, audiologists, specialty providers such as ear, nose, and throat (ENT), genetics, and child development specialists, payers, and early-intervention providers.

Each state team agreed to carry out "prework" including the collection of baseline data, participation in local planning for the collaborative activities, and development of a written state-specific aim statement. Each team also agreed to attend 3 learning sessions (2 face-to-face and 1 virtual) separated by "action periods," during which teams applied what they had learned to conducting local PDSA cycles to test the effects of "small changes" on the functioning of their EHDI systems. Teams also agreed to provide monthly reports on their progress. The collaborative was conducted over a 15-month period from April 2006 to July 2007. At each 2-day learning session, teams heard presentations from content experts and participated in team planning sessions with NICHQ improvement advisors and expert faculty. During the action periods between learning sessions, ~6 months in length, monthly conference calls enabled teams to receive feedback from each other and from faculty on the progress of their improvement efforts.

Every month, teams reported data on core performance measures together with descriptions of their PDSA cycles through a Web-based "extranet" tracking system. Faculty evaluated the reports and advised teams on how to identify promising change strategies and how to plan for implementation and spread of successful improvements.

QI APPROACH TO EHDI SYSTEMS IMPROVEMENT

Before members of the collaborative met for the first time, the NICHQ convened an expert panel of nationally recognized EHDI leaders (including parents) to identify activities with a high likelihood of improving EHDHI systems. This effort included the development of process and outcome measures that were consistent with recommendations from the Joint Committee on Infant Hearing.[18] The panel focused particularly on activities that were likely to lead to failure-free operation over time.[19–21] The team also incorporated aspects of the Nelson et al[22] "clinical microsystems model," which focuses on the frontline clinical interface relationship that connects clinical teams with the needs of individual families and encourages identifying key steps in the care process.

The panel divided the EHDI process into 6 phases of care (shown in Table 1) and developed "change strategies" (suggestions for change in practice that were likely to lead to improvement in quality) for each of these phases. The panel also identified "infrastructure" changes that could be evaluated as to the degree that they would affect all of the phases of care. The results of the expert panel's work were summarized in a "change package" that would guide participating teams and enable them to achieve breakthrough changes in their settings. The change package comprised 3 elements: the conceptual framework (in this case, the

TABLE 1 EHDI Process Phases and Change Strategies

EHDI Phase	Change Strategies
Phase 1: screening (includes initial screening and any rescreening)	Verify PCP with parents and providers for all infants who do not pass screening
	Standardize process for recording screening results in newborn record
	Call PCP to inform him or her that the infant has not passed the screening
	Identify second point of contact for the family
	Perform any rescreening before discharge
Phase 2: refer to audiology and notify medical home (referral for diagnostic testing and linkage with PCP)	Standardize process for referral to audiologist for those infants who do not pass screening
	Schedule audiology appointment within 3 d of not passing the screening
	Streamline payment process and scheduling system for newborns who do not pass the screening
	Coordinate with PCP to verify follow-up plan
Phase 3: confirmation of hearing loss (diagnostic testing and informing PCP of results)	Prepare family and PCP in advance of the diagnostic audiology visit to maximize chances of an effective evaluation
	Use fax-back forms to communicate results and care plan to PCP after referral
	Empower families to be full partners in care-planning: use care notebooks for referral information and educational materials
	Schedule 2 appointments for audiologic evaluation 2 wk apart: cancel second appointment if not needed
	Provide "just-in-time" information for PCPs with standardized evidence-based materials
Phase 4: identify etiology (includes referrals to and appointments with ENT, ophthalmology, genetics, and sometimes developmental pediatrics, cardiology, and/or neurology)	Implement fax-back communication to PCP for all referrals
	Standardize the process for identifying etiology
	Educate the PCP about the medical workup for hearing loss
	Reduce waiting time for appointment with specialty providers
	Develop a communication tool, modeled after AAP guidelines to engage and empower families with information about specialty visits
Phase 5: offer treatment/implement amplification (begins immediately after diagnosis; includes process of discussing communication options and possible intervention pathways with families)	Standardize script for discussing amplification options
	Identify who is responsible for discussing communication options and developing communication plan with family
	Share communication plan with all members of the care team
	Coordinate referral process to minimize authorization delays with insurers
Phase 6: enroll in EI (formal enrollment in an EI program)	Have PCP play coordinating/communicating role between the EHDI and EI programs
	Streamline referral process to EI
	Use fax-back form from EI to PCP to verify that enrollment is complete
All phases: state-level infrastructure	Customize AAP guidelines for medical providers[24] with state resources; distribute to the PCPs
	Create educational documents for parents with appropriate reading levels and languages
	Create a Web-based resource guide that includes information on services for the deaf and hard-of-hearing and clinical tools such as letter and fax templates
	Measure parent experience with EHDI and use the feedback to guide system improvement
	Create and use a registry for infants with hearing loss
	Track progress through the EHDI system and provide active outreach at first system failure

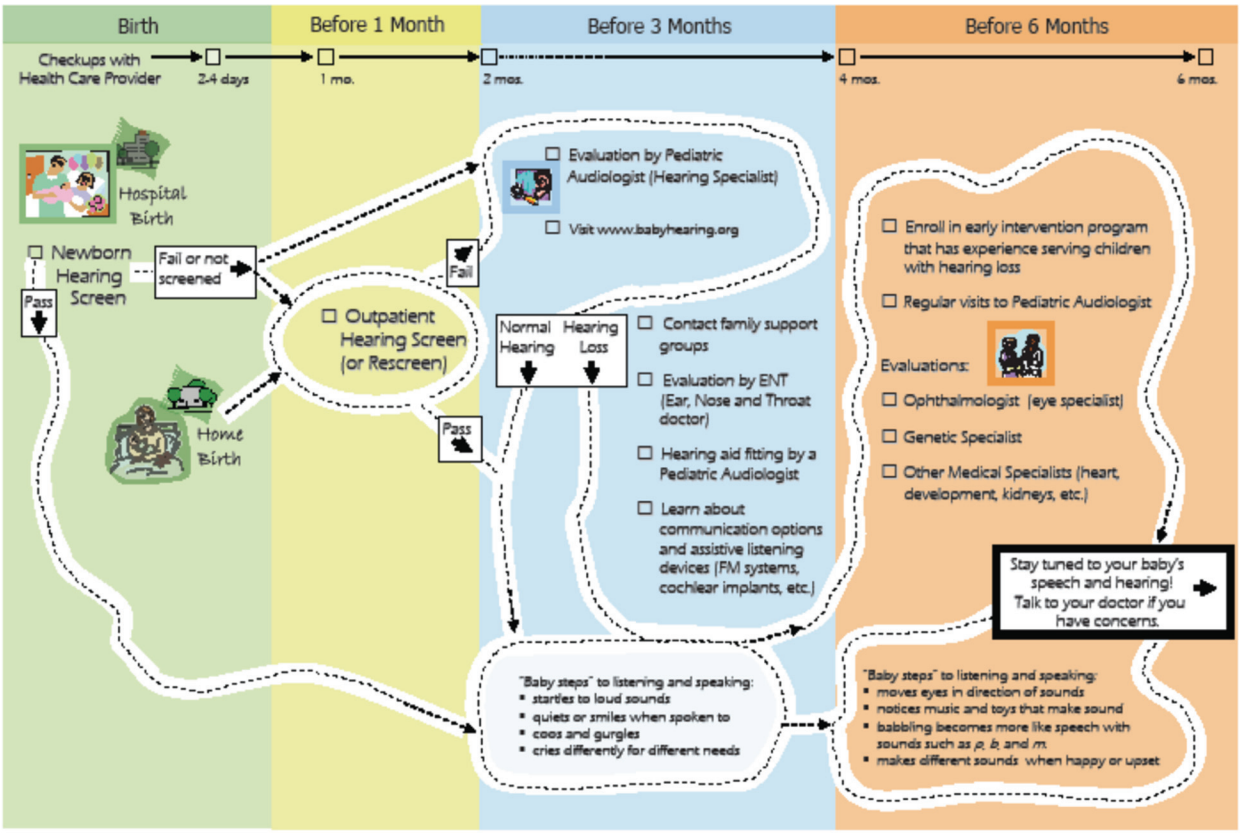
EI indicates early intervention; AAP, American Academy of Pediatrics.

chronology of care described above, including features of an ideal system); the suggested change strategies; and a set of measures to enable teams to track progress toward their goals.

Consistent with a medical home approach to care delivery that was accessible, continuous, coordinated, family-centered, and of high quality,[23] the change package included suggestions to (1) partner with parents in making improvements that families will value, (2) strengthen relationships between providers and encourage them to view themselves as part of a care continuum rather than as stand-alone entities, (3) focus on transitions as key components of care where system failures are likely to occur, (4) enhance communication and transparency across the care-delivery system, (5) reinforce the broader concept of the medical home, and (6) ensure that practice teams are proactive and prepared for all health encounters.

STATE TEAM EXPERIENCES WITH APPLYING QI TO THE EHDI SYSTEM

Participating teams reviewed the change package, selected specific change strategies to test in their area, and created additional change strategies. The teams tested most changes in the screening and early-diagnostic phases. Guided by training in the QI approach at the learning sessions, teams developed locally applicable PDSA cycles based on the change strategies and tested their impact through repeated data collection. Tests of change were initially performed on a small scale (eg, 2–3 cases) and results monitored. Refinements to the change strategies were made through multiple small-scale, rapid-cycle PDSAs. Teams also reported monthly on a series of EHDI system process measures and were encouraged to review 20 cases per measure. The following examples illustrate QI work undertaken by the state teams.



Universal Newborn Hearing Screening, Diagnosis, and Intervention

Learning about Hearing Loss -- A Family's Checklist

Child's Name: _____

Child's Date of Birth: ___/___/_____

Birth

Checkups with Health Care Provider — 2-4 days

☐ Hospital Birth:
Newborn Hearing Screen
Date: ___/___/____
Screening Results

Left Ear	Right Ear
☐ Fail	☐
☐ Pass	☐
☐ Not screened (missed)	☐

Be sure your doctor gets the results. If your baby does not pass the screening on both ears, or was not screened, schedule an Outpatient Screen (or evaluation by a Pediatric Audiologist [Hearing Specialist]).

☐ Home Birth:
Contact _____
to schedule a hearing screening

Before 1 Month

1 mo.

☐ Outpatient Hearing Screen (or Rescreen)
Place: _____
Date: ___/___/____
Screening Results

Left Ear	Right Ear
☐ Fail	☐
☐ Pass	☐

Be sure your doctor gets the results. If your baby does not pass the screening on both ears, make an appointment to see a Pediatric Audiologist (Hearing Specialist).

Before 3 Months

2 mos.

☐ Evaluation by Pediatric Audiologist[1,2] (Hearing Specialist) with experience testing children 0 – 2 years of age. (Babies over 4 mos. old may need sedation.) Be sure your doctor gets the results.
Place: _____
Date: ___/___/____
Test Results

Left Ear	Right Ear
☐ Normal hearing	☐
☐ Hearing loss	☐

☐ Visit www.babyhearing.org

If a baby has a HEARING LOSS, the next steps are:

☐ Contact family support groups

☐ Evaluation by an ENT[1] (Ear, Nose and Throat doctor)
Place: _____
Date: ___/___/____

☐ Hearing aid fitting and monitoring by a Pediatric Audiologist, if needed, including information on loaner hearing aids

☐ Learn about communication options and assistive listening devices (FM systems, cochlear implants, etc.)

Before 6 Months

4 mos. — 6 mos.

☐ Enroll in early intervention program that has experience serving children with hearing loss
Place: _____
Date: ___/___/____

☐ Regular visits to a Pediatric Audiologist

Evaluations:

☐ Ophthalmologist[1] (eye specialist) every year
Place: _____
Date: ___/___/____

☐ Genetic Specialist[1]
Place: _____
Date: ___/___/____

☐ Other Medical Specialists[1] (heart, development, kidneys, etc.) as needed
Place: _____
Date: ___/___/____

Service Provider Contact Information

Health Care Provider:

Pediatric Audiologist:

Early Intervention Provider:

Family Support Group:

Other:

[1] You will usually need a referral from your doctor to see these specialists

[2] Many services may be available at no cost; contact your state Early Hearing Detection and Intervention (EHDI) program coordinator at 1-866-HEAR (4327) or visit www.hearandnow.org

NCHAM

FIGURE 3
Learning About Hearing Loss—A Roadmap for Families.

Linking EHDI With the Medical Home

Communication with the pediatrician is essential if he or she is to be involved in care coordination in accordance with the medical home model. The team wanted to improve the proportion of infants who did not pass the screen and who had their pediatrician correctly identified. Failure to correctly identify the pediatrician at this important first step would have major consequences for communication at later phases of the EHDI process. At baseline chart review of 10 cases, only 50% of newborns who did not pass their hearing screen at the birthing hospital had an identified pediatrician for follow-up. A series of PDSA cycles that evaluated small tests of change revealed that documentation of the pediatrician was best achieved by the screener directly asking the parent at the time the infant did not pass the screen who the infant's pediatrician was. In another effort to improve care coordination, some teams evaluated collection of a second contact name and telephone number, in addition to the mother's, for infants who were referred after screening. Again, use of the screener to collect this information and document it led to improved second-contact documentation, which resulted in improvement in locating families.

These 2 changes also resulted in cost savings. In 1 state, an average of 20 cases per month were identified as lost to follow-up at the beginning of the learning collaborative. After improved documentation of the pediatrician and second point of contact, the number decreased to 5 per month, which translates into a "savings" of 30 to 50 hours/month in outreach-worker time. This team's experience indicated that relatively simple and inexpensive changes at the first phase of the EHDI system improved links with the medical home and enhanced care coordination and led to later cost savings.

Promoting Family-Centered Care

Another team wanted to contact families when they had a child diagnosed with hearing loss to ensure that they were receiving needed services and to address any concerns. In the existing system, the Department of Public Health (DPH) sent a certified letter to the family and advised them that an EHDI coordinator would contact them by telephone. There was no request for parent response. At baseline, the DPH had ~25 open cases per month statewide that needed an average of 2.2 contacts to ensure that the family was receiving all needed services. These activities required ~13 hours/month of staff time. This team tested a change strategy in which the letter was modified to include a toll-free number for families to call. Sixty-five percent of the families called the number, which resulted in ~8 hours/month of staff time saved. This small change acknowledged families as active partners in care rather than passive recipients. The new system had advantages for families in that they could initiate telephone contact at a time that was convenient to them.

Information for Parents: A Roadmap for Families

Parents on state teams identified a need for better information about the "pathway" through screening, diagnosis, and intervention for children with hearing loss. Most states had written information on discrete phases of the EHDI process, but none had a single document designed for parents that spanned the entire route from screening through intervention. Collaborative faculty worked with teams to design "Learning About Hearing Loss—A Roadmap for Families" (Fig 3). The roadmap was designed in a format that is complementary to the American Academy of Pediatrics guidelines for medical home providers[24] so that the 2 schematics could be used together. Some teams customized the roadmap for their state in both English and Spanish. Using PDSA cycles, parents reported on their experience with the roadmap through focus groups and interviews and, as a result, made changes in both the content and the readability level.

Although designed as a handout for parents, the roadmap received positive feedback when used as a "joint communication tool" by parents and professionals to demonstrate the family's location on the diagnostic journey and to clarify the sequential steps needed to complete evaluations. Use of the roadmap in this manner also revealed that some families were not aware of the distinctions between the many professionals involved in the EHDI system (eg, ENTs, audiologists, and geneticists). This process helped the state teams to understand why some families were unaware that multiple visits to different providers were needed to complete the assessment process.

Reducing Delays in the Diagnostic Audiologic Evaluation Process

Participating teams identified a system bottleneck in the long delays and waiting time for diagnostic audiology appointments. Several teams tested expedited appointments for infants within 1 week after discharge, making 2 appointments at the time of discharge, and advance preparation for the visit to increase the probability of confirming the diagnosis at the time of the examination. Although some teams were able to reduce appointment waiting times by either prioritizing appointments for screen refers or increasing staff, none of the teams were able to sustain an increase in the percentage of infants with a completed diagnostic evaluation before 3 months of age. Teams identified multiple factors that

contributed to this system failure: a severe shortage of pediatric audiologists; a need for multiple appointments to determine hearing status; referrals to other specialists (eg, ENTs) during the diagnostic phase; and a need to schedule a longer appointment for a sedated auditory brainstem response evaluation once infants were 3 months of age or older. Future attempts to make improvements in this area may need to focus on testing refinements to the audiology test battery and to increasing the supply of appropriately trained audiologists through either focused trainings in pediatric audiology or importing audiologists from areas where there was little shortage for per-diem sessions.

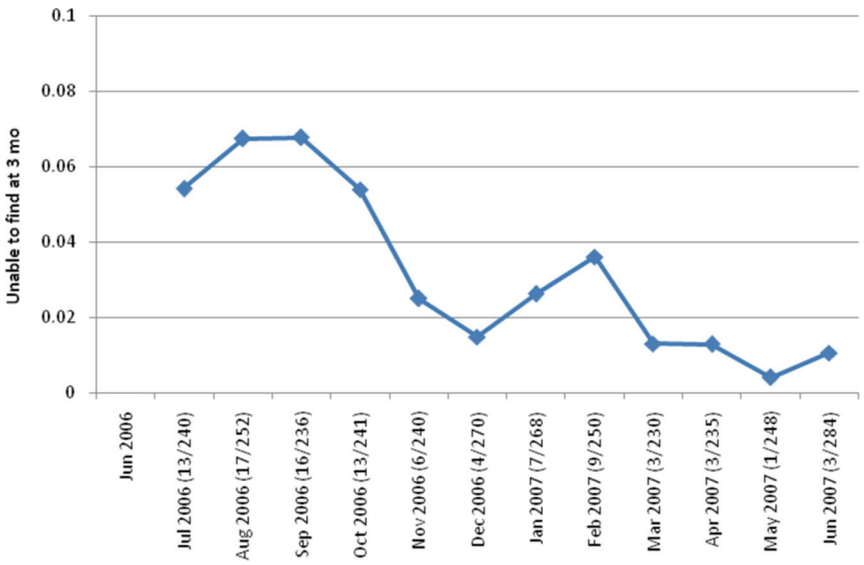


FIGURE 4
Unable to find cases 3 months after screening for 1 team over the course of the collaborative.

Improving Enrollment in Early-Intervention Programs

Collaborative teams were asked to measure the percentage of individual family service plans that were completed by 6 months of age. Teams reported barriers to obtaining this measure, principally because of local interpretations of regulatory requirements (the Health Insurance Privacy and Accountability Act [HIPAA], the Federal Education Rights and Privacy Act [FERPA], and Part C privacy regulations of the Individuals With Disabilities Education Act [IDEA Part C]) that seemed to preclude the sharing of information between education and health care services in the absence of written parental consent. Future QI efforts may be informed by a recent study of this problem, which is reported on elsewhere in this supplemental issue.[25]

ASSESSMENT OF THE EHDI COLLABORATIVE EXPERIENCE

At the conclusion of the collaborative, faculty reviewed (1) data reported to the extranet on EHDI process measures, (2) monthly reports, (3) storyboards that provided information on the contexts in which states had conducted their QI activities, (4) results of an electronic survey of team members on their experience with the collaborative, and (5) individual feedback from team members and faculty. The assessment included analysis of quantitative and qualitative data and led to the following lessons learned.

Minimizing Loss to Follow-up After Newborn Hearing Screening

To monitor the impact of the QI activities, each team was asked to measure at baseline (precollaborative) and monthly thereafter their loss-to-follow-up rate. The measure itself proved problematic. First, a precise, universally accepted definition of loss to follow-up is lacking, and teams varied in how they "operationalized" the measure. Although the current national EHDI reporting system measures loss to follow-up at 1 year, this time period was too long to be useful in the collaborative context, so loss to follow-up at 3 months of age was adopted as a measure. Second, during the prework process, several teams found that cases were being lost to documentation rather than lost to follow-up (ie, infants were receiving needed care and testing, but it was not being documented). A similar difficulty with distinguishing true loss to follow-up from loss to documentation was recently described nationally.[26] Teams reported loss-to-follow-up rates at baseline that were considerably lower than expected, ranging from 0% to 60% (close to 0% in 4 cases). Several teams also found that the number of infants per month who did not pass their screening from the pilot sites participating in the learning collaborative was too small for meaningful trends to be determined. Only 1 team demonstrated sustained improvement in this measure, which was based on statewide data with an average of 250 cases per month (Fig 4).

Factors identified by the team as contributing to the documented improvement were the adoption of a statewide electronic data-management system that provided close-to-real-time case tracking, effective and dedicated state-level leadership, involvement of parent partners in development and distribution of materials to families, and outreach and communication with pediatricians.

TABLE 2 Promising Changes

1. Standardize or "script" the message given to the parents when an infant does not pass the initial screening test
2. Standardize the process for collecting additional contact information for infants who do not pass their screening; get a second point of contact for the family (eg, telephone number of a relative or friend)
3. Verify the identity of the PCP or clinic responsible for follow-up with both the parent and assigned provider at the time the infant is screened before the family leaves the hospital
4. Schedule a follow-up appointment (rescreening or diagnostic evaluation appointment) at the time that the infant does not pass the screening, before the family leaves the hospital, and stress its importance
5. Call the family before the diagnostic audiology appointment to verify the appointment time and place and include the reasons why the appointment is important; offer assistance to get to the appointment if necessary (eg, transport vouchers)
6. Make 2 audiology appointments when scheduling diagnostic evaluations so that the infant who cannot be completely evaluated at the first appointment is scheduled to return within a reasonable time frame; cancel the second appointment if not needed
7. Use a fax-back form at the time of diagnostic evaluation to alert the PCP of the results and need for follow-up
8. Use fax-back forms between all parts of the care continuum (audiology, PCP, specialists, EI)
9. Obtain consent from parents for release of information at first contact with early intervention so that information can be shared between early intervention, the PCP, and the state EHDI database
10. Provide PCPs with early intervention reports with clinically useful and timely information for providers

Promising Changes

The teams identified several additional promising change strategies that were tested, implemented, and spread by at least 1 team. Generally, these changes were small, well-focused actions that had a demonstrated positive effect on some aspect of the EHDI process. Ten changes met these criteria (Table 2). Additional work is needed to establish whether these changes produce sustained improvements in the EHDI process and whether they can be spread beyond the initial teams and to link these changes with validated outcome measures.

Parent Participation in the Collaborative

Family involvement in care delivery is recognized as fundamental to the medical home model.[23,27] This involvement is not limited to the family's participation in its own child's care but includes family input on practice policies and procedures. Effective parent participation ensures that the parents' unique viewpoint of "one who has been there" is integrated into the team-improvement process. Family leaders identified several factors that contributed to successful parent involvement. These factors included (1) parent representation at both national faculty and state team levels (the NICHQ established a national parent chair who worked alongside the clinical chair to assist and support parent leaders at the state level, which created a "point of contact" and a mechanism to ensure that parent leaders were actively engaged on the state teams), (2) identifying, at the outset, family leaders who had a "skill set" to make positive contributions (eg, the ability to share insights and information about their experiences in ways from which others can learn; access to and basic knowledge of community and state resources; ability to see beyond personal experiences and represent the needs of other families; respect of the perspective of others; and the ability to speak comfortably in a group with candor and work in partnership with others), (3) establishing a recommended scope of involvement for family leaders so that they understand what is expected of them and so that teams understand how to utilize family leaders, and (4) providing opportunities for family leaders to convene with one another at the learning sessions and to have parent telephone conferences throughout the collaborative.

Participant Experiences of the Learning Collaborative

Parents were enthusiastic about their participation in the collaborative (Table 3) and professionals (Table 4) reported on important insights into EHDI system performance that resulted from the QI activities. Several of them noted that small tests of change made at proximal points in the care system could significantly affect the way the system was able to perform at later stages (eg, correct identification of the pediatrician before the infant was discharged from the birth hospital, sensitive, yet accurate sharing of information with parents about the need for follow-up after a child does not pass screening). Participation in the collaborative was also an effective means of opening dialogue between different service sectors that have traditionally operated independently (eg, audiology and primary care, health and education). Working on a common task with common goals fostered the development of personal relationships across sectors and disciplines, and between parents and professionals, that facilitated progress of the improvement work. Before the collaborative, professionals reported concentrating on improving their own service but had little opportunity to improve the connections between the services. Parents perceived a system of "silos," disconnected parts, with inherent barriers and limited, if any, communication between sectors. Encouraging all partic-

TABLE 3 Parents' Experiences in the Learning Collaborative

"What I found very helpful, and exciting, is when we actually had the face-to-face learning sessions. . . . I really enjoyed the parent meeting. I felt really connected to the other parents from the other states."
"The face-to-face meetings were probably the most beneficial part of the whole NICHQ [learning collaborative]. When we all got together, we could talk about our personal experiences. I think, like we all said, unless it happens to you, or it's in your own home, nobody really truly understands, you know, and all of us as parents understand what—well, as for myself, to be deaf and also to be raising a deaf child."
"I think what really helped me was how our state team leader e-mailed weekly and the day before to remind us of the team calls that we would have and also would remind us of the NICHQ update calls. That was very helpful."
"For a lot of doctors and staff that I worked with on my team, this was the first time they ever had a parent involved, and it was a really new dynamic, and it took a while to kind of figure out how that was all going to work together."
"NICHQ tends to have some terminology that is kind of acculturated in their organization that I had to learn and stumble through over time, and I think maybe some of it had to do with the 'models of change' and things like that. It would have helped to have a primer prior to the collaborative on terms I might need to know."

TABLE 4 Professionals' Experiences in the Learning Collaborative

"Gaining an understanding that each specific change will only reduce a certain number of babies from being lost to follow-up; the lost to follow-up rate improves when multiple changes occur at the local and the state level."
"As a result of the [parent] survey, we received a parent story that described the anguish and uncertainty they experienced even though the 'numbers' (age at rescreening, diagnostics, amplification) were very good. Without the survey, this story would not have emerged. This stresses the need for a much improved parent-to-parent support system in our state, which is now unfolding."
"The collaborative approach can open doors that were previously closed . . . it's really the only way to get all the involved professionals and parents together . . . that's invaluable for system change."
"It has tied many professionals together in unity to help each other, provide education, and reduce the number of babies lost to follow-up throughout the state."

ipants to view themselves as part of the same system serving the infant and his or her family was a central theme. QI techniques then could be used to eliminate waste, improve flow, and standardize care processes across the entire EHDI system.

Not all feedback was positive. Several teams reported that data-reporting to the Web-based extranet system was technically challenging and time-consuming. One team experienced staff shortages during the collaborative and was unable to report its data. Some professionals expressed doubt that the gains made during the collaborative could be sustained or spread more widely across state systems without additional resources. Teams that reported the greatest gains during the collaborative were frequently those with the most established EHDI infrastructure at the outset.

IMPLICATIONS FOR IMPROVING THE EHDI PROCESS

The collaborative assessment showed that QI could be applied to the EHDI system with positive results in reducing loss to follow-up. PDSA cycles performed by multidisciplinary teams are a promising strategy for driving systems improvement from the ground up. These techniques can be used to move toward a system of care for children and youth with special health care needs that includes the critical characteristics of service coordination, effective communication between providers and family, family participation in care delivery, and flexibility.[28]

Incorporate QI Into EHDI System Development

QI approaches are most likely to be effective in the long-term when included as an integral component of program development. Nationally, there has been considerable variation in how follow-up is conducted after all types of newborn screening, and there is a recognized need for stronger quality-assurance oversight.[29] Raising expectations among all stakeholders, families, providers, and administrators that continuous QI is a standard component of care should result in more widespread adoption of QI techniques into follow-up activities. Resources are needed to accomplish this ongoing work, especially dedicated staff time and staff expertise in data collection and interpretation. "Top-down" incentives, such as making evidence of QI activities a condition of funding, are likely to be effective and have already been incorporated into the EHDI system. Nonfiscal incentives such as recognition of team efforts at the institutional or agency level may also be effective.[14,30] Support of senior leadership at the state level, including the Title V program, for using QI activities has been recognized as contributing to successful implementation.

Involve Families at All Levels of QI Initiatives

Spread of the medical home concept has led to promotion of a more active role for families in guiding service delivery at the pediatric-practice level.[23] However, their inclusion on "advisory boards" and mechanisms for soliciting family feedback remain variable. At the state level, families are typically underrepresented when decisions are

made about systems of care. Families that experience the continuum of care from screening through intervention are often well equipped to bring a systems perspective to QI discussions and develop innovative ideas for improvement. Partnering with state family advocacy organizations may help identify parents who are willing to contribute to QI work. Inclusion of family representatives on EHDI state advisory boards is also now a requirement for federal funding.

Strengthen the Infrastructure for Data Collection and Reporting

As reported in other articles in this supplemental issue, state data systems must be further developed to allow real-time tracking of children's progress through diagnostic and intervention systems.[31,32] Agreement on key EHDI structure process and outcome measures, together with adaptation of the data systems to allow easy reporting of these measures, would facilitate evaluation of the effects of QI initiatives on program operation at the local, state, and national levels. Measures could also be used to help a practice or organization understand its own care process and to compare performance across institutions and state systems.[3] Linkage of screening data with outcome measures including language development and quality of life is an important long-term goal for states. Achieving this aim will require dedicated funding. The development of these data systems could also be informed by PDSA cycles evaluating different approaches to data documentation and transmission.

CONCLUSIONS

This QI initiative, based on multiple PDSA cycles, led to promising improvements in statewide systems of care for infants who require follow-up after newborn hearing screening. Parents played an active role in the QI process in partnering with pediatricians, audiologists, and other professionals to suggest and implement changes leading to measurable system improvements. Ongoing QI efforts hold promise for continued improvements to the EHDI system and for wider developmental services system transformation. Dedication of staff time and strengthening of data-tracking mechanisms can facilitate this process. Successful QI initiatives should reduce waste, inefficiency, and rework in the existing system to offset the investment in QI over time.

Local QI initiatives, whether at individual practice sites, or through regional or statewide collaboratives, are likely to benefit from national exchange of experiences and sharing of successful change strategies. The national annual EHDI conference (www.infanthearing.org/meeting/ehdi2010/index.html) serves as a forum for such an exchange. Sharing successful QI approaches with the wider pediatric community, through peer-reviewed publications and presentations, could speed the transformation of all developmental services and lead to higher-quality care for all children with special developmental needs.

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