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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 re-screening 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 practices¹² 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 health¹⁷ 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 Improvement¹⁵ 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-

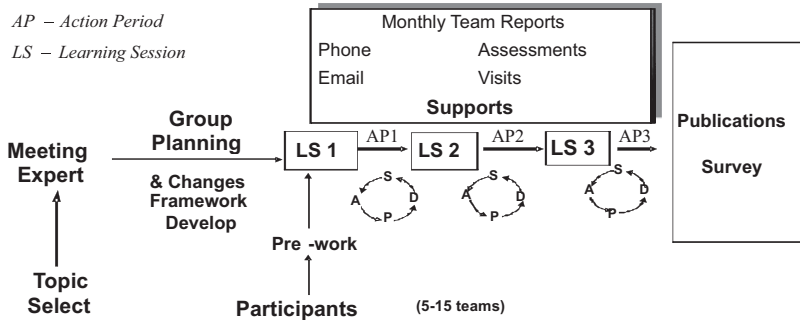


FIGURE 1 Breakthrough-series learning-collaborative model. (Reproduced with permission from Institute for Healthcare Improvement. The Breakthrough Series: IHI’s Collaborative Model for Achieving Breakthrough Improvement. IHI Innovation Series White Paper. Boston: Institute for Healthcare Improvement;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

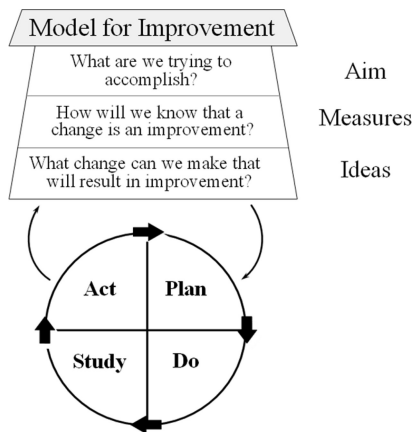


FIGURE 2 Model for Improvement: PDSA cycles. (Reproduced with permission from Langley G, Nolan K, Norman C, et al. *The Improvement Guide: A Practical Approach to Enhancing Organizational Performance*. New York, NY: Jossey-Bass; 1996:10.)

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 EHD 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 EHD coordinator), a data coordinator, and

a parent. The larger extended state team included representatives from other components of the EHD 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 EHD 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 EHD SYSTEMS IMPROVEMENT

Before members of the collaborative met for the first time, the NICHQ convened an expert panel of nationally recognized EHD leaders (including parents) to identify activities with a high likelihood of improving EHD 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 al²² “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 EHD 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)	<ul style="list-style-type: none"> 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)	<ul style="list-style-type: none"> 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)	<ul style="list-style-type: none"> 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
Phase 4: identify etiology (includes referrals to and appointments with ENT, ophthalmology, genetics, and sometimes developmental pediatrics, cardiology, and/or neurology)	<ul style="list-style-type: none"> Provide “just-in-time” information for PCPs with standardized evidence-based materials 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)	<ul style="list-style-type: none"> 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)	<ul style="list-style-type: none"> 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	<ul style="list-style-type: none"> Customize AAP guidelines for medical providers²⁴ 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.

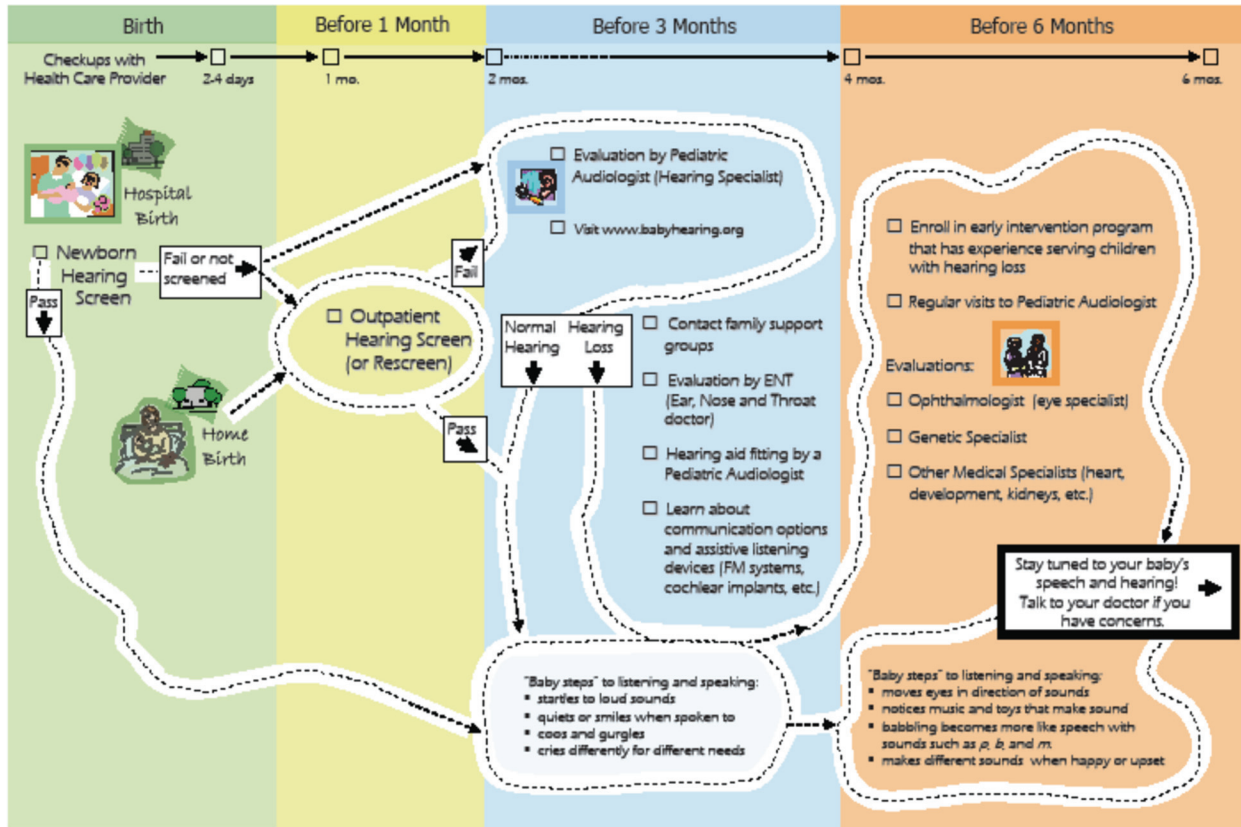
Consistent with a medical home approach to care delivery that was accessible, continuous, coordinated, family-centered, and of high quality,²³ the change package included suggestions to (1) partner with parents in making improvements that families will value, (2) strengthen relationships between providers 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	Before 1 Month	Before 3 Months	Before 6 Months																												
Checkups with Health Care Provider: 2-4 days <input type="checkbox"/> Hospital Birth: Newborn Hearing Screen Date: ___/___/___ Screening Results: <table border="0"> <tr> <td>Left Ear:</td> <td>Fail <input type="checkbox"/></td> <td>Right Ear:</td> <td>Fail <input type="checkbox"/></td> </tr> <tr> <td></td> <td>Pass <input type="checkbox"/></td> <td></td> <td>Pass <input type="checkbox"/></td> </tr> <tr> <td></td> <td>Not screened (missed) <input type="checkbox"/></td> <td></td> <td></td> </tr> </table> 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]). <input type="checkbox"/> Home Birth: Contact: _____ to schedule a hearing screening	Left Ear:	Fail <input type="checkbox"/>	Right Ear:	Fail <input type="checkbox"/>		Pass <input type="checkbox"/>		Pass <input type="checkbox"/>		Not screened (missed) <input type="checkbox"/>			<input type="checkbox"/> Outpatient Hearing Screen (or Rescreen) Place: _____ Date: ___/___/___ Screening Results: <table border="0"> <tr> <td>Left Ear:</td> <td>Fail <input type="checkbox"/></td> <td>Right Ear:</td> <td>Fail <input type="checkbox"/></td> </tr> <tr> <td></td> <td>Pass <input type="checkbox"/></td> <td></td> <td>Pass <input type="checkbox"/></td> </tr> </table> 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].	Left Ear:	Fail <input type="checkbox"/>	Right Ear:	Fail <input type="checkbox"/>		Pass <input type="checkbox"/>		Pass <input type="checkbox"/>	<input type="checkbox"/> 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: <table border="0"> <tr> <td>Left Ear:</td> <td>Normal hearing <input type="checkbox"/></td> <td>Right Ear:</td> <td>Normal hearing <input type="checkbox"/></td> </tr> <tr> <td></td> <td>Hearing loss <input type="checkbox"/></td> <td></td> <td>Hearing loss <input type="checkbox"/></td> </tr> </table> <input type="checkbox"/> Visit www.babyhearing.org If a baby has a HEARING LOSS , the next steps are: <input type="checkbox"/> Contact family support groups <input type="checkbox"/> Evaluation by an ENT ¹ (Ear, Nose and Throat doctor) Place: _____ Date: ___/___/___ <input type="checkbox"/> Hearing aid fitting and monitoring by a Pediatric Audiologist, if needed, including information on loaner hearing aids <input type="checkbox"/> Learn about communication options and assistive listening devices (FM systems, cochlear implants, etc.)	Left Ear:	Normal hearing <input type="checkbox"/>	Right Ear:	Normal hearing <input type="checkbox"/>		Hearing loss <input type="checkbox"/>		Hearing loss <input type="checkbox"/>	<input type="checkbox"/> Enroll in early intervention program that has experience serving children with hearing loss Place: _____ Date: ___/___/___ <input type="checkbox"/> Regular visits to a Pediatric Audiologist Evaluations: <input type="checkbox"/> Ophthalmologist ¹ (eye specialist) every year Place: _____ Date: ___/___/___ <input type="checkbox"/> Genetic Specialist ¹ Place: _____ Date: ___/___/___ <input type="checkbox"/> Other Medical Specialists ¹ (heart, development, kidneys, etc.) as needed Place: _____ Date: ___/___/___ 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
Left Ear:	Fail <input type="checkbox"/>	Right Ear:	Fail <input type="checkbox"/>																												
	Pass <input type="checkbox"/>		Pass <input type="checkbox"/>																												
	Not screened (missed) <input type="checkbox"/>																														
Left Ear:	Fail <input type="checkbox"/>	Right Ear:	Fail <input type="checkbox"/>																												
	Pass <input type="checkbox"/>		Pass <input type="checkbox"/>																												
Left Ear:	Normal hearing <input type="checkbox"/>	Right Ear:	Normal hearing <input type="checkbox"/>																												
	Hearing loss <input type="checkbox"/>		Hearing loss <input type="checkbox"/>																												
Service Provider Contact Information Health Care Provider: _____ Pediatric Audiologist: _____ Early Intervention Provider: _____ Family Support Group: _____ Other: _____																															



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 medi-

cal 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 providers²⁴ 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.

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 con-

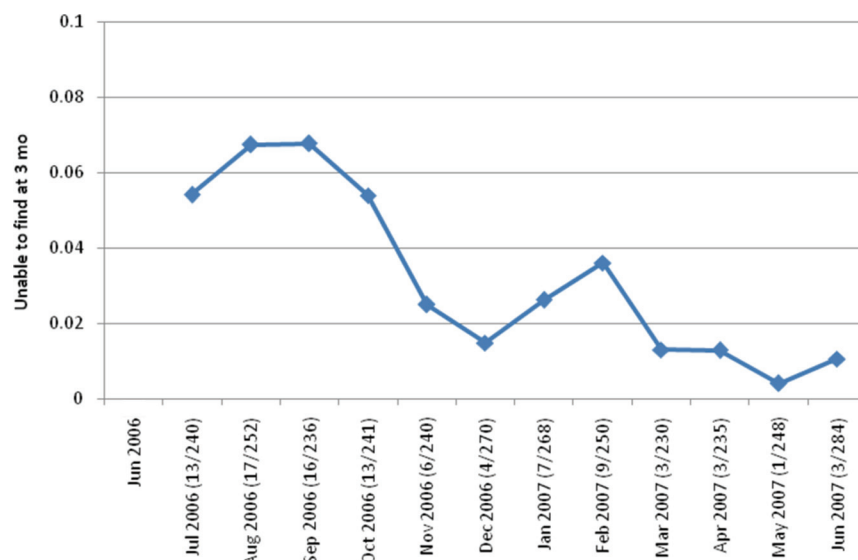


FIGURE 4

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

ducted 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 estab-

lished 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 (Ta-

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

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