




# ENHANCING COMMUNICATION

**Improving Care *for* Infants  
*with* Hearing Loss**





Even the best care in the world can't help patients who don't have access to it. Unfortunately this is the case for about half of the 12,000 U.S. infants diagnosed each year with hearing loss.

# INTRODUCTION



As a result of focused efforts during the past decade, about 95 percent of United States infants are screened for hearing loss. Each year approximately 12,000 infants are found to have hearing loss. However, approximately half of these infants are lost to follow-up, slipping through the cracks of the system. These 6,000 infants with permanent hearing loss miss the benefits of early screening and early treatment and intervention services.

For those infants who do receive follow-up care, many experience delays in diagnostic evaluation and intervention services. In some places, particularly in rural settings, a shortage of pediatric audiology specialty services is often one cause. But equally at fault is the fact that handoffs and referrals between and among hospitals, specialists, early hearing detection and intervention professionals and primary care providers often lack context and coordination, resulting in delay, misunderstanding or confusion. Families can end up feeling that they are navigating an unfamiliar and complex system largely alone, at a time when they are still processing the news of their baby's hearing loss.

This report documents the work of a project, "Improving Follow-Up to Newborn Hearing Screening by Working Through the Medical Home" (hereafter referred to as Newborn Hearing Screening). The project was funded by the U.S. Department of Health and Human Services, Health Resources and Services Administration, Maternal and Child Health Bureau (MCHB) under contract with the National Initiative for Children's Healthcare Quality (NICHQ). The National Center for Hearing Assessment and Management (NCHAM) provided faculty support for the project.

A work group convened in July 2001 by the National Institute on Deafness and Other Communication Disorders identified some of the most serious problems that contribute to delay and loss to follow-up. They include:

- Transportation
- Funding
- Staffing
- Lost messages and ineffective communication
- Language and literacy

Using a learning collaborative model and proven improvement techniques, NICHQ integrated into this project frameworks, strategies and tools from prior work, including work with MCHB addressing the health needs of children and youth with special health care needs (CYSHCN) and their families; the Medical Home Learning Collaborative I (MCLC I) from October 2003 to September 2004; and Spread of the Medical Home Concept (MCLC II) from October 2004 to December 2005.

The current project also integrated previously tested concepts, such as full integration of parent partners, active engagement of Title V and State-level participants and the centrality of the primary care provider (PCP)/ medical home in improvement efforts.

Multidisciplinary teams from eight states in the pilot project have seen breakthrough improvement in follow-up for infants who do not pass their hearing screening.

This project, funded by HRSA/MCHB, will continue until 2010 when NICHQ will produce a definitive list of steps necessary to improve follow-up rates. Expert learning sessions will take place each year and information will be produced for key stakeholders, including audiologists, early intervention providers, pediatricians and parents. This preliminary report of the project to date will continue to evolve with the learning of the collaborative teams.

# ORGANIZING FRAMEWORKS AND DESIGN OF THE LEARNING COLLABORATIVE

## The Breakthrough Series

The Learning Collaborative was built using the Breakthrough Series™ (BTS), a model successfully used by NICHQ (page 6). The BTS enables teams to work together with NICHQ leaders and expert faculty toward a common goal, in a structured sequence that includes planning, pre-work, Learning Sessions, Action Periods and ongoing support activities. This Collaborative focused on testing and implementing changes to reduce the loss to follow-up of infants with hearing loss.

## The Learning Collaborative

NICHQ facilitated Learning Collaboratives for eight State teams in Arizona, California, Florida, Kansas, Michigan, Nebraska, Pennsylvania and Wisconsin. Collaborative faculty helped each State team achieve the collaborative mission and their State's specific aims. Faculty supported the teams by sharing the best available evidence on clinical recommendations, teaching and applying methods for organizational change. Title V directors and Early Hearing Detection and Intervention (EHDI) program directors were also part of each participating State's quality improvement efforts.


The Collaborative focused on making system improvements while simultaneously strengthening the role of the medical home for infants with hearing loss and their families. With the focus on the first year of life, NICHQ used proven quality improvement methodology to identify and test solutions to reduce delay and eliminate loss to follow-up for these infants and their families.

NICHQ relied on a solid foundation of research and the work of several other organizations in the design of this project, including recommendations on the approach to care for infants with hearing loss from the American Academy of Pediatrics and the Joint Committee on Infant Hearing. NICHQ also elicited opinions of authorities in the field concerning “best practices.”

Following the model described above, the first step in developing a Learning Collaborative is drafting a charter that lays out the rationale for the project. A charter describes the reasons for undertaking the work and how the collaborative will be conducted. Elements include goals, methods and strategies and expectations.

Measures of system performance are grouped into three types of “Core Measures”:

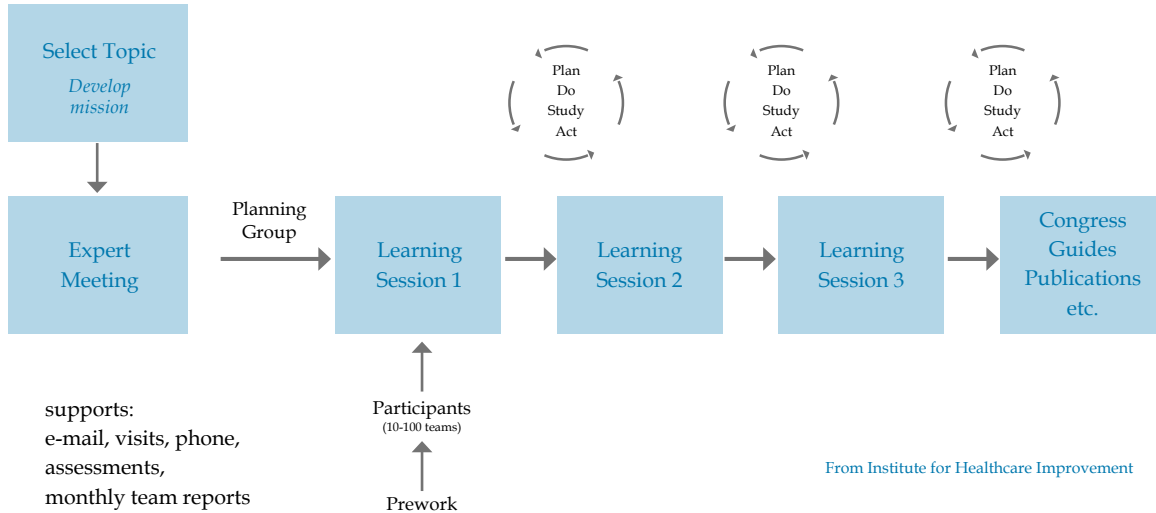
- **Outcome measures** track whether or not the system is achieving the desired results. They are the voice of the patient. They report on the results of the change concepts and strategies in practice as they affect the patient's experience of care. This includes if their outcome has improved and if their subjective experience of care is positive. Outcome measures reveal the effects of key changes.
- **Process measures** let us know if the system is performing as planned. They are the voice of the system. They describe the process of care and the changes in service delivery. Documentation of these processes can be gathered from patient reports or from clinical or administrative records.
- **Balancing measures** show the impact on the system of improvements in outcome and process measures. They provide a perspective on the unintended side effects of change throughout the system: Are you improving some part of the system at the expense of others, such as patient satisfaction or waiting times?

A close-up photograph of a woman smiling as a child is being examined. A hand is holding a medical device, possibly an otoscope, near the child's ear. The child is looking towards the camera with a happy expression. The background is slightly blurred, showing the woman's face and a blue shirt.

“The face-to-face meetings were probably the most beneficial part of the whole project. I think, like we all said, unless it happens to you or it’s in your own home, nobody really truly understands.”

— taken from *Evaluation of Parent Involvement in Collaborative section of Final Report*

Fig. 1: Breakthrough Series Collaborative Model  
(6 – 18 month time frame)



### The Model for Improvement

The approach to organizing and carrying out the improvement work in the Learning Collaborative was based on The Model for Improvement, developed by Thomas Nolan PhD and colleagues at Associates in Process Improvement. The model identifies four key elements of successful process improvement: specific and measurable aims; measures of improvement that are tracked over time; key changes that result in desired improvement; and a series of testing “cycles” (called Plan-Do-Study-Act, or PDSA cycles) during which teams learn how to apply key changes in their own organization. The Model for Improvement is illustrated in Figure 2 on page 5.

### The Care Model for Child Health

The Care Model for Child Health served as a major conceptual framework for this project. The Care Model is designed to improve the outcomes of health care for children through integration of a prepared, proactive management team, an informed and actively engaged patient and family and a supportive and connected community. This framework is a powerful tool in implementing change in pediatric health care.

### Clinical Microsystems Thinking

Paul Batalden and Eugene Nelson’s “Clinical Microsystems Model” has been found to be a useful model for organizing the changes and measures for the improvement work of the Learning Collaborative. After review of the proposed models at the Expert Meeting in January 2006, the Clinical Microsystems Model was included as an organizing framework for the Newborn Hearing Screening Learning Collaborative.

The model helps to outline key components in the improvement process: the key customers, the defined population and their needs, the key processes or big steps in the clinical care process and a system for gaining knowledge of customers and of outcomes.

A clinical microsystem includes all the people and roles, processes and technology in a setting that are directed to meet patient need. The model is patient centered as it starts with clarification of the “patient need.” It then articulates the central processes that the patient and family experience as they move through the clinical setting and care processes.

Originally designed to structure improvement work in a single setting, the model was adapted by NICHQ to conceptualize the care process over

multiple care settings where the infant with a potential or actual hearing loss is diagnosed and treated.

The microsystems in this Collaborative include: the hospital, audiology practice, other diagnostic practices and early intervention programs. It includes the key processes of screening, diagnosis, treatment, and follow-up, as well as the key roles of parents, hospital-based nurses, audiologists, physicians, Medical Home providers, community-based audiologists, the State Title V programs, Hearing Screening Program staff and early intervention staff.

Technology is integral to the microsystem; State data systems for registration and follow-up play an integral role in the system of care. Key to the success of the collaborative was bringing together these key roles and considering them as part of a single system of care for the infant and their family rather than in distinct and separate systems.

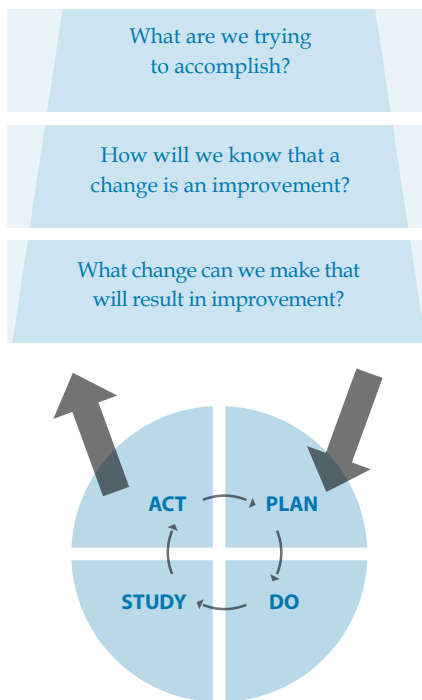
### Reliability Principles

In 2006, the Institute for Healthcare Improvement (IHI) developed a rationale and methodology to help the health care system achieve higher levels of performance when delivering key health care processes. This notion of reliability has direct relevance to the charter and aims of the Newborn Hearing Screening project in seeking to reduce delays and loss to follow up for infants who did not pass their newborn hearing screening.

IHI defined reliability in health care as “the measurable ability of a health-related process, procedure or service to perform its intended function in the required time under commonly occurring conditions.” (IHI, 2006) The reliability of a process should be measured by the number of actions that achieve the intended results, divided by the total number of actions taken. By studying high reliability organizations, Weick and Sutcliff (Managing the Unexpected (2001)) described “hallmark” principles to guide system improvements including “collective mindfulness” and “preoccupation with failure” and the importance of initial product design.

Building on this work, IHI developed a three-tier approach to improving the reliability of health care processes: (1) reduce reliance on vigilance and hard work, (2) consider human factors and reliability engineering, and (3) use sophisticated behavioral designs, taking advantage of habits and patterns, making the system visible to all and using clear and unambiguous communication. The NICHQ Newborn Hearing Screening team was able to adapt these principles to this project with the examples on the following page.

Fig. 2: The Model for Improvement



From Institute for Healthcare Improvement

## Reliability Examples by Level Applied to Newborn Hearing Screening Project

### Level 1:


- Education of PCP/MH staff by specialty providers
- Standardization of procedures to provide feedback of data between practice teams and hospital staff and between specialty providers and primary care
- Standardization of parent information throughout the State

### Level 2:

- Build in redundancy by identifying two points of contact for all infants who “did not pass” newborn screen
- Use checklists and reminders to identify real-time identification of system failures
- Identify a failed newborn screen as a critical test result

### Level 3:

- Develop a care map based on AAP guidelines for patients and clinicians
- Use clear and unambiguous communication between clinicians and families about next steps
- Identify every failed appointment as an opportunity to act and learn
- Identify the reasons for system delays and involve parents in every stage of the care plan



“The journey is different than we expected, but we have the privilege and responsibility of building a foundation for our children which will enable them to accept themselves for who they are.”

—parent of a deaf child



## Site Visits

In preparation for this work, NICHQ conducted site visits to two exemplary programs in Rhode Island and Massachusetts. Those visits helped identify potential best practices and innovative approaches for system improvement.

## Family Leaders, Subject Matter Experts and Advisory Panel

NICHQ had ongoing support from an advisory panel of family leaders, subject matter experts and leadership from HRSA's Maternal and Child Health Bureau, the National Center for Hearing Assessment and Management at Utah State University, the American Academy of Pediatrics, and the Centers for Disease Control and Prevention.

## Expert Meeting

NICHQ then convened a team of experts recruited from national leaders in pediatrics, audiology, nursing, neonatology, otorhinolaryngology (ORL) and early intervention to provide leadership, guidance, and visibility to the Learning Collaborative. The expert team met in January 2006 for a 2-day meeting to review the charter, the proposed change package (see page 11) and measurement strategy for the Learning Collaborative that were developed by the NICHQ team. The experts then made recommendations to the NICHQ team on the proposed approach to the project.

The Expert Meeting provided the development team with validation of many of the changes proposed in the change package and measurement plan. The most significant contribution the experts made to the planning of the Collaborative was in relation to the organizing frameworks. They suggested that the change package and measurements be organized using a process model, to present the change package to the participating teams. The expert meeting participants also supported several recommended changes to tests including obtaining two points of contact for the family when an infant does not pass the initial screen and verifying a primary care provider for these infants before leaving the birth hospital.

## Working with Parents as Partners

"Parents have so much to contribute when it comes to helping improve care for their children," says Janet DesGeorges. "It's just that so often, no one asks for their help."

Janet DesGeorges is Executive Director of Colorado Families for Hands & Voices, and a Parent Leader working with NICHQ on the Newborn Hearing Screening Collaborative. Hands & Voices is a nonprofit, parent-driven national organization dedicated to supporting families of children who are deaf or hard of hearing.

"Family leaders have particular areas of unique expertise," says DesGeorges, "and they have contributed a lot to the NICHQ Collaborative." Family leaders have worked to develop "The Parent Roadmap," a template that helps parents understand where their child is in the EHDI model. They have helped retool a clinical decision-making guide to make it specific to parents of children who are deaf or hard of hearing. They also created a survey of the parents' experience of care, a tool used to gauge parents' impressions about whether measures are being completed by State teams.

"Giving parents the opportunity to engage in this work is not just about making them feel included," says DesGeorges. "Without their input, the system of care we envision will never be fully realized. Parents have been underrepresented in the decision-making about provision of services for their children." The value that parents bring to the table is widely accepted, which is why the Collaborative empowers parents to work together with improvement leaders to build a model of care that places parents in partnership with their children's providers.

"As parents we want to make sure that our kids have the opportunity to succeed to their fullest potential," says DesGeorges. This is a goal shared by pediatric professionals, and the foundation for an effective and productive partnership.



## FINALIZE FRAMEWORK, AIMS, MEASURES, CHANGES

### Aim Statement

The mission of this project was to achieve, in 15 months, a breakthrough improvement to reduce delays and loss to follow-up for infants who do not pass the newborn hearing screen. We built our improvement approach on the existing evidence-based guidelines and time targets of screening by 1 month of age, diagnostic testing by 3 months of age and enrollment in early intervention by 6 months of age.


### Key Outcome Measures

- Reduce by 50 percent the number of infants who “do not pass” the newborn hearing screening test who are lost to follow up 1 year from their date of birth (target 25-30 percent)
- Increase by 50 percent the number of infants with hearing loss who achieve normal developmental milestones (babbling, signing) by 12 months of age
- Double the number of infants with hearing loss who are fitted with hearing aids before 3 months of age


### Key Process Measures

For infants who do not pass the newborn hearing screening test:

- Increase by 50 percent the number of infants with audiologic diagnostic testing by 3 months of age
- Increase by 50 percent the number of infants enrolled in early intervention by 6 months of age
- Increase by 50 percent the number of infants with hearing loss who are linked with a primary care provider (PCP)/Medical Home



“I appreciate the fact they had a national parent chair so that any time I ever had a question, the parent chair was available and returned e-mails, phone calls, etc. I really appreciated how accessible she was to us parents. It was wonderful.”





# CHRONOLOGY OF CARE DELIVERY: FOCUS ON HANDOVERS AND TRANSITIONS

## Identifying Phases of Care

Rather than base the change package on one part of the care system, tests of change were included for all phases of care for infants during the first year of life. NICHQ then developed strategies for change in each of the six phases of care, understanding that microsystems would interact in each of these phases.

### Phase 1: Screening

The screening phase occurs from the time of birth until the infant has received the initial screening and typically a rescreen before they leave their birth facility. This phase primarily involves the staff in the hospital screening program although this project included participation from teams who were working with midwives who attend home births. This phase also addresses the strategies that screeners use to inform the parents of the results of the screening process.

### Phase 2: Refer to Audiology Center and Notify Medical Home

This phase begins at the time the infant is identified as “did not pass” in the screening phase. In some hospitals, the protocol is to have a rescreen after discharge, while others complete the rescreen before the infant leaves the birth facility. Infants who “do not pass” require a referral for diagnostic audiologic testing as well as notification of the Medical Home.

### Phase 3: Confirmation of Hearing Loss

This phase begins with the referral to diagnostic audiology and ends with a confirmation of hearing loss. Phase 3 is often complicated by inherent system delays with limited audiology appointments. This phase also includes improving system capacity to complete the diagnostic evaluation before 3 months of age to avoid the necessity of a sedated exam which necessitates additional system delays. An evaluation of system delays with multiple audiology appointments during the confirmation process is also included in this phase.

### Phase 4: Identify Etiology

Once hearing loss is confirmed, this phase addresses the process of identifying the etiology of the loss. This phase includes referrals to and appointments with ENT providers, geneticists and sometimes other specialty providers.

### Phase 5: Offer Treatment/Implement Amplification

This phase starts with the confirmation of hearing loss and includes providing communication options to the family. Initially the project team focused on offering amplification, that is hearing aids, but the collaborative participants redirected this aim toward educating parents about the variety of communication options that are available at the time of diagnosis.

### Phase 6: Enroll in EI

The final phase starts at the time of confirmation of hearing loss and ends with enrollment in early intervention. During the collaborative, NICHQ learned that the process of enrollment can occur with a referral from the Medical Home, from audiologists and from multiple other referral sources. Understanding and then addressing the communication barriers between the health care and educational system is a challenge for participating States.

## The Change Package

A Change Package is a set of materials and ideas that guide and enable teams who are participating in a Collaborative to achieve breakthrough change in their settings.

A Change Package generally has three elements: a conceptual framework — in this case the chronology of care described above — that describes features of the ideal system for the topic; a set of changes or strategies that have proven to be effective in achieving improvements; and a set of measures that enable Collaborative teams to track progress toward their goals. The tables on pages 12 – 15 include a sample of ideas teams tested by phase of the hearing screening and evaluation process.

Based on the feedback from the Expert Meeting, the NICHQ team supplemented the Clinical Microsystems Model. Since our aim included the provision of safe, timely, appropriate, coordinated and family-centered care, our design strategies for the change package included:

- Identify the family as the source of control, make improvements that would be of value to parents and partner with them in the care of their infants
- Build improvement teams with representatives from all the stakeholders (hospital, primary care, audiology, specialty care, early intervention) in the care continuum; this will strengthen relationships and enhance the perception that they are part of the same system rather than isolated “silos” of care.
- Redesign the system to enhance reliable care delivery for the infant and his family especially at handovers and transition points within the system
- Optimize system performance with an eye to taking waste, frustration, and rework out of the system
- Enhance communication and transparency across the care delivery system
- Reinforce the notion of the Medical Home as the seat of continuing care
- Optimize each health encounter with a prepared and proactive practice team

Participation in NICHQ’s Newborn Hearing Screening Collaborative challenged a lot of assumptions in the pediatric audiology community in Wisconsin, one of eight States participating in the Collaborative. Elizabeth Seeliger MA, CCC-A, the State’s Early Hearing Detection and Intervention Program Director, says the result has been a healthy re-thinking about how things are done, and dramatic progress in getting more babies into early diagnostic assessments with participating audiologists by 3 months of age as a result of Wisconsin’s goal to increase that number by 50 percent.

“We knew that many families were not getting pediatric audiology services, and there was an assumption that there was something inherently flawed in the audiology clinics, whether in their scheduling systems, or in prioritizing pediatric patients, or something,” says Seeliger. Other assumptions were at work as well, she says. “Hospital staff thought that making follow-up appointments before discharge for newborns who didn’t pass the screening test would be too time-consuming for them, and they hadn’t thought about the positive impact for the family or for the audiologists who spent a lot of time scheduling and rescheduling appointments.”

Both these assumptions were proven wrong during the course of the Collaborative, says Seeliger. The team that tested a process for hospital staff to make follow-up appointments prior to the newborn’s discharge discovered that, once a system was put into place to support it, the process was not only efficient, but also highly effective. “The number of families who showed up for follow-up appointments went up dramatically and reached 100 percent during the analysis phase, and the actual time spent by hospital staff was minimal,” says Seeliger.

There were other breakthrough ideas as well. “We learned that parents from small, rural areas who are referred to large urban medical centers can feel worried and unsure about everything from where they will park to their personal safety in the city,” says Seeliger. So a team put together a clear one-page information sheet to reassure parents.

“The Collaborative model is so helpful because the system changes aren’t looked at as system changes, they are seen as small tests of change that feel less threatening,” says Seeliger. “The organized data collection helps us see the evidence of the changes, and enables champions to bring their colleagues on board.”

The Wisconsin experience in the NICHQ Collaborative has been so successful that Seeliger says the State has recently received funding from MCHB to run their own Learning Collaborative, spreading the lessons learned by the NICHQ teams to hospitals and providers throughout the State.

## Pre Phase 1: Preparation and Planning

- Develop an office resource guide for hearing loss (CYSHCN); identify contact persons for each resource; ask all office staff members to identify community resources that provide services to children with hearing loss and their families; assign one person to organize and maintain manual; make resources Web based and include templates for customization
- Organize internal and community resources to facilitate use by the family
- Identify factors most closely linked to loss to follow-up and intervene to improve likelihood that follow-up for these infants will occur
- Engage family in developing the written, collaborative, and culturally appropriate plan of care
- Emphasize the central role of the family in the care partnership
- Provide unbiased information for communication options
- Measure parent experience with newborn screening process
- Identify community resources that provide financial assistance for children and families with hearing loss; provide a summary of resources to practices
- Build service agreements between primary and (sub) specialty care (ENT/ ORL and/or audiology, genetics, ophthalmology and EI); include core competencies, referral guidelines, communication and expectations for access to one another

### **Phase 1: Screening**

- Standardize the process for verifying the PCP/MH with parents and providers for all infants that “did not pass”
- Standardize the process for recording results of newborn hearing screening on newborn records
- Create a list of local PCPs/MHs that are taking new patients
- Communicate results to PCP/MH by using standardized communication tools, such as a letter template
- Call PCP/MH on all infants who “did not pass” to be sure PCP is correct and alert practice about referral
- Produce monthly “did not pass” report and send to Early Hearing Detection and Intervention (EHDI) program
- Identify additional point of contact for family at time of “did not pass” referral
- Refer all infants who “did not pass” to social worker or Visiting Nurse Association (VNA)
- Make referral to audiology center before discharge or perform rescreen before discharge

### **Phase 2: Refer to Audiology Center and Notify Medical Home**

- Standardize approach to confirm diagnosis of hearing loss; template orders and referrals for diagnosis and evaluation
- Standardize process of referral of “did not pass” newborns to audiologist from PCP
- Confirm audiologist appointment with parents at time of PCP visit
- Eliminate ambiguity; establish accountability for who is responsible for following infant; may vary by State
- Streamline referral process needed for payment and scheduling appointments
- Identify all infants who “did not pass” who need follow up; coordinate with PCP/MH to be sure follow up plan is accurate
- Identify strategy to schedule infants who “did not pass” the initial screen to have appointment within 3 days of call (< 3 days to third available new); rescreen immediately after discharge from birth hospital or establish remote site screening
- Implement process to maximize value of diagnostic evaluation; call the night before, be sure the infant is tired and hungry before the examination; plan work to be done before and after visit; create a “prepared practice”
- Make appointment for diagnostic evaluation at time of “do not pass” screening

**Phase 3:  
Confirmation  
of Hearing Loss**

- Empower families to be full participants in care planning; use care notebooks for referral information and educational materials
- Schedule two appointments for audiologist 1 week apart
- Prepare audiology practice to maximize probability of obtaining a good diagnostic evaluation
- Create a care map for the family that outlines expected care through first year of life at the time hearing loss is confirmed
- Use office personnel to do non-diagnostic work during the visit
- Prioritize newborn diagnostic examinations
- Predict and anticipate patient needs at time of appointment
- Use fax-back form to communicate results and care plan to PCP/MH for referrals
- Create list of resources for families of infants with hearing loss; coordinate with State and community resources
- Create and use a registry for infants with hearing loss
- Have specialists provide “just in time” education for PCPs with standardized educational materials

**Phase 4:  
Identify Etiology**

- Implement immediate “fax back” communication to PCP/MH for all referrals
- Standardize process of identifying etiology of hearing loss
- Educate PCP about medical work up for infants with hearing loss
- Reduce time to “third available new” appointment for specialty providers

**Phase 5:  
Offer Treatment/Implement  
Amplification**

- Develop plan for follow up for infant who “did not pass” to return to discuss communication options; schedule into care map for family
- Coordinate referral process to eliminate authorization delays
- Standardize script for discussing amplification options

**Phase 6:  
Enroll in Early Intervention**


- Have PCP/MH coordinating/communication role between EHDI, audiology and early intervention programs
- Streamline referral process to Early Intervention
- Use fax-back form from EI to PCP/MH at the time of enrollment



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**State Level Programs  
(Title V, EI, EHDI, Birth Registry,  
AAP reps, payers)**

- Modify AAP recommendations (flow sheet) to reflect State data; distribute to all practices
- Create a registry of newborns who did not pass the screening phase
- Provide active outreach at first “system failure”
- Standardize “just in time” communication to PCP/MH that includes evidence-based guidelines
- Provide reports with clinically useful and timely information for providers
- Create educational documents for parent use with appropriate reading level
- Improve ability of early intervention programs to identify children with hearing loss
- Identify sources of high rates of refer, discharge without screening and loss to follow up
- Identify PCP practices with high rates of loss to follow up



“We had a lot of fun together and really connected as people which made the team a nice thing to be a part of. We had a few really enthusiastic people who showed others that it could be done.”

—a participating collaborative team member



## RESULTS

### Examples of High Leverage Changes

The Change Package previously described includes multiple ideas for clinical testing, categorized by the phase in the process to which the change was related. All the participating teams also invented other ideas to test. Some elements of the change package were in place for some States before the Collaborative began. Teams tested changes in all phases of the hearing screening and intervention process however some were more common than others. All teams tested changes in the preparation and planning and screening phase of the process. Two-thirds of the teams tested in the referral to audiology, identification of etiology and enrollment in early intervention phases. Over 6 teams tested in the confirmation of hearing loss and in making State level changes. Only three teams tested in the implementing amplification phase.

As the teams progressed through the PDSA cycles, some changes were implemented and became “part of the new process” and some changes were abandoned. As the project came to a close, several teams began spreading the interventions to new settings.

Using the measurement strategy described on the next few pages, teams tracked the impact of changes through data collection, studied the impact of the changes in their PDSA cycles and continued testing until they were confident that the change resulted in the desired improvement. The aim of the Collaborative was to identify those changes that would result in the desired improvements with the greatest value to the system.

We identified those changes that teams were confident in, where their data showed a trend toward improvement and where staff members were ready to embrace the change. The Change Package Analysis identifies changes by State that were (1) tested, (2) moved into implementation and (3) planned for spread.

The analysis revealed those changes perceived to be effective in achieving desired aims by each individual team and in the aggregate by the Collaborative as whole. We identified three levels of High Leverage Changes.

## High Leverage Changes

### **HLC 1: Changes Implemented and/or Spread by More than One Team (N=6)**

- 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
- Standardize process for recording results of newborn screening results on the newborn records – improve the accuracy of the information
- Schedule the follow up appointment (rescreen, or diagnostic evaluation) at time the infant does not pass the screen – before they leave the hospital and stress its importance
- Confirm audiologist appointment with parents at time of PCP visit
- Use a fax-back form at the time of diagnostic evaluation to alert the PCP of the results and the need for follow up
- Organize internal and external resources to facilitate use by family

### **HLC 2: Changes Spread by a Single Team (N=7)**

- Standardize process for collecting additional contact information for babies that do not pass their screens – get a second point of contact for the family, e.g. phone number of a relative or friend
- Create a letter template to fax communication results to PCP/MH
- Educate PCP about medical work-up for infants with hearing loss – link with reporting results and provide “just in time” information
- Use fax-back form between all parts of care continuum – audiology, PCP, specialists, EI
- Create a registry of newborns who did not pass the screening phase
- Provide PCPs with EI reports with clinically useful and timely information for providers

### **Promising HLCs: Changes Still Being Tested**

- Standardize and “script” the message given to the parents when an infant does not pass the initial screening tests
- Call the family before diagnostic audiology appointments to verify appointment time and place and include the reasons why the appointment is important; offer assistance to get the appointment if necessary (eg. transport vouchers)
- Make two audiology appointments when scheduling diagnostic evaluation so that the infant who can’t be completely evaluated at the first appointment is scheduled to return within a reasonable time frame. Cancel the second appointment if not needed
- Obtain consent from parents for release of information at first contact with Early Intervention so that information can be shared between EI, PCP, and the State EHDI database

## Measures and Observations

Over the course of the Collaborative, the teams collected baseline data in April 2006 and monthly data for most measures over a 12-month period ending in July 2007. Collaborative-wide improvements were noted for 10 measures.

### Measure 1: Verified PC

Percent of “do not pass” newborns with assigned and acknowledged primary care provider (medical home) prior to discharge from the birth hospital (goal 100 percent)

Observation: *This measure aims to improve system reliability by accurately obtaining, verifying, and recording the identification of the responsible primary care provider before the infant leaves the hospital. The absence of this information causes rework and contributes to delays and loss to follow-up and it had face validity for the teams.*

### Measure 2: Availability of Newborn Screening Results at the PCP

Percent of first newborn visits with results of newborn screening information available for pediatrician (goal 100 percent)

### Measure 3: Completed Audiologic Evaluation by 3 Months of Age

Percent of infants who “did not pass” the initial screen who have an audiologic evaluation before 3 months of age

### Measure 4: Median Age of Completed Audiologic Evaluation

Median age of referred newborns with completed audiologic evaluation (target < 3 months)

Observation: *This measure is sensitive to referral process requirements, availability of non-sedated and sedated appointments, seasonal variation and local supply of audiologists. Median age varied from a low of 43.8 days to a high of 89.5 days. This measure had value for participating teams and was consistently reported.*

### Measure 5: Time to Third Available New Appointment (in days) for Diagnostic Audiology

Time to third available new appointment for an audiology appointment (goal 2-3 days)

Observation: *Teams tracked time to third available new for both non-sedated and sedated appointments. Since younger infants are less likely to require sedation, teams preferred audiology appointments as soon as possible after the “did not pass” screen. Sedated appointments are scarce and they add cost, require additional staff and contribute to further system delay.*

### Measure 6: PCP Notified of Results of Diagnostic Evaluation by Audiologist at the Time of Visit

Percent of newborns who “did not pass” the initial screen and whose PCP/ MH is notified of results by audiologist (as evidenced by documented phone call or fax form)

Observation: *At baseline, the median of 40 percent of PCPs were notified by the audiologist of the results of diagnostic testing. By the end of the Collaborative, the median progressed to 100 percent by testing specific changes in audiology practices.*

## Measures and Observations (continued)

### Measure 7: Offered Treatment by Audiologist by 3 Months

Percent of infants with permanent hearing loss who are offered treatment (fitted with hearing aids) before 3 months of age

Observation: *During the Collaborative we learned that almost half the infants who did not pass the screen, in any monthly report, were in a “pending” status regarding recommendation for treatment. The confirmation of a diagnosis and a clear “treatment” plan is a complex process that needs further testing.*

### Measure 8: Completed IFSP by 6 Months of Age

Percent of infants with permanent hearing loss enrolled in early intervention program with IFSP developed before 6 months of age

Observation: *By the end of the Collaborative this measure began to show some improvement, moving from an initial median of 39 percent to a median of 80 percent. About half the teams reported on this measure.*

### Measure 9: Unable to Find at 3 Months of Age

Percent of infants lost to follow-up at 3 months of age

Observation: *Although every State did not report each month, the Collaborative made progress on this measure moving from a median of 17 percent to 1 percent. This highlights the importance of early identification of systems failures. Using a State registry that captures all births, one State was able to report on all “did not pass” newborns, and reported an initial “unable to find” rate of 5.42 percent. By the end of the Collaborative their rate was 1.06 percent.*

### Measures 10a-d: The Parent Experience of Care

We used a parent survey to assess parent experience of care. The measures were set to determine the percent of families who experience highly desirable quality care. The survey questions were designed and approved by the parent faculty and team members, were adjusted to a literacy level of 5th grade and one team translated the questions into Spanish. Three of the eight teams agreed to participate in this measurement strategy and the State EDHI program accepted the responsibility for administering the survey. Methodology of administration was left up to the States with both written and phone surveys used. While response rates were low, some deductions could be made from the reported data. The team that administered the survey in both Spanish and English identified a substantial difference in the system functioning and the parents’ perception of their needs being met in the Spanish speaking population.

Family experience of care measures were:

- a. Percent of families who report they received the hearing screening results in the hospital verbally and in writing
- b. Percent of families whose PCP/MH had the results of the newborn hearing screening on hand at their first well baby visit
- c. Percent of families who report they “always” received the help they needed from their providers (doctor, nurse, or audiologist) between screening and diagnosis
- d. Percent of families who report they always received specific information they needed about diagnosis, treatment, and service options for hearing loss

Additional measures included in the measurement strategy that need further testing are:

**Multiple contacts identified**

Percent of newborns who “did not pass” the initial screen with multiple contacts on screening form for follow-up

**Time to third available new appointment (in days) for ENT/ORL appointment.**

Number of days to third available new appointment for ENT/ORL appointment (goal 2-3 days)

**Time to third available new appointment (in days) for genetic appointment.**

Number of days to third available new appointment for genetics appointment (goal 2-3 days)

**Care Map**

Percent of families who have a care map (written plan that maps the steps in the evaluation and intervention phase) provided at the time of confirmed diagnosis

**Median age at “offered” amplification/treatment**

Median age of referred newborns with written amplification/treatment plan documented in medical record

**Parent Involvement**

Parent involvement in the Learning Collaborative was essential to assuring that family and clinical perspectives informed the content and goals of the Collaborative. Parent representatives served as a key link in the communication between the Medical Home and the specialty care provider. Improvement teams learned that by including parents in the improvement efforts they had a more realistic “view” of how the system really works. Parents provided leadership and ideas for change to reduce delay and improve follow-up to newborn hearing screening from their unique family/parent perspective. Ensuring full and effective involvement of parents in the hearing screening and intervention process was essential for the success in this work.

**We identified several factors that contributed to successful parent involvement:**

- Identifying family leaders with a prerequisite level or “skill set” to participate. This skill set could include:
  - Ability to share insights and information about their experiences in ways that others can learn from
  - See beyond their own personal experiences and represent the needs of other families
  - Respect the perspectives of others
  - Speak comfortably in a group with candor
  - Work in partnership with others
- Establishing a “job description” for parent partners so they understand expectations and other team members can effectively partner with them in this work
- Providing structured training in the parent partner role during the collaborative to maximize their effectiveness as team members
- Providing opportunities for parents to meet with each other; plan dinner meetings in advance of the face-to-face learning sessions and build in monthly phone meetings for parent partners led by the parent chair

## Summary

The Collaborative model enabled us to identify several changes that led to encouraging preliminary results.

In summary:

- The proportion of screen refers lost to follow-up at 3 months fell from a median of 20 percent at baseline to a median of 0 percent.
- The proportion of screen refers with a documented PCP increased from a median of 70 percent to 87.5 percent.
- Delays in ENT appointments were reduced by liaising with provider's office to prioritize appointments for newborns with confirmed hearing loss.
- Pooled Collaborative results of change strategies showed that delays and loss to follow-up in the screening and diagnostic processes were reduced as identified in High Level Changes on page 17
- The use of customized tools and information technology facilitated communication between providers and parents, such as:
  - a script for messages given to parents when an infant does not pass the initial screening test
  - Parent Roadmap
  - HIPAA/FERPA release forms; obtaining consent for release of information at first contact to enhance communication between health and education systems of care and State data tracking systems
  - fax-back forms between audiologists, PCPs and early intervention programs to enhance the communication of the screening or testing results and the need for prompt follow-up

The NICHQ team developed many specific strategies and constructed the Change Package with proposed changes for teams to test. The Learning Collaborative helped promote an understanding of the feasibility and usefulness of the proposed strategies and measures. The eight participating States used the NICHQ Extranet, a Web-based data collection and reporting application to help measure collective progress, share ideas with each other and evaluate the effectiveness and utility of change package elements.

The monthly Collaborative Team calls proved to be particularly vital to the functioning and ultimate success of the Learning Collaborative. With guidance from NICHQ staff and Collaborative faculty, teams assessed their progress and shared resources, successes and challenges with other teams. Faculty led discussions on new topics or expanded discussion on specific topics of interest selected from feedback from evaluations and team suggestions. Collaborative calls also provided an opportunity to review overall progress of the Collaborative, reflect on measures and improve upon change concepts for the Collaborative.

As the Collaborative came to a close, the NICHQ team conducted a Harvest Survey to glean useful information about the teams' experience during the Learning Collaborative, and also identify lessons the Collaborative teams would like to share with others engaged in this work. The Harvest Survey yielded a rich resource for NICHQ about what had been learned and accomplished through the Collaborative.



**CONCLUSION** Getting the infant with hearing loss to treatment is a highly complex process, involving State resources, payers, referring physicians, the specialty community and State Title V offices as well as parents and their preferences for treatment. This system of care is complicated by multiple handoffs and the inability of the system to “detect” delays during all phases of the process of care. Nevertheless, the Collaborative model enabled teams to develop many useful strategies to address these challenges and improve care for these infants and their families.





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