

CLOSING THE EARLY HEARING DETECTION AND INTERVENTION FOLLOW-THROUGH GAP ACCELERATING EVIDENCE INTO PRACTICE

I. CHARTER:

The purpose of this charter is to describe the reasons for undertaking a national, statewide and local initiative to improve the hearing screening and follow-up process. The Charter provides historical perspective on the problem that needs addressing, mainly the significant issue of loss to follow-up in each component of the Early Hearing Detection and Intervention (EHDI) systems of care. The charter also provides a summary of how the Wisconsin Sound Beginnings (WSB) Program has identified key improvement strategies as well as a description of the highest leverage strategies included in the recommended Improvement Bundle (see pg. 5).

The information contained in this charter is informed by lessons learned from participation of the WSB Program and its local partners in a National Quality Improvement Learning Collaborative developed by the National Initiative for Children's Healthcare Quality (NICHQ) and the Federal Maternal Child Health Bureau (MCHB), as well as from the testing and implementation of strategies through an intensive statewide replication of the national learning collaborative.

PROBLEM STATEMENT:

Hearing loss represents the most frequent birth defect in the United States (White, 2003). Incidence data demonstrates that each year, 4000 to 8000 children are born in the United States with significant bilateral permanent hearing loss. When children with milder forms of hearing loss or unilateral hearing loss are included, that number almost doubles. Ten years ago, the average age of identification of congenital hearing loss was 2 ½ to 3 years or older and a critical window of development for the child was often missed. Research shows that intervention in the first 6 months of life is particularly important to overall development.

With lessons learned from the approximately 4 million infants are born yearly in the United States that are screened to detect a variety of genetic and metabolic disorders that threaten their life and long-term health, the Federal government passed the Universal Newborn Hearing Screening bill that would extend these screening services to detect congenital hearing loss. The State of Wisconsin also passed legislation in 1999, which has led to the establishment of the WSB Program and has resulted in an increase in screening from 2% of babies in 1999 to 98% of babies in 2009. In May 2010, Wisconsin passes additional legislation that mandates newborn hearing screening and includes babies who are born in out of hospital settings. Nationally, more than 95% of newborns are now screened for hearing loss shortly after birth, which represents one of the most successful and rapid pediatric public health examples of research moving to practice. As a result, there has been a national and statewide reduction in the age at which children with congenital permanent hearing loss are diagnosed. Clear evidence links this early identification and intensive early intervention with significant improvements in school-related measures such as reading, vocabulary, social adjustment and behavior compared to children who did not receive this early intervention (AAP, 1999).

Despite clear evidence of improved outcomes, delays and loss to follow-up continues to plague all stages of the EHDI program: initial screen, referral to audiologist, definitive diagnosis, to linkage with early intervention. Clear opportunities for improvement exist in the 2007 Joint Committee on Infant Hearing

(JCIH) recommended targets for timely and appropriate diagnosis and intervention: specifically pediatric audiologic evaluation before 3 months of age and enrollment in early intervention before 6 months of age.

Along with the development of state EHDI systems, has been the development of systems to collect and analyze data according to the recommendations of the Task Force on Newborn and Infant Hearing. The guidelines recommend developing a tracking program to monitor all referrals and misses and developing mechanisms for communicating results. The task force further stressed that, because of the pediatrician's regular contact with children in the first year of life, they should play a pivotal role in guiding families through the EHDI system. Appropriate and necessary care for the infants with significant hearing loss should be directed and coordinated by the child's physician within the Medical home, with support from appropriate ancillary services (AAP, 1999).

Measure	*National Rates	**Wisconsin Rates 2008
% of newborns who "did not pass" newborn screen who receive a diagnostic evaluation	55.2%	25.1% (387/1544)
% of infants with hearing loss (who are referred) who received an audiologic evaluation by 3 months	40.10%	69.8% (270/387)
% of infants with a confirmed hearing loss who received audiologic evaluation by 3 months	Data not available	47.4% (45/95)
% of infants enrolled in early intervention program	65.6% (5.7 -100%)	44.2% (42/95)
% of infants (early identified) who are enrolled in early intervention before 6 months of age	45.28% (range 3.85-100%).	57.1% (24/42)
% of infants loss to the system	44.8%	33.5% (1155/3447)

* National Data compiled by the Directors of Speech & Hearing Programs in State Health & Welfare Agencies (2003).

** WI rates are compiled from data collected in the WE-TRAC System

The American Academy of Pediatrics (AAP) defines a medical home as "accessible, family-centered, continuous, comprehensive, coordinated, compassionate, and culturally competent care" (AAP, 2004). Although the number of infants with a medical home is unknown, a survey of Title V directors estimated that 63% of Children and Youth with Special Health Care Needs (CYSHCN) are connected with a medical home (White, 2003). Despite the clear need and widespread desire for "medical homes" for CYSHCN (Sia, 1992; Bishop, Woll & Arango, 1993) the medical home concept has been slow to spread in primary care practice, due in part to: lack of awareness; limited implementation of the concepts; pragmatic barriers, including time, knowledge, role definition, and reimbursement; and limited skills in the methodology of changing practice behavior.

Finally, the New Freedom Initiative announced in 2001 charges all states with implementing a strategic plan that will allow every CYSHCN access to a medical home by the year 2010. Achieving this mission will entail creating public and private partnerships at the local, community, and state level; building systems of care for CYSHCN that will link families to medical home; allocating sufficient resources to support services provided through medical homes; and, assuring CYSHCN access to care that is family-centered, culturally-competent, and coordinated at all service levels. (AAP, n.d.)

The problem and challenge can be summarized as follows:

Approximately 12,000 babies are born each year with hearing loss. With loss to follow-up rates at approximately 50%, currently about 6,000 infants with permanent hearing losses are missing the benefits associated with early identification and intervention. Further, only about half of the children with special

health care needs are currently linked with a Medical Home. Delays in care are exacerbated by a shortage of pediatric Audiology specialty services (audiologists, pediatric ENT/ORL) (White, 2003) especially in rural and underserved areas. Solutions to eliminate loss to follow up and provide necessary services and resources can best be accomplished through a community systems approach that ultimately includes a Medical Home strongly linked with specialty care services that these children need.

PURPOSE OF EHDI QUALITY IMPROVEMENT:

Since 2006, the EHDI Quality Improvement Initiative has strived to create partnerships with professional communities at the national and local level, influenced by family participation, in order to build a coordinated responsive system of care for these infants and their families.

The purpose of the National Learning Collaborative (2006-2007) and the Wisconsin Replication (2008 – 2009) of the EHDI Quality Improvement Initiative was to improve the quality of care delivered to newborns with hearing loss through system redesign using proven, evidence-based practices. By working through the medical home, we aim to provide safe, timely, appropriate, coordinated, and family-centered care for infants with, or suspected of having, permanent hearing loss. The goal of these quality improvement initiatives were to determine the best strategies, that when effectively implemented, would consistently improve short and long term outcomes for infants with hearing loss and their families. We aimed to eliminate delays in care and interventions and to eliminate loss to follow-up for all infants who do not pass the newborn hearing screen, by assuring that all newborns receive timely referrals, complete diagnostic evaluations, and appropriate linkages to supportive services.

HISTORY OF EHDI QUALITY IMPROVEMENT:

A work group on “Communicating the Need for Follow-up to Improve Outcomes of Newborn Hearing Screening,” 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 barriers
- Funding barriers
- Staffing barriers
- “Lost messages” and ineffective communication
- Language and literacy barriers

Other contributing factors to loss to follow-up were identified during the faculty planning sessions. They were that medical home providers were unaware of the hearing screening results when seeing a child for regular check-ups and that families did not understand the need for follow-up or how to access it. In other words, EHDI Systems of care are duplicative, disconnected, inadequate or otherwise out of compliance with the JCIH standards of care. Informed by this work, the primary emphasis of the National Learning Collaborative was to improve the systems of care for infants who do not pass the newborn screen or develop hearing loss during the first year of life and their families. The Chronic Care Model and microsystems thinking were used as a framework to test strategies that strengthened the links between the several components of primary and specialty care that provide follow up to newborn hearing screening. The care processes that are addressed are definitive diagnosis, early intervention, entry into appropriate care and services, and connection to a medical home. The National Learning Collaborative focused on enhancing communication and interaction between the family, medical home and specialty care providers at the interfaces of care while strengthening the capacity of the WSB Program to support implementation and spread of this model.

The WI EHDI Learning Collaborative Replication Project assisted 11 community teams achieve this mission and their specific local and regional aims. The faculty supported the teams in meeting the Collaborative goals by sharing the best available scientific knowledge on creating safe and reliable

systems and by teaching and applying methods for organizational change. Both collaborative focused on an identified set of measurable, achievable goals and process measures set to evaluate progress toward meeting the goals. They are as follows:

QUALITY IMPROVEMENT GOALS:

- Increase to 100% the number of babies screened for hearing loss before hospital discharge or prior to one month of age for out of hospital births (with the exception of those who refuse under religious tenets).
- Reduce by 70% the number of infants who “do not pass” the newborn hearing screening test who are lost to follow up one year from their date of birth.
- Increase by 70% the number of infants with hearing loss who achieve normal developmental milestones (babbling, signing) by 12 months of age.
- Increase by 50% the number of families of infants with hearing loss who are connected with another parent prior to their child’s first birthday.

KEY PROCESS MEASURES:

- Increase by 50% the number of infants with completed audiologic diagnostic testing by 3 months of age.
- Increase by 50% the number of infants enrolled in early intervention by 6 months of age.
- Increase by 50 % the number of infants with hearing loss who are linked with an informed Primary Care Provider (PCP)/Medical Home (MH).
- Increase by 50% the number of families who are referred to the Guide By Your Side Program.

MISSION OF THE CLOSING THE FOLLOW-UP GAP MEETINGS:

The mission of the Closing the EHDI Follow-up Gap initiative is to share what we have learned from all of these previous quality improvement initiatives. The mission is to spread evidence - based best practices in order to assure that infants born in any community in Wisconsin will experience care known to reduce delays and eliminate loss to follow-up if they do not pass the newborn hearing screen.

Communities new to the EHDI Quality Improvement Initiative will benefit from the experiences of the Wisconsin participants in the national learning collaborative as well as the experiences of communities of practice throughout WI who have planned, tested, revised tested and implemented a variety of different strategies in order to come up with the ones that work best! This initiative will expand on the Maternal Child Health Bureau’s (MCHB), the National Initiative for Children’s Healthcare Quality’s (NICHQ), and the Wisconsin Sound Beginnings Program’s previous work addressing the hearing health care needs of newborns and their families by enhancing capacity within the health care delivery system in collaboration with the Children and Youth with Special Healthcare Needs (CYSCHN) Programs, local public departments and the State Title V program.

RECOMMENDED IMPROVEMENT BUNDLE:

The Institute for Healthcare Improvement (IHI) has developed the concept of “bundles” to help health care providers more reliably deliver the best possible care for patients undergoing particular treatments with inherent risks. A bundle is a structured way of improving the processes of care and patient outcomes: a small, straightforward set of evidence-based practices that, when performed collectively and reliably, have been proven to improve patient outcomes. The Wisconsin Sound Beginnings Program has participated in the evaluation of many different strategies aimed at improving each part of the EHDI system of care. Participation in the National NICHQ Learning Collaborative provided the forum to test many different strategies, both in a variety of states as well in a variety of healthcare settings. The most effective strategies were then promoted, tested and evaluated by communities throughout Wisconsin. Vigorous data collection and evaluation within the learning collaborative settings, have demonstrated that

the strategies included in the EHDI Improvement Bundle are effective regardless of the size, location or make-up of the organizations or communities. Although the interventions are not based on randomized controlled trials, what is called Level 1 evidence, they have been proven effective time and time again in communities and healthcare facilities across Wisconsin. They are also noted improvement strategies in the article titled *Improving Follow-up to Newborn Hearing Screening: A Learning Collaborative Experience* (2010, Pediatrics). Another thing that makes a bundle unique is that the changes are all necessary and all sufficient, so if you remove any one of the recommended strategies, you will likely not get the same results — meaning: the patient will not have as high a chance of getting to timely and effective follow-up care. The EHDI Improvement Bundle is a cohesive unit of steps that must all be completed to assure your best chance at success.

EHDI COMMUNICATION & DOCUMENTATION BUNDLE
PROVIDER TO FAMILY
Provide clear communication about next steps using the EHDI Care Map
Standardize communications (written and verbal) with parents in their first language whenever possible about hearing results and next steps
PROVIDER TO PROVIDER
Communicate all did not pass results to the PCP/Medical Home as a critical value requiring confirmation
Identify, Document, and Reaffirm two points of contact for families of infants who did not pass (i.e. a relative or friend)
EHDI COORDINATION & MAPPING CARE BUNDLE
Verify the PCP/Medical Home before discharge
Schedule the follow-up appointment prior to discharge, stressing importance with families
Prioritize newborn diagnostic exams; create expedited slots and schedule two consecutive appointments
Remind families of appointments one day in advance
Offer a referral to Guide By Your Side as standard practice