

Developing a Strong Early Hearing Detection and Intervention Program

by Janet M. Farrell

“In June of 2007 my son Henry had his hearing screened shortly after he was born. I remember the sinking feeling I felt when the screener told my wife and me that neither of Henry’s ears passed. We were told that the screen is not a perfect test, but that Henry should be seen by an audiologist.

“Weeks later at Henry’s audiology appointment, we learned that Henry had a hearing loss. It was difficult, both practically and emotionally, to put this into perspective. During this confusing time, we received a call from a parent outreach specialist at the Massachusetts Department of Public Health, Universal Newborn Hearing Screening Program, to discuss Henry’s diagnosis and the intervention services that we could get for him. The outreach specialist helped us to identify and organize the next steps in our plan for Henry’s care. In addition, talking with another parent of a child with hearing loss helped us realize we weren’t the only ones going through this, and bolstered our confidence that we could be strong enough to give Henry a good start and a good life.”

—Richard Wentworth

Connecting families to other families is a guiding principle of the Massachusetts Universal Newborn Hearing Screening Program. The program is committed to being a coordinated, comprehensive, family-centered, culturally competent system of care that addresses the needs of families whose infants receive newborn hearing screening services in Massachusetts. Audiologists praise the program’s determination to ensure that every baby—regardless of a family’s language or changing location—receives screening and, equally as important, appropriate diagnostic and intervention services.

Comprehensive State Law

Massachusetts recently celebrated the 10-year anniversary of passage of Chapter 243 of the Acts of 1998, An Act Providing for Hearing Screening of Newborns, one of the strongest newborn hearing screening laws in the nation. The law calls for an early hearing detection and intervention (EHDI) program that requires:

- A hearing screening test to be performed on all newborn infants in the birthing facility prior to discharge
- All health insurers to cover newborn hearing screening with the Commonwealth as payer of last resort

- Hospital newborn hearing screening protocols approved by the Department of Public Health
- Training and supervision of hospital newborn hearing screening personnel by a licensed audiologist
- Referral for audiological follow-up at centers approved by the Department of Public Health, with the Commonwealth as payer of last resort for testing
- An Advisory Committee for statewide newborn hearing screening

Six major components have contributed to the success of the Massachusetts program: engaging stakeholders, screening, diagnosis, intervention, data management, and outreach and follow-up.

Engaging All Stakeholders

The Massachusetts Department of Public Health (DPH) recognizes the importance of engaging key stakeholders in the development of new programs. The Massachusetts Universal Newborn Hearing Screening Program was developed in collaboration with a dedicated community of parents, consumers who are deaf and hard of hearing, legislators, audiologists, physicians, hospital staff, early intervention and specialty-service providers, public health officials, geneticists, and others. The strength of the program is due to their hard work and commitment to the principle of early identification of hearing loss in the newborn population. The Advisory Committee has



Henry Wentworth (at 17 months), whose hearing loss was identified and who receives services through the Massachusetts EHDI program, enjoys the flowers in Chicago's Millennium Park. "Flower" was one of Henry's first signed words.



At 21 months, Henry knows and uses the sign and spoken word for "baby," and enjoys taking care of his doll and menagerie of stuffed animals.

overseen the development of regulations, guidelines, policies, data collection, and quality assurance efforts, which include ongoing data analysis to understand disparities in receiving follow-up care and access to intervention services, surveys to understand families' level of anxiety and satisfaction, and participation in multi-state evaluation of loss to follow-up in state EHDI Programs.

Representatives from each of the 29 DPH-approved audiological diagnostic centers meet three times per year. "Both the Advisory Board meetings and the diagnostic test centers meetings have had an extremely beneficial effect on interaction among service providers in Massachusetts," said Marilyn Neault, director of habilitative audiology at Children's Hospital Boston. "The stakeholders who care about children with hearing loss have come to respect and inspire one another across the state, to the benefit of the children and families served."

Screening

Identifying key contacts in each facility (e.g., newborn hearing screening program directors, audiologists, and data staff) and maintaining contact with them are crucial. It is important to establish guidelines/regulations to ensure screening protocols are carried out consistently throughout the state. Clear communication policies also are key, with families receiving screening results orally and in writing in the family's preferred language.

It is essential that infants who fail the screen receive follow-up. When infants fail the screen, the medical home should be notified and an appointment made for audiological testing prior to discharge. In Massachusetts, follow-up testing is performed exclusively at DPH-approved audiological diagnostic centers.

There are approximately 79,000 births in Massachusetts each year and the newborn hearing

screening rate from 2003 to 2006 has been approximately 99% (Centers for Disease Control and Prevention [CDC], 2003, 2004, 2005, 2006). In less than five years (data collected July 2001–December 2006), more than 1,000 infants were diagnosed with permanent hearing loss. The median age of diagnosis in 2006 was 1.25 months of age for newborns who failed their hearing screening(s); 92.8% of newborns who failed their hearing screening(s) received follow-up audiological testing in 2006 (7.2% were lost to follow-up). The CDC estimates that nationally, more than 46% of infants who failed hearing screening in 2006 were lost to follow-up or their results could not be documented (CDC, 2008).

Diagnosis

States should identify appropriate audiological follow-up services. Massachusetts audiological diagnostic center guidelines require facilities

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to submit protocols for DPH approval. The written guidelines include protocols for staffing and support services, including pediatric ratios; information on follow-up and documentation; capabilities for testing procedures; calibration of equipment; pediatric sedation; adherence with the Americans with Disabilities Act; policies for interpreters; management plan for confirmed hearing loss; fees and services; agreement to provide data; and quality assurance/quality improvement indicators. The centers must demonstrate the capacity to make appropriate referrals to specialty care and EI, in collaboration with the child's medical home. If amplification is recommended, plans should be in place to fit the device within one month of diagnosis. The guidelines also require the directors of the centers to meet three times per year for trainings developed by the EHDI program.

Intervention

According to the Joint Committee on Infant Hearing (JCIH), the goal of EHDI is to maximize linguistic competence and literacy development for children who are deaf or hard of hearing. Infants with hearing loss should receive appropriate intervention at no later than 6 months of age. Professionals with expertise in hearing loss should provide the intervention services.

In Massachusetts, all children with hearing loss are eligible for early intervention. Of the 226 infants identified with hearing loss in Massachusetts in 2006, 152 (67.3%) were enrolled in EI (20 were deceased, declined services, or moved out of jurisdiction). Fifty-four infants (23.9%) were not documented as receiving early intervention services in Massachusetts and CDC statistics indicated 33.9% nationally were not documented as receiving services. According to analysis of data (Liu et al., 2008), families with infants with milder degrees of hearing loss or unilateral hearing loss were less likely to utilize EI services compared to families of children who have more severe loss of hearing.

Data Management

The JCIH recommends uniform state registries and national information databases that incorporate standardized methodology, reporting, and system evaluation. The success of state EHDI programs is measured by minimizing the number of infants who become lost to follow-up/lost to documentation (LTF/LTD).

Massachusetts has a statewide surveillance and tracking system created to assist staff in implementing and evaluating newborn hearing screening program activities. The system has three components: electronic birth certificate (EBC), audiological evaluation report,

EHDI in the United States: A Brief History

It is important to understand the history of a movement like early hearing detection and intervention because of the enormous amount of effort that preceded the passage of state newborn hearing screening laws.

As early as 1965, the Babbidge report to the U.S. secretary of health, education, and welfare recommended national implementation of "universally applied procedures for early identification and evaluation of hearing impairment." Some states had programs to identify hearing loss early in high-risk infants—but a more comprehensive approach was necessary because of the estimated 50% of infants with hearing loss who had no known risk indicator (U.S. Preventive Services Task Force, 2008).

Early Developments

During the years that followed, technology companies developed and tested screening equipment. To determine the feasibility of implementing newborn hearing screening nationally, the Maternal and Child Health Bureau of the U.S. Department of Health and Human Services supported a 1989 demonstration project at Utah State University that

helped 50 hospitals develop newborn hearing screening programs. Marion Downs, a renowned pioneer in pediatric audiology who was a driving force behind the newborn hearing screening agenda, demonstrated that identification and intervention must be accomplished well before 6 months of age for optimal development to occur intellectually, linguistically, and orally.

Goals of 1, 3, & 6 Months

In 1998, U.S. Surgeon General C. Everett Koop established a priority goal that all children with significant hearing loss be identified before age 1. His recognition of the developmental delays caused by late identification of hearing loss was further strengthened by the Healthy People 2010 Objective, 28-11: "Increase the proportion of newborns who are screened for hearing loss by age 1 month, have audiological evaluation by age 3 months, and are enrolled in appropriate intervention services by age 6 months."

Another driving force in the effort to identify infants with hearing loss early has been the Joint Committee on Infant Hearing (JCIH), which has been meeting for more than 30 years

and has published several position statements. In 1994, JCIH endorsed universal detection of hearing loss in newborns and infants and the 3- and 6-month goals. JCIH also recommended that screening occur prior to hospital discharge. The most recent position statement (JCIH, 2007) is used actively by state EHDI programs.

Universal Screening

The Maternal and Child Health Bureau awarded the first Universal Newborn Hearing Screening grants to states and territories in 2000. The awards were used to implement physiologic testing of newborn hearing prior to hospital discharge and are strongly tied to ensuring a medical home and family-to-family support services.

The Centers for Disease Control and Prevention (CDC) also developed a program to support states and territories through cooperative agreements. The goal is for every state and territory to have a complete EHDI tracking and surveillance system that ensures children with hearing loss achieve communication and social skills commensurate with their cognitive abilities.

and family intake record. The EBC provides screening results, and demographic and medical information for all infants screened for hearing loss in Massachusetts, and is linked to early intervention data to ensure families receive services. Routine reports are distributed to hospitals and audiological centers to complete missing data and monitor quality.

Outreach and Follow-up

Assuring a low false-positive screening rate is a critical component of performing effective outreach. The Massachusetts EHDI staff use data collected to ensure screening is performed and to call families to confirm that an appointment is made when newborns fail a hearing screen. Staff stay in touch with the family until a diagnosis is achieved and assist audiologists in tracking missed appointments. Massachusetts EHDI staff developed a parent information kit that is provided to each family by the audiologist at diagnosis. The parent outreach specialist calls each family soon after diagnosis to connect the family to other state resources and provides support and technical assistance. The parent outreach specialist stays in contact with the family until the family is enrolled in

early intervention and continues to be available for support as needed. Families are connected to ongoing support through the Massachusetts Commission for the Deaf and Hard of Hearing, early intervention programs, and Family TIES, a parent-to-parent match program.

Cultural Competency

Delivering culturally competent services will improve care and assist in meeting the EHDI goals. Programs and providers should value diversity, increase cultural awareness of staff, and employ a diverse, culturally and linguistically competent workforce. The Massachusetts EHDI Program uses EBC information to identify ethnicity and the preferred languages of parents, including American Sign Language (ASL), and tailors outreach efforts accordingly. Staff seek to be responsive to each family's needs.

Medical Home

A strong EHDI program will ensure that infants with hearing loss have a medical home. Communication with the medical home should occur at all stages of the EHDI process. According to the

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JCIH, the infant's pediatrician or other primary health care professional is responsible for monitoring the general health, development, and well-being of the infant. That professional must ensure that the audiological assessment is conducted on infants who do not pass a hearing screen and must initiate referrals for medical specialty evaluations. Infants with confirmed hearing loss should be evaluated by an otolaryngologist who has knowledge in pediatric hearing loss and have at least one examination to assess visual acuity by an ophthalmologist experienced in evaluating infants.

In addition, families should be offered a genetics consultation. Each state has a designated American Academy of Pediatrics champion who works with the state to ensure resources about hearing loss are available to providers.

Quality Assurance and Quality Improvement

Parental satisfaction is evaluated at all levels of the EHDI system in Massachusetts. In a recent study conducted in the state, parents of newborns who had been screened for hearing were asked if they were to have another baby, would they want to have the baby's hearing screened. Ninety-nine percent of families responded "yes" to this question. The study also indicated that parents were grateful for identification of hearing loss and early intervention services, and supported newborn hearing screening nationwide (MacNeil, Farrell, Liu, & Stone, 2007).

Additionally, Massachusetts uses data to understand disparities in care, including factors that correlate with a greater risk of some infants becoming lost to follow-up. Infants born to mothers who were nonwhite, covered by public insurance, smokers during pregnancy, or residing in western, northeastern, or southeastern Massachusetts were at higher risk of becoming lost to follow-up on audiological evaluation.

Of children with hearing loss, those with a unilateral, mild, or moderate degree of hearing loss, normal birth weight, or living in the southeastern or Boston

region were more likely to go without early intervention services (Liu et al., 2008).

Continued Surveillance

Massachusetts data clearly indicate that some infants who pass their newborn hearing screen are later identified with hearing loss. EHDI programs must remain vigilant to ensure that children with later-onset hearing loss are identified as early as possible and are connected to services. The JCIH risk criteria should be used and developmental milestones, hearing skills, and parental/caregiver concern should be monitored by the child's medical home.

Looking Back

"Having a strong centralized database and follow-up procedure is key to any good screening program, but the Massachusetts Department of Public Health's EHDI Program sets the gold standard," according to Neault.

"Given a legislative mandate with minimal funding, a small staff excels in grant procurement and implementation for data management and follow-up. They keep high professional standards while doggedly chasing every baby whose screening result has not been resolved, no matter what language the parent speaks or how many times the last name or address have changed.


"The audiologists in Massachusetts are well aware how fortunate we are to have such a strong DPH driving the success of our EHDI program," Neault said. "We see the results every day in our work, serving toddlers with early-identified hearing loss whose language development is on par with their hearing peers."

EHDI Success/Henry at 20 Months

The system of care in Massachusetts has contributed to the early identification of Henry's hearing loss. His father, Richard Wentworth, said, "Henry is currently seen twice a week by his early interventionists and also attends an EI playgroup twice a week. He wears bilateral hearing aids and is comfortable using

the growing number of signs that he has learned (upwards of 45 words at last count) to communicate needs and feelings, and to describe what he sees.

"Recently, Henry has begun using more verbal cues. His receptive language, both verbal and signed, is excellent. He loves reading time and enjoys meeting new people. In short, Henry is exactly where he needs to be, and we couldn't be prouder of him!"

The story of Henry and his family—and the stories of hundreds of other young children in the state—are the driving force behind the Massachusetts EHDI initiative. 



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Selected References

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