

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

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

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

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

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

One study that informed the workshop deliberations was an evaluation of the universal newborn hearing-screening and intervention program commissioned by the Maternal and Child Health Bureau, Health Resources and Services Administration, and conducted by Mathematica Policy Research. In the second article in this issue, Shulman et al<sup>18</sup> report on quantitative and qualitative findings from their survey of 55 state and territorial screening programs supplemented by 8 site visits. They identified 4 types of barriers to system performance: lack

of service-system capacity, especially lack of a sufficient number of audiologists trained to evaluate infants; lack of provider knowledge, including an inappropriate “wait-and-see” attitude among some primary care providers; family challenges in obtaining services, including difficulties with transportation and obtaining insurance authorizations and gaps in information flow, such as poor communication between hospitals and providers; and data systems that are inaccessible to clinicians. Their recommendations for system improvement include improving data systems to support follow-up to ensure that all infants have a medical home and improving family-to-family support services. Shulman et al also identify concerns about federal confidentiality laws as an important factor that limits the sharing of information on children across government agencies and private groups. In the next article, Houston et al<sup>19</sup> explore this theme further. They conclude that providers can find ways to work efficiently within the regulations by obtaining parental consent using coordinated consent forms that incorporate the elements required by the Health Insurance Portability and Accountability Act of 1996, the Family Educational Rights and Privacy Act, and Part C privacy regulations, by including an option on the child’s individual family service plan for parents to give permission for a copy to be shared with the child’s pediatrician and other health care providers, and by ensuring that families always have copies of diagnostic evaluation results, treatment plans, and individual family service plans that they can share with providers as they wish.

The next 2 articles tackle the important issue of finance. McManus et al<sup>20</sup> investigated Medicaid reimbursements of hearing services for children. They found that state Medicaid fees for

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

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

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

whose patients have limited access to specialized interventions.

The authors of the final article of this supplement issue report on experience with a large national learning collaborative focused on minimizing loss to follow-up after newborn hearing screening.<sup>23</sup> Using quality-improvement techniques, teams from 8 states worked with the National Initiative for Children's Healthcare Quality to improve their systems of care for children with hearing loss. Pediatricians worked alongside audiologists, hearing screeners, interventionists, otorhinolaryngologists, and families to suggest and try improvement strategies. The teams found that infants who did not pass their hearing screens frequently lacked correct documentation of the primary care provider who would be responsible for future follow-up. This system deficit resulted in a barrier to effective communication of screen results and case tracking. The collaborative identified simple, yet effective, change strategies that affected the care process (eg, verifying the primary care provider's identity and ob-

taining a second contact number for families before hospital discharge). Correct documentation of the primary care provider before discharge from the birthing hospital could have a large impact on broader systems of care for young children. The collaborative also found that more work was needed on defining indicators of system performance. This collaborative experience revealed that it was possible to apply quality-improvement techniques to systems of care that involve hospitals, pediatric offices, and intervention services. Pediatricians who are embarking on quality-improvement initiatives that tackle the continuum of care between primary care and community-based services may find this report of interest.

As states continue to work toward improving their systems of care for children with permanent hearing loss, we hope that the information in this supplemental issue will prove useful in both recommending action steps and describing new tools and techniques to use when implementing them. The

multidisciplinary and collaborative nature of much of this work reflects the high degree of cooperation and communication between the responsible federal agencies, pediatricians, audiologists, and other providers together with a strong partnership with parents and family advocates. This ongoing partnership between parents and professionals will continue to drive system improvements for the deaf and hard-of-hearing and may serve as a model for broader improvements to developmental services.

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