Tune In to Newborn Hearing Screening

March 2005

All children should have the opportunity to communicate with their family. Every day, 33 infants are born with significant hearing loss. Until recently, almost half of them would have been missed until later in childhood.¹ A hearing loss that is undetected for even the first six months of a child's life can critically compromise their speech, language, cognitive and social skills compared to children identified earlier.²

In the last decade, states have successfully tackled this issue through newborn hearing screening programs. The percentage of babies screened for hearing loss at birth has risen to an all time high of almost 90 percent — a 65 percent increase in the past five years.3 Currently 38 states have laws that require newborn hearing screening. However, the success of screening programs depends on followup services and connecting families to early intervention programs, not just testing. To provide exemplary care for these infants requires that screening programs be connected to pediatric audiology services, appropriate early intervention programs, family support (including appropriate educational materials), and tracking and data management activities.4

The State Role

Maternal and child health programs (MCH) in the states and territories coordinate screening and follow-up services. MCH programs, supported in part by the Title V Maternal and Child Health Services Block Grant, are devoted to improving the health of all women and children, particularly the under- and uninsured. These programs collect annual data to evaluate and monitor newborn hearing screening programs across the states.

The Federal Role

Significant federal support provides the foundation for state newborn hearing screening. In 1993 the National Institutes of Health Consensus Development Conference recommended that all babies be screened for hearing loss before hospital discharge. In 1999 Congress established federal grants to address this "silent" epidemic. Congress also passed the

Children's Health Act of 2000 (P.L. 106-310) that included support for early hearing screening and evaluation of all newborns, coordinated intervention and rehabilitation services, and provided for ongoing research.

In 2000 the Joint Committee on Infant Hearing endorsed the goal of universal detection of infant hearing loss before one month of age and the provision of intervention services by six months of age. Later in 2000 the federal Maternal and Child Health Bureau awarded the first grants to 22 states to assist with early hearing detection and intervention programs (EHDI). Six months later, the Centers for Disease Control and Prevention awarded 15 state grants to assist with developing EHDI tracking and data management systems.

The EHDI programs have allowed states to rapidly expand their ability to screen newborns for hearing problems. However, as increasing numbers of newborns across the country are being screened, MCH programs are acutely aware that effective EHDI programs require more than an initial hearing test. Follow-up has been hindered by the lack of adequate tracking information, changes in the names or addresses of families, absence of a designated medical home for the infant, a lack of audiologists equipped and trained to work with young infants, and health insurance that refuses to cover follow-up services.5 Currently, only half of infants with a diagnosed hearing loss are enrolled in early intervention programs at their six-month birthday. There is more work that needs to be done.

Recommendations

To achieve the national *Healthy People 2010* goal of hearing screening of 100 percent of newborns by one month of age, the Association of Maternal and Child Health Programs (AMCHP) recommends that Congress consider the following changes as it moves forward with the reauthorization of the newborn hearing screening programs.

1. Maintain funding for newborn hearing screening activities within the Health Resources and Services Administration. 6 Currently, HRSA receives an

annual appropriation through the Labor, Health and Human Services, and Education appropriations bill to fund universal hearing screening in the states. This funding has contributed significantly to the gains in the number of newborns screened for hearing loss. As states reach the end of their first round of EHDI grants, most have successfully established universal screening programs but need more assistance to further develop follow-up systems. Without funding specifically for EDHI programs, progress will be lost. Now is not the time to stop the progress or the funding.

- 2. Strengthen newborn hearing screening by investing in follow-up. Although nearly 90 percent of newborns in the U.S. are screened for hearing loss, making sure that babies receive appropriate and timely diagnostic and intervention services remains a significant challenge. States need the flexibility to shift funds from testing to follow-up services based on their success with their EHDI program. States should have the option to use CDC and MCHB EHDI funds to:
- Expand existing systems, where appropriate, for the timely reporting of newborn hearing screening results.
- Remove barriers and initiate effective strategies to provide families timely follow-up services.
- Coordinate ongoing follow-up treatment with individuals, families, primary care physicians and specialists.

3. Promote federal policies that improve coordination of services for children with hearing loss. Policies should support stronger coordination of services for children with hearing loss. Families raising children with hearing loss have to navigate complex medical, social and educational systems that may be new to them. MCH programs promote coordination through a medical home, which uses health professionals to help families through these systems. Social and educational services, such as the Individuals with Disabilities Education Act, offer help for children with hearing loss, but, without guidance, some families may not find their way to them. Legislation that strengthens linkages among federal-state programs (e.g., EHDI, Medicaid, Part C of IDEA) will help meet the needs of

families and ensure that no child is left behind

because of a hearing loss.

The Association of Maternal and Child Health Programs represents state public health leaders and others working to improve the health and well-being of women, children, youth and families, including those with special health care needs. For more information contact Meg Booth at mbooth@amchp.org or (202) 775-0436.

Endnotes

¹ White, K.R. (October 1997). <u>The scientific basis for newborn hearing screening: Issues and evidence</u>. www.infanthearing.org/summary/index.html

² Yoshinaga-Itano, C., Sedey, A., Apuzzo, M., Carey, A., Day, D., & Coulter, D. (July 1996). <u>The effects of early identification on the development of deaf and hard-of-hearing infants and toddlers</u>.

³ American Academy of Pediatrics Press Release "Annual Report Card on Infant Hearing Screenings Shows Positive Progress Towards the Detection of America's Number One Birth Defect" May 2004.

⁴ Newborn Hearing Screening State Report Card, World Council on Hearing Health. May 2004.

⁵ Joint Committee on Infant Hearing 2000 Position Statement. www.jcih.org/posstatemts.htm

⁶ President proposed in FY 2003, 2004, and 2005 to eliminate funding for the HRSA Universal Hearing Screening program and move program authority to the MCH Block Grant.