EHDI in Idaho (Early Hearing Detection & Intervention)

Idaho Sound Beginnings

Every young child deserves the ability to communicate. Language is acquired with greater ease during certain sensitive periods of infant and toddler development. Cognitive, social, and emotional development is influenced by the acquisition of language.

According to Clinical Preventive Service Recommendations: congenital hearing loss affects approximately 3 per 1,000 children; **even mild or unilateral hearing loss can affect a child's potential to develop speech, language, social skills and school performance, including grade retention;** and hearing loss may be present at birth or may occur later. The numbers increase to 6 per 1,000 children with late onset hearing loss. In addition, when compared to other preventive interventions and to commonly accepted cost-effectiveness benchmarks, newborn hearing screening is cost-effective.

The three EHDI benchmarks are: 1. completion of hearing screening (including any necessary rescreening) by one month of age; 2. completion of audiology testing by three months of age; and 3. appropriate intervention by six months of age, including enrollment in early intervention programs.

All Idaho birth hospitals screen for hearing loss. Statewide, over 98% of infants born in hospitals receive at least an initial screening. In collaboration with Idaho hospitals, audiologists, physicians, and other providers, the Idaho Sound Beginnings (ISB) program is committed to refining the statewide system to identify those infants most at risk of having a hearing loss and connecting them to effective resources and support. ISB wants to ensure that all children with any level of hearing loss (including mild and unilateral) are referred within two days of diagnosis to the Idaho Infant Toddler Program (Part C of the Individuals with Disabilities Education Act (IDEA)).

How are we doing? Over the past 8 years, we have early identified approximately 34 babies with hearing loss each year. Based on the national statistics of 3 out of every 1,000 babies having a congenital hearing loss we could be missing about half of the Idaho babies born with hearing loss.

Where are they? Who are they? And, most importantly, where are the gaps in the safety net for these babies? These are questions EHDI programs have been struggling with nationwide.

Some of these gaps have been identified and addressed in Idaho:

A system for providing hearing screenings for home birth babies has been established with the cooperation of the Idaho Infant Toddler Program, and information has been provided to midwives for distribution. (Call 2-1-1, the Idaho CareLine)

This information has also been included in new educational brochures, and Obstetricians and birth and parenting instructors have received these brochures to include in their prenatal parent packets. It has been proven that parents who have prior knowledge of the screening are more likely to follow through with testing when indicated.

A system is being piloted whereby parents of referred babies may receive personal contact from a parent consultant, who is also the mother of a baby with early diagnosed hearing loss. The parent consultant will be able to reassure the parents, describe the testing process, explain why further testing is needed to determine whether a hearing loss exists, explain why hearing is so important at this early age for brain development and language learning, provide information on financial services that they may be able to access for the testing, and answer any other questions that the parents may have...up to and including, "How can I get my child to the audiologist without a car?"

Primary care physicians may soon be receiving more timely reminders about those babies at highest risk for hearing loss. (the updated listing of risk factors can be found at www.jcih.org. and these risk factors will soon be reflected on the new ISB referral form.)

An article in the October 2008 issue of "The Idaho Pediatrician" addressed the benefits of early intervention as well as the benefits of continuous regular surveillance in the medical home. Nationally, the Joint Committee on Infant Hearing (JCIH) 2007 Position Statement recommends: regular surveillance of developmental milestones, auditory skills, parental concerns, and middle ear status using objective standardized screening of global development with a validated assessment tool at 9, 18, and 24 to 30 months of age or at any time if the health care professional or family has a concern. Infants who do not pass the speech-language portion of the screening should be referred for speech-language evaluation and audiology assessment. A list of pediatric audiologists is available from Idaho Sound Beginnings.

This recommendation for continuous 'surveillance' in the medical home is in addition to the previous recommendations for the primary care provider to be aware of the newborn hearing results for every baby and to encourage parents to receive follow-up screening and confirmatory testing as indicated. Parents tend to take the referral more seriously when the primary care provider underscores the importance of the diagnostic hearing test.

Not every baby who refers from their hearing screening will be diagnosed with a hearing loss, but every baby who refers is at an increased risk for hearing loss. Due to the absence of easily observable 'symptoms' at this young age (most babies with hearing loss can hear and respond to louder voices and environmental sounds) many parents report that they are not concerned about their baby's hearing. Another frequently heard comment is that their baby just had fluid and this has been taken care of. They are unaware of the invisible nature of hearing loss and the potential for lost learning opportunities during this critical period of brain development.

Approximately 600 babies are lost to follow-up each year in Idaho - babies who are at highest risk for hearing loss after not passing their screening. These potentially unidentified babies, along with those who are at highest risk for late-onset or progressive hearing loss deserve to be found.

This quote by the dad of a three year old boy who is hard of hearing says it all:
"I wish we had found out sooner. I can not waste any more time – he is so behind already."

Cynthia Carlin B.S., EHDI Program Coordinator; and Andrea Amestoy R.N. EHDI Educational and Parent Consultant welcome your comments, suggestions, and insights. They can be contacted at carlinc@dhw.idaho.gov, amestoya@dhw.idaho.gov, or 208-334-0829.

Joint Committee on Infant Hearing. (2007). *Year 2007 position statement: Principles and guidelines for early hearing detection and intervention. Pediatrics, 120, 898-921.* www.jcih.org
*See Appendix 1. Risk Indicators Associated with [ ] Hearing Loss in Childhood

Newborn Hearing Screening: The Role of the Primary Care Provider, Albert L. Mehl, M.D. FAAP, Chairman, Colorado Infant Hearing Advisory Committee, *Newborn Screening News,* Colorado Department of Public Health.

A Purchaser's Guide to Clinical Preventive Services: Moving Science into Coverage. Washington, DC: National Business Group on Health; 2006.)

National Workshop on Mild and Unilateral Hearing Loss, workshop proceedings, July 26-27, 2005, www.cdc.gov/ncbddd/ehdi