



MARCH 2015

EHDI E-MAIL EXPRESS

The monthly newsletter of AAP Early Hearing Detection & Intervention Program

This is an e-mail communication from the American Academy of Pediatrics (AAP) "Improving the Effectiveness of Newborn Hearing Screening, Diagnosis and Intervention through the Medical Home" project funded through cooperative agreements with the Maternal and Child Health Bureau (MCHB), Health Resources and Services Administration (HRSA) and the Centers for Disease Control and Prevention (CDC), National Center of Birth Defects and Developmental Disabilities (NCBDDD). It is designed to provide AAP Early Hearing Detection and Intervention (EHDI) Chapter Champions with resources and current clinical and other information. The EHDI E-Mail Express is sent on a monthly basis. Please feel free to share the EHDI E-Mail Express with colleagues working on or interested in childhood hearing detection and intervention issues. Distribution information appears on the last page.

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NATIONAL TECHNICAL RESOURCE CENTER FOR NEWBORN HEARING SCREENING AND INTERVENTION—BY KARL WHITE, PHD

The federal Maternal and Child Health Bureau has announced that the National Center for Hearing Assessment and Management (NCHAM) at Utah State University has been selected after a competitive review to serve as the **National Technical Resource Center for Newborn Hearing Screening and Intervention** from April 1, 2015 to March 31, 2020. An abstract for the approved project is given below. More information about NCHAM activities is available at www.infanthearing.org. Copies of presentations and posters at the recent 2015 National EHDI Meeting in Louisville, Kentucky can also be found at NCHAM's website.

Problem: The importance of Early Hearing Detection and Intervention (EHDI) is widely recognized, and more than 95% of newborns in the U.S. are now screened for hearing loss. However, many babies who do not pass the screen are lost to follow-up, and there are significant problems linking EHDI systems to diagnostic, early intervention, medical home, and family support activities.

Purpose: This National Technical Resource Center (NTRC) will assist state agencies and other federal and non-federal partners in the development, improvement, and operation of sustainable statewide newborn hearing screening and intervention (often referred to as EHDI systems).

Goals: Statewide EHDI systems will ensure that all infants (1) are screened for hearing loss, and those who do not pass the screening (2) receive diagnostic evaluations before 3 months of age and (3) are enrolled in early intervention programs where necessary before 6 months of age. Additional goals include (4) appropriate family support, (5) linkages with a medical home, (6) creating sustainable systems for screening young children for hearing loss throughout early childhood, (7) statewide EHDI data and tracking systems that are linked with other relevant public health data, and (8) disseminating information about EHDI to relevant constituencies.

Methodology: Gaps in the system noted by State EHDI Coordinators, families, collaborators, and other EHDI experts will be addressed through technical assistance activities, including resource development, education and training, forums for communication and coordination, policy initiatives, telehealth technologies, quality improvement activities and data collection.

Coordination: Activities will be coordinated and often jointly implemented in partnership with professionals and family members, in cooperation with individuals and organizations that serve children with hearing loss, State EHDI systems, and appropriate federal agencies.

Evaluation: Needs assessments, data collection, and product/process evaluations will be integrated into all activities. National Advisory Committees will regularly review the workscope and make suggestions for improvement.

AAP EHDI Chapter Champions who have questions or suggestions about how to improve EHDI systems and services can contact karl.white@usu.edu.

WELCOME NEW AAP EHDI CHAPTER CHAMPIONS

The American Academy of Pediatrics' Early Hearing Detection and Intervention (EHDI) program is pleased to introduce the following new chapter champions who have joined over the past few months: Autumn Kiefer (WV), Leslie Lestz (TX), Parul Bhatia (CA 2), and Sheevaun Khaki (OR). We welcome the new champions and look forward to supporting them in their EHDI work going forward!

UPCOMING EVENTS

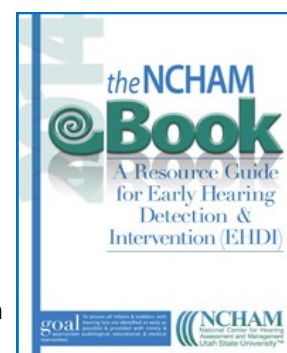
Event	Date	Location	Details
ECHO Webinar: Planning Evidenced-Based Hearing Screening	April 8, 2015	Webinar	Website
NCHAM Webinar: EHDI System Self-Assessment using JCIH Early Intervention Recommendations: A Foundation for Continuous	April 23, 2015	Webinar	Website
2015 American Society for Deaf Children Conference	June 25-28, 2015	Indianapolis, IN	Website

EARLY HEARING DETECTION & INTERVENTION E-BOOK FROM NCHAM

The [EHDI e-book, *A Resource Guide for Early Hearing Detection and Intervention*](#), from the National Center on Hearing Assessment and Management (NCHAM), is a 'go to' source for chapter champions and others involved in EHDI.

This month we continue to offer information from the NCHAM e-book, a comprehensive online resource. In Chapter Nine, authors Susan Wiley, MD, FAAP, Rachel St John, MD, FAAP, and Candace Lindow-Davies review the considerations for caring for children who are deaf or hard of hearing (Deaf/HH) and also have medical or developmental difficulties. These children have been described as Deaf/HH Plus, and the additional difficulties that may present can delay the age of identification, age of implementation of intervention services, and require a more diverse team to support the child. The authors point out that many risk factors for hearing loss can overlap with risk factors for developmental delays, such as certain genetic syndromes, prematurity, congenital infections, and meningitis.

A table is also provided which outlines the increased rates of conditions among children who are Deaf/HH in comparison to rates among the general population. Due to the increased medical complexities, it is important for medical home providers to be proactive with monitoring and ongoing surveillance. The authors point out that the Joint Committee on Infant Hearing created a goal in the 2013 Supplement to the 2007 Position Statement, stating *that all children who are Deaf/HH with additional disabilities and their families have access to specialists who have the professional qualification and specialized knowledge and skills to support and promote optimal developmental outcomes*. They describe the various skills needed by primary care providers and medical specialists to care for children who are Deaf/HH Plus. The chapter closes with a series of recommendations for medical providers to effectively communicate with families and provide meaningful support for children who are Deaf/HH Plus and their families.



PHYSICIAN SURVEY: ADDRESSING EHDI MISCONCEPTIONS

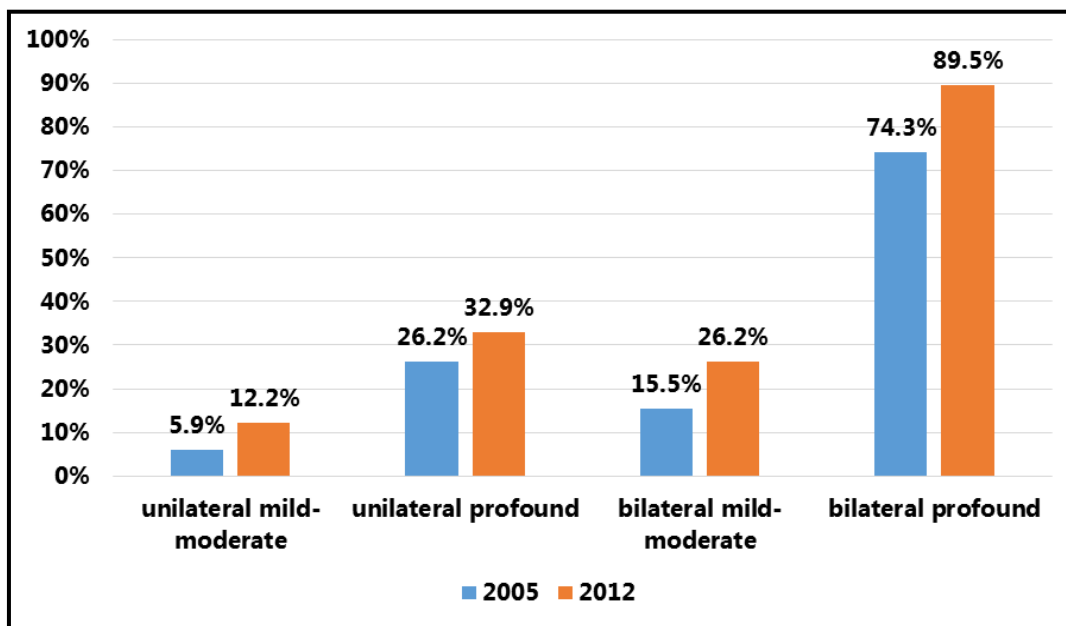
The National Center for Hearing Assessment and Management—along with support from state EHDI coordinators and the American Academy of Pediatrics—conducted a self-report survey with pediatricians and other clinicians who provide care for infants and young children. The purpose of this survey, conducted in 2012, was to:

- Understand the degree to which medical homes are engaged in EHDI activities
- Update our understanding of physician attitudes and knowledge regarding EHDI since the 2005 survey conducted on this topic
- Drive strategies to support physicians in their role within EHDI systems

In the EHDI E-Mail Express, we are reviewing some of the questions presented in the survey and the results related to pediatrician responses. We hope to identify and examine what gaps in understanding and practice, if any, still persist.

Question: Children with which of the following hearing losses may be candidates for cochlear implants?

Results: Percentage of Physicians Reporting by Year



As shown in the table, nearly 90% of physicians who responded to this survey were able to correctly identify that children who have a bilateral profound hearing loss are candidates for cochlear implants. However, there are still a small number of physicians who may incorrectly feel as though children who are diagnosed with a unilateral or bilateral mild-moderate hearing loss may be candidates for cochlear implantation. Although there are some circumstances where a child who presents with a unilateral profound hearing loss might be a candidate for cochlear implants, typically children with unilateral or bilateral mild and moderate hearing loss are not considered candidates for cochlear implant intervention.

Chapter Champions should be aware of these results and can tailor education efforts to ensure that physicians are aware of the various interventions available for deaf or hard of hearing infants and children as well as be able to effectively communicate the wide range of intervention options to these families.

NEW—BOYS TOWN NATIONAL RESEARCH HOSPITAL— ONLINE MODULES FOR HEALTH PROFESSIONALS

Boys Town National Research Hospital has developed two new online training modules for medical professionals that will be made available in the spring and summer 2015. The modules focus on family-centered service delivery for children who are Deaf/HH.

The first, [Family-Centered Assessment & Planning Practices for Children Who Are Deaf or Hard of Hearing](#), is a six-hour module that through which a practice model which is founded on early intervention and relationship-based practices is presented. The second, [Family-Centered Practices for Serving for Children Who are Deaf or Hard of Hearing](#), is a four-hour module designed to help medical practitioners enhance collaboration with families to improve support for children who are Deaf/HH.

For more information or to register for these online modules, visit the [Boys Town National Research Hospital Web site](#).

THE VALIDITY OF FAMILY HISTORY AS A RISK FACTOR IN PEDIATRIC HEARING LOSS

Although family history has been considered a risk factor for permanent congenital, delayed onset, or progressive hearing loss by the Joint Committee on Infant Hearing (JCIH) since 1973, studies have rarely isolated family history from other potential confounding risk factors. [This retrospective cohort study](#) identified, rescreened, and tracked 4,138 children who had family history as the sole risk of hearing loss out of 380,000 children who received newborn hearing screening between 2004 and 2011. The authors aimed to determine the prevalence of family history as the sole risk factor for hearing loss among infants and children who were identified with congenital or late-onset or delayed hearing loss. Additionally, they sought to identify if there were any causal linkages, in regards to specific familial relationships from which the family history of hearing loss was derived.

The study found that while the prevalence of family history in the entire screening cohort was found to be 1.1%, prevalence of family history among children identified with congenital hearing loss was 7.3%. Interestingly, the authors found that the prevalence of family history as the sole risk factor among children who were identified with late-onset or delayed hearing loss was 36.8%, which shows a stronger correlation between family history and late onset hearing loss. The authors conclude that infants who have a family history of hearing loss should be identified and receive targeted surveillance throughout early childhood in order to diagnose potential late-onset or delayed hearing loss should it occur and to link those children with the available interventions as quickly as possible.

Source: Driscoll C, Beswick R, Doherty E, et al. The validity of family history as a risk factor in pediatric hearing loss. *International Journal of Pediatric Otorhinolaryngology*. 2015; (website: <http://dx.doi.org/10.1016/j.ijporl.2015.02.007>)

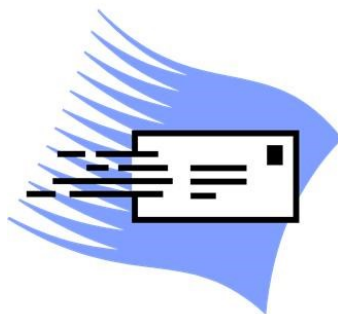
AMERICAN PARENT PERSPECTIVES ON QUALITY OF LIFE IN PEDIATRIC COCHLEAR IMPLANT RECIPIENTS

Children with severe to profound bilateral hearing loss may be candidates for auditory assistive devices such as cochlear implants (CI), should the family decide that is the best option for their child. This intervention can help children develop oral communication skills and influence psychosocial outcomes for children. The authors seek to examine parent perceptions of CI-specific health-related quality of life (HRQoL) in children with CIs. The authors used eight HRQoL domains for the analysis: communication; general functioning, well-being, self-reliance, social relations, education, effects of implantation, and supporting the child.

The study found that while the mean score for each of the eight domains was above average (indicating above average quality of life), parents rated communication, general functioning, and social relations most positively. Parents rated education significantly lower than the other domains, suggesting that they may feel their children are not progressing as expected in academics, even after the CI intervention. The authors note that this perception has been corroborated in other studies, but can be due to a variety of factors such as inconsistent access to educational resources for individuals with CI, and high expectations on the part of the parents, among other factors.

The authors also found no statistically significant difference between parent perceptions and age of the child, age of CI activation, or duration of CI experience. In general, parents report positively on HRQoL for their child with CI. Professionals working with pediatric CI candidates or recipients should continue to work with parents to further understanding of the psychosocial issues beyond communication to enhance outcomes for their child.

Source: Kumar R, Warner-Czyz A, Silver CH, et al. American parent perspectives on quality of life in pediatric cochlear implant recipients. *Ear & Hearing*. 2014; (website: <http://journals.lww.com/ear-hearing/Abstract/2015/03000/>)



Distribution Information:

The AAP EHDI Program implementation staff send this e-mail update to the Academy's EHDI Chapter Champions, other interested AAP members, staff and state EHDI coordinators. For additional information on hearing screening and to access previous editions of the EHDI E-mail Express, click on the following link <http://www.aap.org/en-us/advocacy-and-policy/aap-health-initiatives/PEHDIC/Pages/Early-Hearing-Detection-and-Intervention.aspx>. Previous e-mail updates are available upon request from Stephen Crabbe, scrabbe@aap.org or (847) 434-4738. If you would like to unsubscribe to the update, please notify staff by responding to this e-mail.