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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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A REFLECTION FROM SUSAN WILEY, MD, FAAP

As a developmental pediatrician, state Early Hearing Detection and Intervention (EHDI) chapter champion, and AAP EHDI Leadership Team member, I have long been on board with the importance of the EHDI work and the mantra of "1-3-6". I have no doubts that the *EHDI E-Mail Express* is "singing to the choir" as those who read this have similar passions. Today, I would like to turn the spotlight on the "6" of 1-3-6.

While the EHDI system's loss to follow-up (LTF) is a critical aspect of the work for many states, early intervention (EI) services for children who are deaf/hard of hearing (D/HH) are also of the utmost importance. When I am in meetings that include parents of children who are receiving intervention services, there is a common theme—encouraging professionals to improve their experiences with intervention services ("Please meet the needs of those you have already identified!").

The Joint Committee on Infant Hearing (JCIH) has recognized the importance of this with their 2013 [Supplement to the JCIH 2007 Position Statement: Early Intervention After Confirmation That a Child Is Deaf or Hard of Hearing](#). This statement identifies 12 goals for providing effective intervention services. The following are included among the goals outlined in the statement:

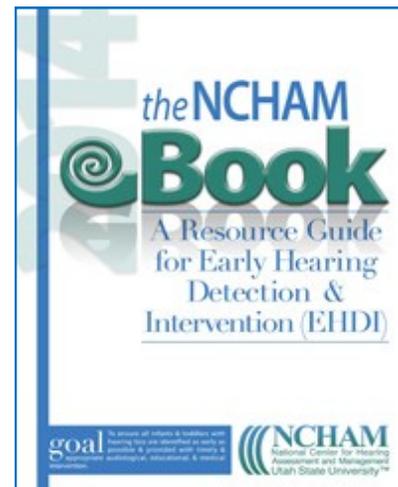
- 1) **process-related** goals [such as access to timely and coordinated entry into EI, appropriate tracking of services and monitoring of progress; goals 1, 6];
- 2) guidance around **types and breadth of services for children** who are D/HH [such as uniform coverage irrespective of degree of hearing loss, knowledge of service coordinators, intervention specialists, consistent information and implementation of best practices as the field evolves; goals 2, 3, 7, 12];
- 3) **culturally competent services** [both for non-English and culturally diverse families as well as related to culturally and linguistically appropriate language support competence, including access to support, mentorship, and guidance from individuals who are D/HH; goals 5, 9];
- 4) access to the breadth of services and interdisciplinary models for children who are D/HH Plus [goal 4]; and
- 5) active participation of families and individuals who are D/HH within the implementation of EHDI systems at local and state/territory levels [goals 8, 10].

This document can serve as a guide for all of us—states, early intervention programs, and early intervention providers, medical providers—to evaluate our programs, interventions, and our interactions. Through these 12 goals, we can identify strengths and gaps in services. While we want to identify every child who is D/HH, once we do, we should strive to have intervention services be able to meet the unique needs of every child and family whose journey we share. By doing so, we can make a world of difference.

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 Eight, author Gail Padish Clarin, AuD, reviews Auditory Neuropathy Spectrum Disorder (ANSD), its various etiologies, presentations, and management. While approximately 40% of ANSD cases have genetic basis, the majority of cases have been found to be due to genetic factors that are syndromic, non-syndromic, or mitochondrial in nature. The author describes the various genetic syndromes that have been associated with ANSD, including the following: Charcot-Marie Tooth Disease, Leber's Hereditary Optic Neuropathy, Fredreichs Ataxia, Mohr Tranabjaerg Syndrome, Refsum's Disease and Mitochondrial disease. In addition, the chapter outlines the various risk factors for ANSD and points out that Neonatal Intensive Care Unit (NICU) graduates have a higher risk of developing ANSD, which is why Automated Brainstem Response (ABR) screening is recommended by the Joint Committee on Infant Hearing (JCIH, 2007) for babies admitted to the NICU for five days or more. This is because ABR screening can detect hearing loss caused by absent or abnormal cochlear nerve function, even with normal cochlear function.



The chapter highlights the fact that over 50% of ANSD cases have co-morbidities that include developmental and physical delays that contribute to learning and speech/language outcomes. Due to the multi-faceted nature of ANSD cases, it is recommended that such cases be managed by multi-disciplinary teams that include pediatric audiologists, speech language pathologists, primary care physicians, pediatric subspecialist clinicians, and physical and occupational therapists, as necessary. In addition, it has been found that in some cases, amplification can help improve speech and language outcomes for children diagnosed with ANSD. The author also provides a step-by-step approach to the various diagnostic testing methods that should be implemented in order to properly diagnose an infant or child with ANSD and to identify the intervention services that best fit the needs of that child and their family.

UPCOMING EVENTS

Event	Date	Location	Details
CDC & NCHAM Webinar: Collecting Developmental Outcome Data on Children Who Are Deaf and Hard of Hearing	January 14, 2015	Webinar	Web site
NCHAM Move the Needle Webinar: Is Meeting the Needs of	February 11, 2015	Webinar	Web site
2015 National EHDI Meeting	March 8-10, 2015	Louisville, KY	Web site
American Academy of Audiology: AudiologyNOW! Conference	March 25-28, 2015	San Antonio, TX	Web site

PHYSICIAN SURVEY: ADDRESSING EHDI MISCONCEPTIONS

The National Center for Hearing Assessment and Management (NCHAM)—along with support from state EHDI coordinators and the American Academy of Pediatrics (AAP)—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 upcoming editions of the EHDI E-Mail Express, we will review some of the questions presented in the survey and the results that pediatricians provided. We hope to identify and examine what gaps in understanding and practice, if any, still persist.

Question: What is your best estimate of the earliest age at which:

- A. A child can be definitively diagnosed as having a permanent hearing loss
- B. A child can begin wearing hearing aids
- C. A child with permanent hearing loss should be referred to early intervention services

Results: Percentage of Physicians Reporting by Year

Year	<1 mos	1-3 mos	4-6 mos	7-9 mos	10-12 mos	>12 mos
A. 2005	51.9%	10.8%	12.4%	15.3%	0.3%	9.3%
A. 2012	20.9%	37.0%	24.8%	2.3%	10.2%	5.3%
B. 2005	38.3%	9.0%	11.2%	22.2%	1.2%	18.1%
B. 2012	12.2%	26.9%	31.9%	3.7%	16.6%	9.1%
C. 2005	61.6%	8.0%	9.9%	13.1%	0.4%	7.0%
C. 2012	26.9%	33.3%	25.3%	2.5%	8.1%	4.2%

The data reflect that many physicians still are not aware of the age at which children can be definitively diagnosed as having a permanent hearing loss. **Although this diagnosis can be made prior to one month of age, only 21% conveyed this knowledge in 2012, compared to 52% in 2005.** The ability to make a diagnosis within 3 months of age was recognized by 37% of physicians, but about 42% of physicians believed the child must be over 3 months of age in order for a diagnosis to be made; this contradicts the 1-3-6 message. The same misinformation pattern is evident regarding the age at which a child can begin wearing hearing aids. Although the correct answer is “as soon as a child is diagnosed and ideally within the first month or two of age”, only 39% of physicians responded by selecting the correct timeframe. This actually indicates that in 2012 fewer physicians were aware of the age at which a child can begin wearing hearing aids compared to 2005, when almost 48% of survey respondents selected the correct answer.

These data reflect that a good deal of education is required to ensure physicians understand the importance of early identification, management and treatment. As an AAP Chapter Champion, your leadership in ensuring your colleagues are knowledgeable about EHDI and their role in early detection and treatment is critical. Chapter Champions are encouraged to work with their state EHDI coordinator and AAP chapter to distribute these survey findings to pediatricians in your state in an effort to reinforce these fundamental messages.

For additional information on survey results, click on the summary [here](#).

THE VALUE OF ROLE MODELS—A REFLECTION

DIANE BEHL, MED, NATIONAL CENTER FOR HEARING ASSESSMENT AND MANAGEMENT

Many of us have had a role model in our lives growing up—a person whose behavior, example, or success was emulated by us as well as others. Families of newly-identified children who are deaf or hard of hearing (D/HH) may be at a loss in terms of having any role models to guide their vision of their child’s potential. A D/HH role model is typically an adult who is D/HH and supports families of newly-identified children by sharing their personal experience and knowledge, offering a unique perspective to support the family in their journey to foster their child’s development.

In 2013, NCHAM conducted a survey to learn about programs throughout the United States that provide opportunities for families of children who are D/HH to connect with adults who are D/HH. Surveys were sent to EHDI coordinators, Part C coordinators, schools for the Deaf, and national organizations (National Association of the Deaf, Alexander Graham Bell, and Hands & Voices, among others). Results and written survey responses were gathered electronically and follow-up interviews were conducted with the programs identified.

Of the programs identified through the NCHAM survey, nine were invited to participate in a Learning Community that NCHAM formed to learn more about expanding and improving existing opportunities for families of children who are D/HH to interact with adults who are D/HH. The Learning Community coined the term “D/HH Adult Role Model” versus “deaf mentor” to convey the breadth of the providers and the diversity in their roles. The Learning Community focused on sharing information and resources, as well as networking between the different programs. To learn more about efforts in your state, visit the link below and reach out to your EHDI coordinator, local schools for the deaf, or family support organizations. More details about the NCHAM Learning Community can be found on the NCHAM [website](#).

Hands & Voices is an example of one such organization that actively promotes D/HH role models; more information on their specific efforts can be found on their [website](#).

AG BELL REPORT: HEARING AID RETENTION FOR INFANTS AND YOUNG CHILDREN

The results of the Pediatric Hearing Aid Retention Project Survey were described by Jane R Madell, PhD and Karen Anderson, PhD in an article for *Volta Voices* (Sept/Oct 2014). The article highlights the multiple challenges surrounding keeping hearing aids on infants and young children. Among the difficulties in keeping hearing aids in children's ears include the proclivity for young children to remove them as part of exploration, removal due to emotional unease, as well as unwillingness to use hearing aids due to cultural sensitivities.

This survey was directed at parents and audiologists who were members of the American Academy of Audiology; 286 and 101 responses, respectively, were received from these target audiences. The survey examined the feelings of parents and audiologists towards a number of different hearing aid devices and retention accessories and asked them to rate the devices based on effectiveness, durability, ease of use, and safety.

Overall, the survey found that parents and audiologists preferred a wide range of devices, but most notable in the survey results was the differing view that families and audiologists have on the devices examined in this survey. In addition, between 20-55% of parents were not even aware of certain devices mentioned in the survey, which may show that parents are not aware of the full range of devices available for use by their children. The results of the study show that a gap may exist in what audiologist may feel is effective and recommend to parents, in contrast to what families are finding to be truly beneficial in improving hearing aid retention. The authors recommend that audiologists and families consult regularly to determine if children are having trouble with hearing aid retention and to make sure they understand all of the available hearing aid retention options available.

Source: Madell, JR, Anderson, K. Hearing Aid Retention for Infants and Young Children. Volta Voices. 2014, September/October.



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.