EHDI-PALS: A REFLECTION FROM ROBERT CICCO, MD, FAAP

The Pennsylvania Chapter of the American Academy of Pediatrics has partnered with the Pennsylvania Department of Health and the state EHDI program over the years to promote newborn hearing screening and assure quality in screening procedures, tracking and follow-up of babies born in Pennsylvania. It has become increasingly apparent that a successful EHDI program must address issues such as lost to follow up and assure that babies not passing the newborn screen receive appropriate referral for diagnostic testing and treatment.

There are a number of barriers in accomplishing this goal, especially in a large state like Pennsylvania (PA), where many deliveries occur far from the three major urban centers in the state. There is a need for PA EHDI to better define the group of audiologists across the state performing diagnostic evaluations and assure that families are referred to audiology centers that are appropriate for their diagnostic and treatment needs. Furthermore, it is vital that those audiologists provide timely and accurate reporting to the program so that appropriate public health tracking can occur. Finally, due to the proximity of bordering states, many babies born in PA are receiving audiology services in neighboring states (and vice versa). All these factors contribute to the need for PA EHDI program, families and the referring physicians an easy access to audiologists involved in the care of children with hearing loss.

We have found that Pediatric Audiology Links to Services (EHDI-PALS) can successfully meet this need and are currently promoting its use across Pennsylvania. EHDI-PALS will not only direct families and referring physicians to accessible and appropriate services, but will also give the program information about those audiology practices complying with public health reporting. This will assist the program in finding children lost to follow up due to untimely and inaccurate reporting.

The challenge ahead for Pennsylvania is to encourage more audiology practices to become part of the EHDI-PALS system and strategies are currently being developed to do so. EHDI stakeholders in the state expect that EHDI-PALS will become an integral part of the Pennsylvania EHDI program that provides transparency in audiology services and greater communication of essential EHDI information.

For more information on EHDI-PALS and audiological services in your state, visit the EHDI-PALS website.
WELCOME NEW AAP EHDI LEADERSHIP TEAM

The American Academy of Pediatrics (AAP) Early Hearing Detection and Intervention (EHDI) program is pleased to introduce the new AAP EHDI Leadership Team! This team will work with AAP staff to shape the future strategic direction of the AAP EHDI program and will be tactically involved with EHDI activities throughout the year. In addition, their combined experience in multiple aspects of EHDI will be utilized to help mentor and support the activities of the AAP EHDI Chapter Champions around the country. Please join me in welcoming the following members of the newly established AAP EHDI Leadership Team:

- Bob Cicco (PA)
- Jack Levine (NY)
- Carlos Duran (DE)
- Rachel St John (TX)
- Brad Golner (AZ)
- Susan Wiley (OH)

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 Five, author Diane L Sabo, PhD reviews the various assessment techniques and protocols for identifying hearing loss in newborns, infants, and young children. The author introduces and describes physiological assessment techniques such as Auditory Brainstem Response (ABR), Auditory Steady-State Response (ASSR), Otoacoustic Emissions (OAE), and Acoustic Immittance Measures. While the author describes the evidence for using each test, she devotes the largest portion of the article to discussion of ABR and the development of the technique in recent years. In particular, the article outlines the recommended ABR protocol to be followed by audiologists and also highlights the need to test using both air and bone conducted stimuli in order to accurately describe the hearing loss. In addition, the author discusses a potential shift from the typical click stimulus towards a chirp, and its effect on the ABR technique’s ability to measure a range of frequencies.

Although the chapter focuses on physiologic testing, it does highlight the value of behavioral testing techniques in identifying hearing loss for children over 5-6 months of age. While some behavioral techniques can yield stable results in terms of hearing thresholds, it notes that care must be taken by audiologists to eliminate false positives using control trials with no stimulus. The chapter makes the point that audiologic diagnosis is a process that often takes time and multiple visits. The role of the audiologist must include working with the families of children with hearing loss to promote understanding and counseling throughout the diagnostic process.
As a special edition to the Morbidity and Mortality Weekly Report (MMWR), the National Center on Birth Defects and Developmental Disabilities (NCBDDD) at the Centers for Disease Control and Prevention (CDC) published a supplement which outlines the progress towards the national 1-3-6 benchmarks for Early Hearing Detection and Intervention (EHDI) programs across states. These benchmarks, which are endorsed by multiple national organizations including the Joint Committee on Infant Hearing (JCIH), recommend that hearing screening occur no later than age 1 month, diagnostic audiologic testing no later than age 3 months, and enrollment in early intervention no later than age 6 months. The study uses data from the 2009-2010 CDC EHDI Hearing Screening and Follow-up Survey (HSFS) and compares it to similar data from 2005-2006, to analyze progress towards these goals.

The article points out that hearing screening rates for infants have increased from 94.7 to 97.6% between 2005 and 2010 and that the percent being screened before one month of age has increased from 81.4 to 93.4% during that time. Additionally, EHDI programs during this time have effectively raised the rate of diagnosis in children who fail the final hearing screening from 31.9% in 2005-2006 to 50.3% in 2009-2010. In 2009-2010, 65.2% of patients who received early intervention (EI) services did so before six months of age, which was an increase from 57.1% of infants accessing the same services before six months of age in 2005-2006.

Although many gains have been made towards the national benchmarks, the article notes that of infants failing hearing screening, 42.1% received no diagnosis and were considered loss to follow-up or loss to documentation (LTF/LTD). In the data from 2005-2006, 55.4% of infants who failed the final hearing screening received no diagnosis and were considered LTF/LTD. The data from 2009-2010 indicates that infants born in specific demographic groups such as mothers aged 15-19 years (43%), mothers with less than a high school education (45%), as well as mothers who are Native Hawaiians/Pacific Islanders (24%) and American Indians (15%) were less likely to return for follow-up services than other demographic groups.

The authors conclude that improved strategies in health information technology and coordination between existing clinical and public health providers will enhance the dissemination of necessary EHDI information (including national EHDI benchmarks and necessary referrals) to parents including and help reduce the number of infants with hearing loss that are LTF/LTD.

This study analyzes the results from a survey that was disseminated to parents with children under three years of age that were diagnosed with hearing loss. The authors investigate the effect that parents perceived challenges related to hearing aid management and their psychosocial well-being have on overall hearing aid use and effectiveness. While past studies have shown that mothers of children of with disabilities have an elevated risk of distress, few studies have sought to include the feelings and behaviors of fathers as this one does. This study sought to analyze the amount of information that parents receive regarding their child’s hearing loss, information about necessary skills and management of interventions, as well as the level of support families feel they receive from health care professionals.

The study found that the parents reported that audiologists were their main source of information regarding their child’s hearing loss diagnosis and interventions, however 43% of parents felt that they were not given information about other types of hearing devices other than hearing aids. Some important skill areas that parents felt were not frequently taught by audiologists were how to troubleshoot hearing aids and how to do a Ling 6 Sound Test. In addition, parents felt that some skills were never taught by any professional, including how to teach other caretakers how to perform a hearing aid listening check, how to teach others to put hearing aids on their child, and how to teach others to troubleshoot hearing aids). While mothers reported receiving the majority of their skills instruction from audiologists, fathers were more likely to report learning skills from another parent.

Both mothers and fathers agreed that their audiologist helped them understand what to expect in terms of how their child would benefit from hearing aid use. However, parents felt that audiologist did not spend enough time discussing the emotions they felt related to hearing loss as well as how to talk to others about their child’s hearing loss. While the study found that the majority of mothers and fathers did have the ability to manage their emotions in a healthy way, almost half reported that depression was causing their ability to manage hearing aid use to be somewhat or very difficult. In addition, the authors found that there was statistically significant correlation between hearing aid use and parent challenges with hearing aid management, perception of benefit with hearing aids, and the extent of hearing aid use challenges (eg, child behavior, activities).

The authors do acknowledge the small sample size and limited demographic selection for the study (91% Caucasian, 82% English primary language) may limit generalization, however it is possible that the extent of parent challenges may be greater in the general population. The study identifies a number of ways that parents still feel as though they could use additional support and suggest that audiologists, early interventionists, and other primary care providers target these needs when it comes to caring for families and children with hearing loss.

There are currently more than 37 million Spanish speakers living in the United States as of 2013 and projections show that the number could increase to more than 40 million by 2020 (US Census Bureau 2011). This is in large part due to a rising number of births in families who speak Spanish as their primary language. For this reason, it is imperative that pediatricians, audiologists, and other primary care providers are able to provide Early Hearing Detection and Intervention (EHDI) resources for families whose primary language is Spanish. A number of organizations have developed Spanish-language EHDI resources, and a few of these are listed below:

- **Hands & Voices (Manos y Voces):** Unbiased parent-to-parent support and Spanish-language resources for families and children who are Deaf or hard of hearing.

- **American Speech-Language-Hearing Association (La Asociación del Habla, Lenguaje y Audición):** The national professional, scientific, and credentialing association for audiologists, speech-language pathologists, hearing scientists, support personnel, and students. The organization provides Spanish-language information for the public and families with children who are Deaf or hard of hearing.

- **Alexander Graham Bell (Listening and Spoken Language Knowledge Center in Spanish):** Resources for advancing listening and spoken language for individuals who are Deaf or hard of hearing.

- **Gallaudet University (Resources for Hispanic Deaf and Hard of Hearing Population):** Resources providing contacts, publishers/distributors, and on-line links to assist Spanish speaking individuals who are Deaf or hard of hearing.

**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](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.