

EHDI E-MAIL EXPRESS

The monthly newsletter of Early Hearing Detection and 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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FROM YOUR CHAIR



The role of the medical home provider in Early Hearing Detection and Intervention (EHDI) is one that is critical to the development of a child that is identified with hearing loss. As a medical home provider, you become the advocate and a partner for the child and the family. And, this role of advocacy is key if any EHDI program is to be effective and successful.

It is important that as a provider you develop a relationship of trust with the family in which they feel their values and culture are being respected and heard. It is also important that you be knowledgeable about the resources in your community in order to link them up with the most appropriate services.

As a medical home provider, you are used to parents asking a myriad of questions as they adjust to new infants during the first year of life. When the infant is diagnosed with hearing loss, the parents ask all the routine questions, but will have many more as they navigate the various follow up systems. Be ready for them. As you support them in linking with diagnostic and early intervention services, they may wonder what this process is all about, how it is supposed to work, or why team members want to come to their home. There are a number of helpful parent resources, some of which are in this newsletter edition that can assist you as a medical home provider in addressing these questions.

When it comes to early intervention, you may also be asked by the family, "how do I know if the program is working for my baby? What should I expect?" The answer to these questions are highly individual and must be based on the goals of the family, the needs of the infant or child, and available resources. Some veteran parents of children with hearing loss have developed a "[wish list](#)" for their early intervention program located on the Hands and Voices Web site. The site also provides some insights on [quality components of an early intervention program](#).

Use these and other resources to be prepared to help parents and families of a child who is deaf or hearing of hearing. And know, that sometimes you won't have the best answer or the right answer, but you should be ready to direct them to where they can find it.

- Albert Mehl, MD

UPCOMING EVENTS

Event	Date	Location	Details
AG Bell LSL Workshop Series	January 12—13, 2012	Miami, FL	Web site
Moog Center for Deaf Education Early Intervention Workshop for Teachers and SLP's	February 16—18, 2012	St Louis, MO	Web site
2012 National EHDI Meeting	March 5—6, 2012	St Louis, MO	Web site

NEW STUDY FINDS ONE IN FIVE AMERICANS HAS HEARING LOSS

A new study led by Johns Hopkins researchers and published in the November 14 *Archives of Internal Medicine* finds that nearly a fifth of all Americans 12 years or older have hearing loss so severe that it may make communication difficult. These findings suggest that many more people than previously thought are affected by hearing loss and are considered to be the first nationally representative estimate of hearing loss.

Study leader Frank Lin, M.D., Ph.D., an assistant professor with dual appointments in both the Department of Otolaryngology-Head & Neck Surgery at the Johns Hopkins School of Medicine and in the Department of Epidemiology at the Johns Hopkins Bloomberg School of Public Health, and his colleagues used data from the National Health and Nutritional Examination Surveys (NHANES), a research program that has periodically gathered health data from thousands of Americans since 1971. The researchers analyzed data from all participants age 12 and over whose hearing was tested during NHANES examinations from 2001 to 2008.

Using the World Health Organization's (WHO) definition for hearing loss (not being able to hear sounds of 25 decibels or less in the speech frequencies), the researchers found that overall about 30 million Americans, or 12.7 percent of the population, had hearing loss in both ears. That number jumps to about 48 million, or 20.3 percent, for people who have hearing loss in at least one ear. These numbers far surpass previous estimates of 21 to 29 million.

"This gives us the real scope of the problem for the first time and shows us how big of a problem hearing loss really is," Lin says. Read more: <http://www.medicalnewstoday.com/releases/237630.php>.



BOOKS/RESOURCES FOR PARENTS OF A CHILD WHO IS DEAF OR HARD OF HEARING

As part of Gallaudet University, the Laurent Clerc Deaf Education Center is dedicated to improving the quality of education afforded to deaf and hard-of-hearing students from birth to age 21 throughout the United States of America. Information regarding helpful books and resources for parents of children who are deaf or hard of hearing can be found on the Laurent Clerc National Deaf Education web site at <http://clerccenter.gallaudet.edu/InfoToGo/563.html>.

Information on this web site page notes that all parents face challenges in raising children. Because the parent of a child who is deaf or hard of hearing may face additional parenting challenges and require specific information and assistance in order to make informed decisions about the needs of the child, the National Deaf Education staff compiled a listing of books and resources that present a variety of experiences and philosophical approaches, encouraging parents and family members to consider a range of options. The information is organized in six categories: books written by parents for parents of deaf or hard of hearing children; books written by professionals for parents of deaf or hard of hearing children; books by deaf adults about their experiences growing up deaf; books written by hearing authors who grew up in families with deaf parents; books for children about everyday experiences of children who are deaf or hard of hearing; and, resources for follow up.



In developing this list, the National Deaf Education staff have tried to identify books 1) that focus on parent experiences and topics specific to different stages of a child's development; 2) autobiographical and biographical accounts that highlight the reality that a deaf child becomes a deaf adult; and 3) books for children that can assist siblings in understanding what it is like to be deaf or hard of hearing.

STATE COMMISSIONS & OFFICES ON DEAFNESS

Various state commissions and/or agencies are mandated to serve deaf or hard of hearing people. While the scope of services differs from state-to-state, these programs provide a variety of valuable services. Among the functions are advocacy, information gathering and dissemination, referral to appropriate agencies, interpreting services, statewide planning and job placement and development. To contact the commission in your state, visit the following http://www.gallaudet.edu/clerc_center/information_and_resources/info_to_go/resources_statewide_services_for_deaf_and_hard_of_hearing_people.html.



HANDS & VOICES—WHAT DO I NEED TO KNOW?

Hands & Voices (www.handsandvoices.org) is a nationwide non-profit organization dedicated to supporting families and their children who are deaf or hard of hearing, as well as the professionals who serve them. It is a parent-driven, parent/professional collaborative group that is unbiased towards communication modes and methods. Its diverse membership includes those who are deaf, hard of hearing, and hearing impaired and their families who communicate orally, with signs, cue, and/or combined methods. Below is a feature on one of the organization's many useful resources.

Communication Considerations A-Z™: A parent in Indianapolis posed the question, "If I'm a hearing person, how do I even know what I don't know about raising and educating a child who is deaf (or hard of hearing)?" At Hands & Voices, members and staff thought that was a very good question....and the answers are complex and evolving. So they shed some light on it through a series called *Communication Considerations A-Z™*.

Communication Considerations A to Z™ is designed to help families and the professionals working with them access information and further resources to assist them in raising and educating children who are deaf or hard of hearing. Some of the best families and professionals were recruited to share their insights on the many diverse considerations that play into communication modes and methods, and so many other variables that are part of informed decision making. To access articles in alphabetical order ranging from ASL to Cochlear Implants, Acoustical Adaptations to Research to Self-Advocacy for Teens....simply click on a letter at the top of the following page/link and scroll through the topics: <http://www.handsandvoices.org/comcon/index.html>. Articles on all topics are concisely written by qualified authors who answer four specific questions:

- What is (selected Communication Considerations topic)?
- What issues are at the forefront of (this consideration)?
- What should every parent or professional know about (fill in the blank)?
- Where else can I find information about (this subject)? (Author/expert provides up to three recommended resources including books and/or websites)

Keep visiting the site to see new topics as they are added.



NEED DATA OR INFORMATION ABOUT STATE EHDI PROGRAMS? USE THE CDC STATE PROFILE!



The Centers for Disease Control and Prevention (CDC) State Profile (<http://www.cdc.gov/ncbddd/hearingloss/ehdi-states.html>) is a searchable, online database that provides specific information, including data, about EHDI programs in states and territories. The database is intended to help parents and professionals find information about EHDI programs in their state; and allow information to be shared between states and territories for program planning and evaluation.

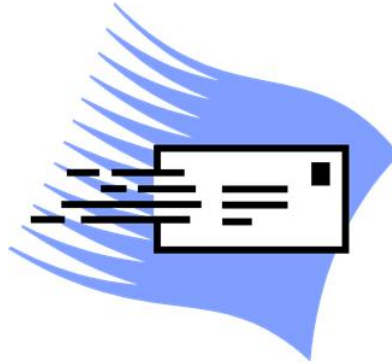
The State and Territorial Profile includes information about all aspects of the EHDI process, such as program structure, screening and referral procedures, tracking and surveillance systems, and educational materials. A key objective of this resource is to assist states and territories in program planning and evaluation, and to inform parents, other government agencies, and providers about EHDI programs across the United States.

WORDS OF INSPIRATION...



You can't do anything about the length of your life, but you can do something about its width and depth.

~ Shira Tehrani



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.medicalhomeinfo.org/how/clinical_care/hearing_screening/. Previous e-mail updates are available upon request from Faiza Khan, fkhan@aap.org or (847) 434-4924. If you would like to unsubscribe to the update, please notify staff by responding to this e-mail.