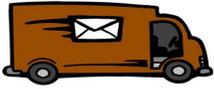




# EHDI E-MAIL EXPRESS

The monthly newsletter of AAP Early Hearing Detection & Intervention Program



AUGUST 2014

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## FROM YOUR CHAIRPERSON

Friends,

This month's column is about the word "disability."

That's not a very pleasant word. I'm sure there are a dozen new and perhaps preferred words that have been proposed over the years as a replacement for "disability." Perhaps "differing ability," or "unique ability," or "special ability." I'm just guessing. I don't really know. And not knowing this decade's preferred terminology, I seem to hear my sweet mother's voice in my ear as I write this, reminding me as a child: "If you can't say something nice, don't say anything at all."

But I also remember giving a presentation in the early 1990s to a committee of the American Academy of Pediatrics, specifically the "Committee on Disabilities." It was a presentation about the brand new efforts at a handful of hospitals to begin doing hearing screening on every newborn baby. It was a presentation about the dramatically improved outcomes that result from early diagnosis rather than late diagnosis. It was a presentation about how a possible "disability" for the deaf or hard of hearing newborn potentially could be "erased," about how the child who was diagnosed early could have language and learning outcomes equivalent to the baby with normal hearing. I'm sure I used the word "disability" more than once in that presentation. I'm not proud of that today, but that was the best word I had at the time, and it was perhaps the best word for that particular audience, at least back then.

Over the years, I have learned much about deafness. I am not deaf, and I am not hard of hearing. I will never qualify to speak on behalf of the Deaf community. But I have learned to think of deafness as a quality that defines, in part, a very human attribute, a human-ness, a spirit born of a shared signed language, a spirit born of hands connected to heart, a shared way of being in the world, a visceral connection to a community of family and friends. And today, it is easy for me to separate an older word, "disability," from a newer knowledge and a broader appreciation of deafness.

And if deafness, in this context, can be seen as so much different, and so much more than a "disability," might I even consider "hard of hearing" in a similar light? I can't tell. I don't know. In the words of the King of Siam (as sung in the musical *The King and I*), "Tis a Puzzlement."

What I do know is that much depends on context. Much depends on environment. And much depends on a community's choice to accept or not accept.

In thinking of the word "disability," I can't help but recall the opportunity I was afforded some years ago to visit Gallaudet University in Washington, DC. I was on the campus of that distinguished university to participate in a meeting of the Joint Committee on Infant Hearing. As most readers of this column will know, Gallaudet University is an institution that leads the way in education and career development for deaf and hard of hearing students. But rather than the school's international reputation and its track record of quality research, it was the environment of a shared signed language that left me dumbfounded. With the one unscheduled hour that I spent in a large common room (and in the absence of other hearing individuals), I was fascinated by the comings and goings, the quiet but boisterous joy of non-verbal interactions, the near-silent noise of signed conversations, the greetings and interruptions, the debates and salutations, all offered with sweeping arm gestures and flying hands and fingers, all in a language that I couldn't comprehend, and all in the context of a culture and a community that I could scarcely grasp. That was the day I learned about the word "disability." That day I saw and felt for the first time the idea and the label of being "disabled." For that was the day I could newly recognize that only one person in that room might be considered to be... perhaps... "disabled." And that person was me.

Join me this journey of appreciation, friends. I didn't like the idea of feeling "disabled." But it opened a door to new learning for me. And isn't that just what a university is meant to do?

Be well,

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## WELCOME NEW AAP EHDI PROGRAM STAFF

The American Academy of Pediatrics EHDI program is pleased to welcome a new program manager—Stephen Crabbe! Stephen joined the Academy earlier this month and will be providing part-time management and oversight to EHDI activities. Stephen brings great experience to the EHDI program as he spent the last few years managing public health community-based programs—serving as Regional Coordinator for a community-based infectious disease surveillance program in South Sudan for the Carter Center and the South Sudan Ministry of Health. In this role, he worked with local health departments and the United Nations to develop and implement programs in newly endemic areas of the country. Stephen received his Masters in Public Health from Emory University. He can be reached via email at [scrabbe@aap.org](mailto:scrabbe@aap.org).

## AAP EHDI PROGRAM ANNOUNCES A NEW INTERACTIVE RESOURCE: STATE EHDI REQUIREMENTS

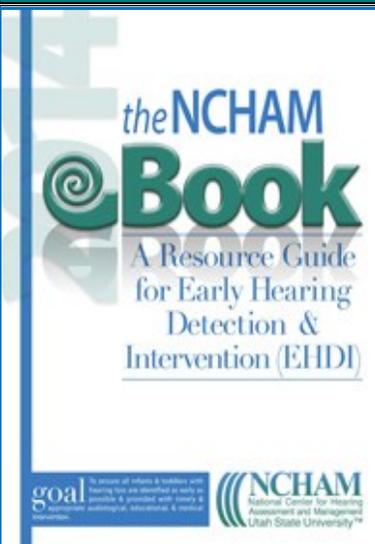
The AAP EHDI program is pleased to share a new resource. Now, compiled in one place, is a state-by-state guide on EHDI legislation, reporting requirements and procedures. Using a question-and-answer format, you will be provided links to additional information on:

- whether your state has a law or regulation requiring hearing screening
- whether your state has hearing screening guidelines
- whether your state uses the AAP EHDI *Guidelines for Pediatric Medical Homes*
- whether pediatricians are required to report hearing screening results
- who oversees early hearing detection and intervention in your state



You can access this resource on the [EHDI](#) page of the Academy's website, under Resources and Tools. We encourage you to explore and share this resource.

## 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, is a 'go to' source for chapter champions and others involved in EHDI.

This month, we continue to offer a glimpse of the NCHAM eBook, a comprehensive online resource. In [Chapter Three](#) authors Randi Winston, AuD, CCC-A and Jeff Hoffman, MS, CCC-A outline the importance and function of tracking and surveillance data management systems. They profile national standards from the Centers for Disease Control and Prevention 1-3-6 goals, Healthy People 2020, the Universal Newborn Hearing Screening and Intervention (UNHSI) Program of the Health Resources and Services Administration/Maternal and Child Health Bureau (HRSA/MCHB), and the Joint Committee on Infant Hearing (JCIH) 2007 position statement. Noting that the requirements of state EHDI programs vary widely, the authors review suggested strategies for systems that optimize follow-up in inpatient birth centers, out-of-hospital birth centers, and among outpatient providers.

Following a comprehensive overview of typical inpatient hospital activities on tracking, reporting, and follow-up, the chapter goes on to describe factors that lead to loss to follow up/documentation. Understanding these provides the basis for measuring a state EHDI program's effectiveness, validity, progress, outcomes, strengths, and weaknesses. A Strengths-Weaknesses-Opportunities-Threats (SWOT) Survey concludes the chapter as one resource for EHDI programs to use to build more effective systems.

## UPCOMING EVENTS

Event	Date	Location	Details
American Speech-Language-Hearing Association (ASHA) Convention	November 20-22, 2014	Orlando, FL	<a href="#">Web site</a>

## MARVEL COMICS REVISITS CHARACTER WITH HEARING LOSS



Did you know that, at one time, Marvel character Clint Barton – AKA Hawkeye – wore hearing aids after suffering hearing loss due to – what else – a fight? Encouraged by [Signing Time](#) host Rachel Coleman, Marvel Comics writer Matt Fraction wrote deafness back into the character in [Hawkeye #19](#), released in July 2014. Both Coleman and comic book reviewer Timothy Merritt have children with hearing loss, and both were touched by this depiction of Hawkeye, who uses empty ‘speech bubbles’ to convey the absence of a face-to-face or signed conversation. Upon reading the issue, Coleman’s daughter, to whom the issue is dedicated, said “That is exactly what it’s like when you’re deaf!” After reading [Hawkeye #19](#), Merritt and his wife made the decision to teach American Sign Language to their son. Read more [here](#).

## FREE ONLINE PARENT ADVOCACY TRAINING COURSE

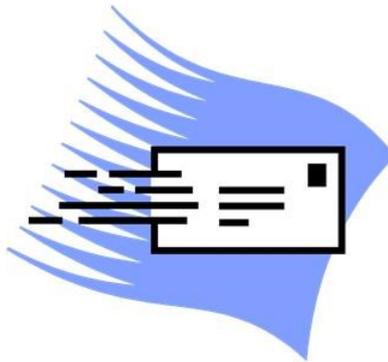
The Alexander Graham Bell Association for the Deaf and Hard of Hearing offers a [free online course](#) to help parents and educators build knowledge and confidence as they become advocates for their children living with hearing loss and work with local school districts and service providers. The course focuses on Part B of the Individuals with Disabilities Education Act (IDEA) and the Individualized Education Plan (IEP), preparing adult allies to play a role in obtaining appropriate intervention and educational services for deaf/hard of hearing children. Visit the [Listening and Spoken Language Knowledge Center](#) website for more information.

## BEST PRACTICES IN FAMILY-CENTERED EARLY INTERVENTION FOR CHILDREN WHO ARE DEAF OR HARD OF HEARING: AN INTERNATIONAL CONSENSUS STATEMENT

A diverse panel of experts convened in June 2012 to develop a consensus on the essential principles that guide family-centered early intervention (FCEI) with children who are deaf or hard of hearing (D/HH). The group consisted of individuals from 10 nations and included parents, deaf professionals, early intervention program leaders, early intervention specialists, and researchers. Because the implementation of best practices was variable and inconsistent across the represented nations, the panel sought to create a Principles Statement to promote widespread implementation of validated, evidence-based principles for FCEI with children who are D/HH and their families, which was published in the *Journal of Deaf Studies and Deaf Education*.

Ten best practice principles are outlined, each accompanied by steps to be taken by providers and/or programs. The principles address a range of topics from early, timely, and equitable access to services to program monitoring. Related resources and citations to the evidence base are listed for each principle. A concluding Call to Action seeks to raise awareness of the Principles Statement among policy makers and colleagues in the field, to recruit parent leaders, to support research, and to embed these best practices in guidelines and other thought-leading publications and venues.

Source: Moeller MP, Carr G, et al. *Best Practices in Family-Centered Early Intervention for Children Who Are Deaf or Hard of Hearing: An International Consensus Statement. Journal of Deaf Studies and Deaf Education 2013;18.4:429-445*



***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](mailto: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.*