

OVERVIEW

EARLY HEARING DETECTION AND INTERVENTION:

how far we've come, how far we've yet to go

By Barbara Raimondo

The February 2011 National Early Hearing Detection and Intervention (EHDI) conference marked its tenth annual event. During the opening plenary, speakers looked back and described the progress and accomplishments of past years. They highlighted activities of the various federal agencies, medical organizations, and individuals who helped move EHDI systems to where they are today. In this article, I would like to highlight the progress made towards providing family support and including the Deaf community in these systems.

Twenty years ago, when she was 11 months old, my daughter was identified as deaf at a national children's hospital. Although I was horrified to know that she had missed nearly a year of language input, I was told how "lucky" it was that she was identified so "early." I left the hospital with no information about what to do next, whom to contact, or what early intervention services were available.

Five years later my son was identified at the same hospital. Since his sister was deaf, I thought it would be a pretty good idea to get his hearing levels checked. He really was identified early—he was only a few weeks old. Again, I left the hospital with no information about what to do next, whom to contact, or what early intervention services were available.

I am grateful that things have changed.

Prior to the proliferation of EHDI services, the average age of identification of a deaf child was 2.5. A hard of hearing child might have been identified as late as age 4 or 5. For many children, late identification impacted language-learning ability.

Today, it is not uncommon for a child to be identified within the first few months of birth and for the child and family to be on a good path early on. Now, nearly 100 percent of all babies born in American hospitals have their hearing screened within the first day or two of life. So EHDI's task is complete, right?

Not so fast.

EHDI systems are based on a "1-3-6" plan. By 1 month old, the child should have his or her hearing screened. If the screen indicates that he or she needs a confirmatory hearing assessment, then that assessment should take place by the time the child is 3 months old. If the child is found to be deaf or hard of hearing, he or she and his or her family should be enrolled in a quality early intervention program by the time the child is 6 months old.

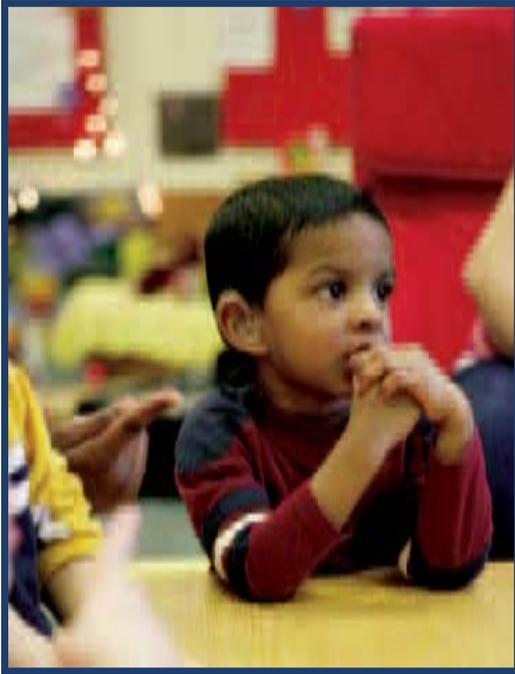
Unfortunately, this is not happening in many cases.

First, data from the Centers for Disease Control and Prevention indicate that many children who are referred from the screen for confirmatory testing do not receive this follow-



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up. Next, of the children who receive follow-up and are identified as being deaf or hard of hearing, many of those children and families are not connected with early intervention (Centers for Disease Control and Prevention, 2007). Third, one study showed that while most early intervention programs have professionals on staff with an early childhood special education background, less than half have professionals who received their training in the education of deaf children (Stredler-Brown & Arehart, 2000). This indicates that many families are not receiving the specialized services necessary.

Research documents that early identified children who receive appropriate early intervention services from qualified providers achieve significantly higher language outcomes than those who do not (Yoshinaga-Itano et al., 1998). These critical elements—“early identified,” “appropriate early intervention services,” and “qualified providers”—must be in place. In their absence, early identification may be detrimental. This is because families may feel confused and helpless about

finding information and services, and they may even feel angry. These feelings can affect their sense of well-being and even the child’s development because the parent-child relationship can be impacted by the family’s sense of well-being (Sass-Lehrer, 2002).

So, things aren’t so great. On the other hand, it is not all gloom and doom either. State systems do recognize the need for screening, follow-up, information for parents, and links with early intervention. While families in the past either missed early intervention all together or found it only by chance, systems today are working towards a seamless transition from screening to identification to early intervention and are starting to take into account the quality of that intervention.

In my view, one of the most important pieces to look at is the representation of the Deaf community in these systems. This is for several reasons. First, when systems value and respect deaf adults enough to make them key players in their work, that shows they value and respect deaf babies as well. Every parent wants his or her child to be valued and respected. Second, who better to inform hearing people about the lives of deaf people than deaf folks themselves? The most caring and well-intentioned hearing person cannot fully know what it is like to experience life as a deaf person in our society. The third reason is based on simple justice and common sense. Would there be, say, an important movement to improve the education and lives of women that is run solely by men?

While other elements are critical—such as accurate evaluation of the child’s hearing levels and parent-to-parent support—in my view the area of biggest lack is involvement of the Deaf community. In other words, it is well

understood that families need the support of other families and that hearing assessment technology must be reliable. However, it has taken longer for decision makers in EHDI systems to recognize the need for Deaf community involvement. Let’s review the progress.

National EHDI Conference

During the first National EHDI conference, attended by several hundred people, there was one deaf presenter—who was also the only deaf attendee—and a handful of parents. The rest of the conference-goers were professionals (i.e., state EHDI coordinators, pediatricians, audiologists, etc.). At the 2011 conference, there were dozens of Deaf community members and allies and many parents. This recent EHDI conference had a greatly increased number of presentations by deaf individuals. There were also presentations by hearing speakers that were focused on supporting deaf children, such as through the use of visual communication. One of the keynote speeches was given by Howard Rosenblum, the new director of the National Association of the Deaf. Last year the Antonia Brancia Maxon Award for EHDI Excellence was presented to Dr. Beth Benedict, the first deaf recipient of this award.

National Center on Hearing Assessment and Management (NCHAM) E-Book

NCHAM has been publishing an on-line resource guide for EHDI issues. The latest version (National Center on Hearing Assessment and Management, 2011) includes a chapter on the importance of, and strategies for, including members of the Deaf community in EHDI programs.

Consensus Report

Several years ago a group of stakeholders came together to identify critical elements in EHDI systems (Marge & Marge, 2005). Among them were

representatives from Gallaudet University, the U.S. Department of Education, state EHDI systems, parent organizations, and others. That meeting resulted in a report, *Beyond Newborn Hearing Screening: Meeting the Educational and Health Care Needs of Infants and Young Children with Hearing Loss in America*. Recommendations from that report included:

- EHDI systems should subscribe to the wellness model upon which the physical and psychosocial integrity of children and adults who are deaf or hard of hearing is based.
- Early interventionists and health care providers must become knowledgeable about different models of the deaf experience...as a life experience and/or cultural community...
- Early intervention programs should recruit trained adults who are deaf or hard of hearing to serve on the coordinated service team.

Joint Committee on Infant Hearing (JCIH)

JCIH, composed of medical, audiological, and educational organizations, has published seven position statements on EHDI since 1971. Its 2007 paper (Joint Committee on Infant Hearing, 2007) advised that “adults who are deaf



or hard of hearing should play an integral part in the EHDI program” and families “should be offered opportunities to interact with other families who have infants or children with hearing loss as well as adults and children who are deaf or hard of hearing.” It also noted that “Almost all families choose at some time during their early childhood programs to seek out both adults and child peers” who are

deaf or hard of hearing. It stated “... intervention programs should include opportunities for involvement of individuals who are deaf or hard of hearing in all aspects of EHDI programs.”

JCIH is working on a position statement on early intervention that is expected to be completed in 2011. This paper includes further recommendations on Deaf community involvement; language development, including signed language; and skills of the early intervention provider.

Information for Parents

EHDI systems are providing families with more information, and many positive resources are available. For

example, the California Department of Education, along with others, recently released a video on the benefits of using American Sign Language with young children (*Through Your Child's Eyes*, 2011).

Despite these movements in the right direction, EHDI systems have yet to maximize partnerships with Deaf community members. These statements from these influential professional bodies are encouraging, yet there still are very few—if any—deaf individuals with decision-making authority in these systems.

EHDI programs and EHDI Deaf community involvement have come a long way in 10 years, but there is much room for improvement in both areas.

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