

Early Hearing Loss Detection and Intervention: A Mother's Story

Submitted by Teresa McMahan; Edited by Dorothy Taylor

On April 23, 2002, Lesa Coleman, the mother of two daughters with hearing loss, testified before a committee of the U.S. House of Representatives that is considering appropriations for the Health Resources and Services Administration (HRSA). The President's 2003 budget eliminates a part of HRSA's funding that supports the Early Hearing Detection and Intervention (EHDI) program, which assists states in developing and implementing newborn hearing screening, diagnosis, and intervention.

Early, effective identification of hearing loss is critically important. The subsequent early intervention helps families foster their child's language development, whether it be through aural-oral, signed English, American Sign Language, or other avenue. Mrs. Coleman's story, shortened for this newsletter, demonstrates what a difference early detection and intervention makes. The entire testimony can be found in the *Congressional Record*.

A Personal Story

I have a very simple message — early hearing detection intervention can dramatically turn lives around. Without early hearing detection and intervention children with congenital hearing loss face delayed language, speech, and learning development, which can lead to educational deficits and behavioral problems. Unless hospitals are doing universal newborn hearing screening there is no way for parents or physicians to know if there is a hearing loss. I would like to share with you my experience with my daughters Corinne, age 9, who was diagnosed late at age 2 and Emily, age 7, who was diagnosed at birth.

When Corinne was born she looked and responded very normally, but as months progressed, she didn't seem to be talking. We counseled with our pediatrician who encouraged us to watch and wait three months, six months, and then twelve months. We watched and waited, but Corinne showed no improvement. Finally, without the approval of our pediatrician, we scheduled a hearing test when she was twenty-two months. Corinne failed the hearing test, and at age 2 (the average age of diagnosis without a newborn screen) Corinne was fitted with hearing aids.

Developmentally, just think about what two-year-olds are notorious for. Corinne tried to do all of those things with her hearing aids. She sucked them, threw them, and tried to hide them. We had a solution — hearing aids to assist her hearing — but no means to keep them on. Finally a few months later by a stroke of luck, we found a hat that we cinched on and she couldn't get her hearing aids off. So Corinne wore that hat from sun up to sun down.

Soon after diagnosis, we tried to enroll Corinne in an early intervention program, but because of the school calendar, it was late spring and no one could take us on their case until early fall

because of summer break. She was eventually admitted to early intervention at age 2-1/2, but was soon forced to exit the program because early intervention stops at age 3. Corinne started preschool at age 3 with essentially no expressive and very little receptive speech. To improve her communication skills we started speech therapy, which resulted in hundreds of hours and thousands of dollars over the course of four years.

Our Emily was born when Corinne was age 2-1/2. She was tested at birth with the appropriate equipment and had a hearing aid at 5 months. Emily did not reject her aids. She left them in and just soaked up the sound. Emily was enrolled in an early intervention program at 6 months where her speech was monitored regularly. She developed speech normally right along with her hearing peers. Emily has never had to have regular speech therapy. Her vocabulary has been very expressive, confident, and dramatic.

The contrast in our experiences dealing with every aspect of essentially the same hearing loss in both girls has been dramatic. From testing, to aiding, to early intervention, speech therapy, language development, socialization, and ongoing voicing and speaking confidence issues—our younger daughter Emily has had a tremendous advantage because of her earlier identification. Now, Corinne and Emily would like to make a brief statement.

Emily: “I’m Emily, and I’m so glad I got tested when I was born, I haven’t had to work as hard as Corinne. Thank you.”

Corinne: “I am Corinne and because there was no newborn hearing screening when I was born I had lots and lots of speech therapy. My little sister Emily didn’t have to do all that work. I wish that all kids with a hearing loss could be identified early like she was. I really hope you will put the money for hearing testing back in the budgets to help other kids. Thank you.”

There Still is Much to be Done

The Colemans’ story was so compelling that the congressional committee chairman and the other committee members gave the family a standing ovation when the two girls finished.

Many states now have Universal Newborn Hearing Screening or have passed legislation for its establishment, but it does take funding to adequately implement an early detection system. A large number of states have good intervention programs to work with the families of children who are identified with hearing loss. As programs receive increasing numbers of identified newborns with hearing loss, though, more and more early interventionists need guidance and training in serving these infants and their families effectively.

Interventionists and parents should be familiar with their state’s identification, diagnosis, and referral system. If interventionists have not had training related to hearing loss and the associated educational issues, they will need to know where to get that training. They, along with the families, will want to know how to contact knowledgeable resources. The fervent hope is that funding and administrative commitment will be available to support them.

Sources of Information for this Article

National Center for Hearing Assessment and Management (NCHAM); Karl R. White, Director. NCHAM provides technical assistance to states in establishing and operating their EHDI systems: www.infanthearing.org.

National Campaign for Hearing Health (NCHH). The NCHH Web site has extensive information: www.hearinghealth.net.

Boys Town National Research Hospital has an excellent Web site for families: www.babyhearing.org (see description below).

SKI-HI Institute develops programs and provides training in early intervention: www.skihi.org.