

hard of hearing children: STILL OVERLOOKED

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This article is excerpted from Parents and Their Deaf Children: The Early Years by K.P. Meadow-Orlans, D.M. Mertens, and M.A. Sass-Lebrer (2003, Gallaudet University Press). The book reports the results of Gallaudet's National Parent Project. It includes the responses of 404 parents of 6- and 7-year-old deaf and hard of hearing children to wide-ranging questions about their early experiences, and focuses on follow-up interviews with 80 parent respondents.

Children with mild and moderate hearing losses were called “forgotten” a quarter century ago (Davis, 1977), and more recently called “overlooked” (Ross, 1990). The disheartening experiences of parents with hard of hearing children interviewed for Gallaudet’s National Parent Project suggest that many of their children were overlooked and neglected by professionals during the early years of their lives.

Yet the numbers of children with mild or minimal hearing loss greatly exceed those of children with severe or profound hearing loss. In fact, the numbers of children increase as decibel loss decreases. (For estimates, see Bess, 1985; Niskar, Kieszak, Holmes, Esteban, Rubin, & Brody, 1998; Schein, 1996.)

More than half of the parents who responded to the survey considered their children to be hard of hearing rather than deaf.





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Left: A national parent survey coordinated by Gallaudet University suggested that hard of hearing children were too often overlooked during the early years of their lives. *Photo courtesy of the Cochlear Center.*



Above: Newborn screening in an increasing number of states provides hope that hard of hearing babies will be identified and begin to receive services during the crucial first years of life. Photo courtesy of the American Speech-Language-Hearing Association.

A positive development is the increasing number of states with legislation providing universal newborn hearing screening, and still more states that provide screening on a voluntary basis. In May 2002, 65 percent of hospitals had instituted programs to test newborn infants for hearing loss (National Center for Hearing Assessment and Management 2002).

It has been shown that newborn screening leads to earlier identification and intervention, especially for children with a hearing loss in the moderate to profound range, and that early intervention is associated with accelerated language development (Yoshinaga-Itano, Sedey, Coulter, & Mehl, 1998). Despite

dramatic improvements in identification, however, services for hard of hearing children have not kept pace with those provided to children with a profound hearing loss. Professionals, as well as parents, too often assume erroneously that once hard of hearing children are fitted with hearing aids, they will function like children without a hearing loss.

Delay in Identification

Parents of hard of hearing children reported that their children's hearing

loss was identified later than the hearing loss of deaf children—at an average age of 28.6 months compared to an average age of 14.5 months for deaf children.

This family illustrates how children with a mild or moderate loss may escape identification for long periods, even when the family members are observant and their medical care is excellent:

Yes, we knew something was wrong. But her hearing loss is moderate and it's conductive and she got to be very good at reading lips. So she would look like she's doing something else and I'd say something to her and she knew enough to look at me but then ask me again. Like say, "What?" But then by the time we finally got it diagnosed, she had been through thirteen other hearing tests.... She got her hearing aids finally when she was 4...She...had already started speech therapy. But even when I told her speech therapist,...she said, "Really? She's hearing impaired?"

Consequences of Delay

A clear consequence of delayed identification or misdiagnosis of a hearing loss is the wasted time that might have been devoted to intervention services. However, other less obvious consequences are reported by parents, both for themselves and for their children. These concerns include the parents' own feelings of guilt, as well as the children's worrisome behavior and lack of self-esteem.

One parent notes:

I felt guilty because I had been, I guess, punishing her for not listening or not responding, but she really didn't hear me.

Another mother echoes these feelings:

I guess my big thing was I blamed myself for not knowing until such a late age.

One child had a high frequency hearing loss, suspected by his parents when he was



3 years old, but not identified until he was 5 and a half:

The damage [done by delayed identification] was to his self-esteem because...the kids would say, "How come he talks funny? How come he talks like a baby?" And so what happened is he stopped talking. And there would be days at preschool where he would go through the whole day without saying a word to a single person...There was a long period of time when he would wet his pants every single day because he didn't want to ask the teacher to go to the bathroom. And we never knew it was hearing-related until we had him screened for kindergarten.

The few studies that have focused on the social or behavioral status of hard of hearing children have reported severe problems for some children. In one

study, parents characterized their hard of hearing children as having problems with "aggression, impulsivity, immaturity, and resistance to discipline and structure" (Davis, Elfenbein, Schum, & Bentler, 1986, p. 60). In another study, teachers rated hard of hearing children, even with minimal losses, more negatively than children without a hearing loss for independence, attention to task, emotional lability, and social confidence (Culbertson & Gilbert, 1986).

Parents of all children in the survey identified 8 percent as having "behavior

Below: Parents report that even though hard of hearing children outnumber deaf children, they are less likely to receive services.

problems." Hard of hearing children were given significantly lower scores on the survey's behavior rating scale compared to deaf children. Overall, the data suggest that behavior is not seen as a serious problem by these parents. However, the consequences associated with behavioral concerns can be painful for the child and for family members, as

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these illustrations show:

She has a younger brother and two younger sisters. She does have some rough times where she can be pretty mean but I think that comes out of a lot of frustration.

Another child came to live with her mother and stepfather when she was 3. Her hearing loss had not been identified, but she was enrolled in a special preschool for children with behavior problems.

When my wife and I first got married, her ex had custody. And when we got her there were some behavioral problems and that's why we put her [in that program] and then after she'd been in that program



for about six months we found the hearing loss. We think that probably had something to do with the behavior problems also.

Services to Parents Lacking

The data suggest that parents of hard of hearing children do not feel as well served as parents of deaf children. These parents were much less likely to have received information about deafness or sign language instruction, or to have had opportunities to participate in parent groups. They were somewhat less likely to have received information on legal rights, behavioral development, and school choices, or to have had access to individual counseling.

One mother of a hard of hearing child has written a book about her experiences titled *Not Deaf Enough* (Candlish, 1996). She observes that professionals, as well as parents, too often take the position that deaf children need a great deal of extra help and attention, but that hard of hearing children can manage very well if they are given hearing aids and preferential seating. Her son suffered from these attitudes, and she herself was often avoided by the parents of deaf children because her child was more advantaged than theirs. As she put it, her child was “not deaf enough.”

That theme is echoed by one of the mothers interviewed for this study:

I went to the library to get books to help

my son understand [his hearing loss]. And the only books that were available were for profoundly deaf people. There were several books about them but nothing related to [my son] because he only has a high frequency hearing loss.

The Double Edge of “Positive Coping”

Responding parents also described important positive coping abilities that they and their children had developed. The interviews showed parents’ acceptance of their child’s hearing status and their attachment to and admiration for their children as unique individuals with talents and endearing characteristics. These children are

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meeting and surpassing their parents' expectations:

She's a wonderful, outgoing little girl. She's got lots of personality and a strong love for animals... She's a wonderful kid and I think deafness is part of her personality.

She's very outgoing, on the go all the time... She's always very bright, very seldom sad... She's basically the light of my life... coming along very well.

He's very energetic and active and a real good singer. He's got a wonderful personality, likes other kids, and he's a character. People really enjoy being around him. Loves... vehicles and anything he can take apart and explore, loves the outside.

Paradoxically, the positive coping skills developed by hard of hearing children sometimes contributed to their difficulties. These children typically communicated very well in one-on-one and face-to-face interactions, and their good lipreading skills tended to mask the extent of their hearing loss, lulling parents and teachers into believing that they understood more than they did.

Dealing with the Present— Looking to the Future

Hard of hearing children and their families need more services that address the specific problems related to minimal hearing loss. Children with minimal hearing loss should benefit from the growing practice of screening newborns for hearing loss. However, universal screening will not obviate the need for continued screening during the preschool years, particularly to identify

children whose minimal hearing loss stems from repeated ear infections, illnesses, or accidents.

Despite many advances in identification and intervention, hard of hearing children continue to be forgotten and overlooked in comparison to their peers with severe and profound hearing losses. To be “not deaf enough” subjects children and their parents to unnecessary disadvantages.

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