



## **The Experiences of Families Who Have a Young Child with a Hearing Loss and Another Health Condition/Disability: Research Study Results: A Report for Families**

### **Project description:**

“Children with Early Hearing Loss and Existing Comorbid Health Conditions in New Jersey: State Data and the Experience of Families” was a research collaboration between The Elizabeth M. Boggs Center on Developmental Disabilities – New Jersey’s University Center for Excellence in Developmental Disabilities, and the New Jersey Department of Health and Senior Services’ Early Hearing Detection and Intervention Program. It was funded through a cooperative agreement between the Association of University Centers on Disabilities and the National Center for Birth Defects and Developmental Disabilities – Centers for Disease Control and Prevention. The project began in September 2007 and was completed in August 2010.

The main purpose of this project was to learn about the experience of families who have young children with an early hearing loss and another health condition or disability, as well as the experiences of audiologists who provide services to these children.

The study had 3 parts: Part 1 was a written survey of families; Part 2 was a telephone interview with some of the families who had completed the written survey; and Part 3 was a survey of audiologists in New Jersey who treat young children with a hearing loss and other health condition/disability.

The survey booklet sent to families contained both English and Spanish versions of the survey. Families were also given the option of requesting to participate in the study in other languages, using the AT&T language line (none of the families requested this option).

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In order to help make sure that the research was grounded in the real life concerns of families, a Family Advisory Committee (FAC) was formed. The FAC, which was made up of parents of children who had a hearing loss and other health condition/disability, provided extensive input throughout the project.

### **Who participated in the study:**

The children who were included in this project ranged in age from 2 to 5 years old, had failed their initial newborn hearing screening test (or left the hospital before a screening test was done), and had one of 97 other health conditions/disabilities identified by the research team. The children were identified through New Jersey's Special Child Health Services Registry, the Early Hearing Detection and Intervention Program database, and New Jersey's Electronic Birth Certificate.

Out of the 420 families who were mailed a survey, 55 completed it (44 in English and 11 in Spanish).

The majority of the families chose one of the following 2 groups to describe their child's hearing loss status: Group A (26 families) – Child had another hearing test and has been diagnosed with a hearing loss; Group B (15 families) – Child had another hearing test and may have a hearing loss but a clear diagnosis has not been made.

Forty-five families of the 55 who completed the survey agreed to be contacted to participate in Part 2 of the project, which were phone interviews. A total of 17 families were interviewed, 12 in English and 5 in Spanish.

Out of the 496 audiologists in New Jersey who were sent the audiology survey, 123 completed the survey. 82 of those audiologists reported that they evaluate and treat children under the age of 5.

### **What we learned from the study:**

One of the main goals of this project was to learn if having another health condition/disability affected the treatment of the child's hearing loss, or if having a hearing loss affected the treatment of the other health condition/disability. The majority of parents surveyed said that one condition had no effect on the other. However, 42% of parents of children with an identified hearing loss (Group A) did say that it took more time to help their child with his/her hearing loss/communication needs. This may be because although for many health conditions there are specific tasks that need to be done, communication needs are present in every single parent-child interaction throughout the day. In fact, communication as an ongoing concern, including for the future, was expressed by a number of parents. One said,

“My fear is that he won’t be able to be independent...That he’s not going to learn how to do things and that he won’t be able to communicate when he gets older.”

In describing what is important for health professionals to know about their child, parents said that it was important that they know about *both* the hearing loss *and* the other health condition/disability. Beyond that, however, parents also wanted health professionals to be able to see their child as a *whole person*. As one parent said,

“He needs to be seen more as an individual instead of a syndrome or a classical child with hearing loss. There is some perception that it is all cookie cutter, and doctors need to recognize that each hearing loss is individual and each child is different, with different needs... and that each child needs to be looked at as a whole.”

Another parent said,

“... They [doctors] can’t just look at her with her disability and think that this is it. Realize that she is growing, changing, and developing everyday.”

The strength of parental love and appreciation for their child, regardless of how significant the challenges, was powerfully captured by asking parents to describe what they most enjoy about their child. Here’s an example of the kind of responses that were shared by many of the parents:

“He is actually the happiest child you will ever meet. He has had 13 brain surgeries but you would never know it. [He is] pretty typical besides delays. [He is] smart, funny, always happy no matter what.”

While the majority of parents said that they felt their child’s primary doctor listens to their concerns about their child’s health, and were understanding of their situation as a parent of child with a hearing loss and another health condition, fewer of the parents thought their child’s primary doctor was knowledgeable about their child’s hearing loss and other health condition. In addition, about half of the parents said they were the one who was responsible for bringing their child’s medical information to different doctors’ appointments. Other challenges related to handling their child’s hearing and other health conditions included time spent coordinating different appointments, fitting appointments into their schedules, and waiting for available appointment times.

Lack of good communication between audiologists and pediatricians was a concern that was raised by both parents and audiologists. In addition, 87% of the audiologists surveyed reported that children under age 5 with multiple disabilities were referred to their services by schools. This means that good communication is important

not only between audiologists and doctors, but also between audiologists and other professionals that provide care for the child.

The audiology survey indicated that many audiologists are not as comfortable as they would like to be performing audiologic evaluations, or providing aural habilitation/rehabilitation, to children under 5 with multiple disabilities. A high percentage responded that they would find it useful to receive further training in this area.

**What we didn't learn from the study:**

This study provided some interesting insights into the experiences of families who have children with a hearing loss and another health condition. However, there were several limitations to the study, and the one that is perhaps of greatest concern is that there were many families who did not respond to the survey. It is hard to know all the reasons for this, but our concern is that it may have to do with issues of literacy, poverty, language, or culture, or the exceptionally high care-giving demands of families who have children with multiple disabilities. Many of these present ongoing challenges in research, and we will continue to try to find ways to address them in future research studies that are done.

**Next steps:**

It will be important that the results of this research be shared with professionals who provide services to children with a hearing loss and another health condition/disability. This will be done through journal articles and presentations. Of particular importance will be encouraging the development of more in-depth interdisciplinary training and family-centered approaches for audiologists and other health care professionals.