

Outcomes for Children Who Are Deaf-Blind After Cochlear Implantation

Research Brief: Family Perspectives on Cochlear Implants

This research brief is the result of a study, *Outcomes for Children Who Are Deaf-Blind after Cochlear Implants*. It is a summary of an article about a family survey conducted in fall 2009 in which 60 families participated. The results of this initial study were helpful in the development of a second study which is currently in place. For additional information about the family survey see:

Bashinski, S.M., Durando, J. & Stremel Thomas, K. (in press). Family survey results: Children with deaf-blindness who have cochlear implants. *AER Journal: Research and Practice in Visual Impairment and Blindness*.

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A cochlear implant is a hearing device that is surgically implanted by a medical team to help people learn to hear. The cochlear implant has “an electronic system that stimulates the hearing nerves directly sending a sensation of sound to the brain” (Wheeler, 2008, p.10). Several research studies have been published concerning the “post-implant patterns of progress for children who are deaf; however few exist about children who are deaf-blind” (Bashinski, Durando, & Stremel Thomas, in press).

The continued increase in the number of families thinking about cochlear implants for their child supports the need for increased information in order to help families make a more informed decision. Examining how families feel about the process of obtaining an implant and the outcomes their child experienced is critical to families who contemplate a cochlear implant as an option. The purpose of this brief is to provide information to families of children with deaf-blindness that may be considering a cochlear implant for their child.

An initial study, *Outcomes for Children Who Are Deaf-Blind after Cochlear Implants* (CIDB), collected information from 2006 to 2009 on children between the ages of 10 months and 12 years who are deaf-blind who had recently received cochlear implants. The CIDB study research team was interested in learning from families how cochlear implants impacted their children’s development of communication, social interaction, and functional life skills. As the team began to assess children and talk with families about changes in their children following

implantation, the following question emerged: *How did the families who participated in the study feel about their child's implant, and how did they perceive the implant's impact—on both the child and the family?*

The CIDB research team decided that a family survey would be a useful way to gather information about this question. After a review of the *Children with Cochlear Implants: Parental Perspectives* questionnaire (Archibold & Lutman, n.d.) the team decided to develop a survey that was shorter in length and targeted on specific areas of interest. A new family survey was developed and piloted with families of children who are deaf-blind. A total of 60 families of the 71 contacted completed the new survey. Each of the participating families has or had a child with deaf-blindness with at least one cochlear implant. Ethnic diversity of the families varied, 19 states were represented, and the most common causes of the child's deaf-blindness were CHARGE syndrome or complications of prematurity.

The findings presented in this brief are limited to the family survey and are not inclusive of all the information the researchers learned about outcomes for children with deaf-blindness after cochlear implantation. It is important to remember when reviewing the findings of this study that they derive from a first investigative effort with a group of children who are known to be exceptionally unique. Therefore, it cannot be assumed that the findings would apply equally to every child with deaf-blindness.

Key Findings from the Family Survey include:

- Families told us –
 - 85% of parents agreed that, *“knowing what they now know, they would again make the decision to seek a cochlear implant for their child”*.
 - 63% of parents said *“my child enjoys wearing the implant”*.
- When families were asked about the spoken language of their children –
 - 53% felt the spoken language had not yet improved in the home
 - 67% stated their children *“demonstrated improvement in responding to feelings expressed through vocal inflections”*
 - 62% shared their children were *“entertaining themselves by listening to music, watching television, or playing games”*.

Children identified as deaf-blind are often not totally deaf and totally blind; however over 85% of the population experience physical or cognitive disabilities, complex medical needs, or behavior challenges (Killoran, Davies, & McNulty, 2006). Findings from the Family Survey emphasized the need for:

- Effective strategies for ensuring the implants stay in place for children with motor challenges / cerebral palsy.
- Support from schools and support centers – families told us
 - “*The center does not have knowledge of children with multiple disabilities.*”
 - “*The school does not encourage wearing of the implant; the teacher seems to think it an unnecessary hassle.*”
- When families were asked about what is needed, they said.
 - “*Teachers are interested in supporting the child and family, but they don’t feel they have the skills.*”
 - “*Effective staff training leads to more successful outcomes.*”
 - One family’s response – “*Since getting a new teacher of the deaf, who is trained in auditory training, our son’s progress with his cochlear implant has skyrocketed.*”

Information about outcomes for children with deaf-blindness who have received a cochlear implant is still preliminary. Results of this family survey represent only the opinions and perceptions of families who *did* choose to pursue a cochlear implant for their child with deaf-blindness. Families of children who inquired about an implant for their child with deaf-blindness but did not proceed were not surveyed. Also, families of children with deaf-blindness who discontinued wearing their cochlear implants were not included in this survey research.

The families of the children who have been implanted and the researchers conducting the cochlear implant studies are discovering many small details that over time may lead to significant conclusions. Findings to date, with children who are deaf-blind and the majority of whom have additional disabilities, reflect even greater variability than research findings for children with only deafness who have received cochlear implants. The presence of cognitive disabilities, physical disabilities, and/or complex health issues, in addition to varying levels of vision impairments, are factors that impact outcomes to varying degrees across the age span of the children included in this initial CIDB study.

Resources

Archibold (sic), S., & Lutman, M. (n.d.) *Children with cochlear implants: Parental perspectives.*

Royal National Institute for Deaf People.

Bashinski, S. M., Durando, J. & Stremel Thomas, K. (in press). Family survey results: Children with deaf-blindness, who have cochlear implants. *AER Journal: Research and Practice in Visual Impairment and blindness.*

- Bashinski, S.M., Stremel Thomas, K., & Durando, J. (2009, July). *Impact of cochlear implants for children with concurrent hearing and vision loss: Preliminary findings*. Paper presented at the OSEP Project Directors' Meeting, Washington, DC.
- Durando, J. (2010). *Outcomes for children who are deaf-blind after cochlear implantation: Data summary*. The Teaching Research Institute: Western Oregon University. Research supported by US Department of Education, H327A050079.
- Killoran, J., Davies, P., & McNulty, K. (2006). *The NTAC outcomes and performance indicators: A system for documenting outcomes for children and youth with deaf-blindness, their families, and the service providers and systems that serve them*. Monmouth, OR: Teaching Research Institute, Western Oregon University.
- Wheeler, A. (Ed.) (2008). *Deafblindness and cochlear implantation*. Nottingham, United Kingdom: The Ear Foundation and Sense.

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