Cochlear implants in children: ethics and choices

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LIKE MANY readers of this journal, I have followed the cochlear implant controversy with a cautious and curious stance, not wanting to take sides with any level of passion. As an educator, I would welcome any technological advance that might enhance cognitive and/or linguistic development in deaf children. Months ago, I saw a segment on television about a young deaf girl who received an implant. I watched as she was playing in the yard and “heard” an airplane flying overhead. The thought that she was made aware of something in the environment and this may have stimulated her thinking about the world around her was quickly lost when the medical doctor and interviewer focused on how long it would be before the young girl would speak like her hearing peers. “Wrong focus,” I thought.

Before advocating the use of such technology on a large-scale basis, I would want to see some research results showing its potential for improving the quality of life. Deaf education has a long history of armchair philosophizing about technology. Closed and open captions, the TTY, and now the Internet, for example, have all been touted in books, magazines, and journals in terms of their potential effects on learning. Yet, there is no great body of research that provides evidence of benefits beyond increased access to information for deaf and hard of hearing people.

A glimpse into history also provides some understanding of why there is so much emotion attached to technological advances. “Advances” in voice telephony led to a ninety-year delay in access to the telephone for deaf people. “Advances” in adding the sound track to silent movies led to more than forty years of lost access to films. For hundreds of years, deaf people, viewed as “disabled,” have been treated with chemical and electrical “cures,” sent up for airplane dives, and subjected to a multitude of other medical fixes. Emotions have long been a part of Deaf education history.

The Deaf community has long included many different types of people, and we have experienced technology’s impact in different ways. The TTY, for example, eliminated the need for face-to-face communication, saving deaf people long drives to a Deaf club or to the homes of family members and friends just for personal communication. In turn, instant messaging and the Internet may be having an impact on the need for the TTY. Regardless, the TTY would never have come about without collaboration between signing and non-signing deaf people in the National Association of the Deaf and the Alexander Graham Bell Association for the Deaf (through the organization now known as Telecommunications for the Deaf, Inc., or TDI). All the while, American Sign Language (ASL) has become recognized as a true language and is used increasingly by many deaf and hearing people. A number of universities and state education departments recognize ASL as a foreign language.

As a deaf person myself, I have deaf friends who have had a range of experiences with cochlear implants. One just received an implant at the age of fifty-six and is delighted with it. So are two friends who are in their thirties. Another received hers fifteen years ago and blames the implant for migraines and frequent nausea. A fourth friend had several implants over the past ten years and does not use an implant now. It only makes me curious.

I have wondered also about the range of experiences younger deaf children have with implants. While at a conference at James Madison University last fall I dropped in at the end of a presentation by a cochlear implant expert and was delighted to see him advocating continued use of sign language with implanted children. Yet I also read an article about a school established for implanted children that would not allow the use of sign language. Meanwhile, some teachers in K-12 programs tell me that they see a difference in academic performance among implanted children, while others say that they have children who never notice when the implant batteries have stopped working.
This same sense of curiosity led me to read the book *Cochlear Implants in Children: Ethics and Choices*, by John B. Christiansen and Irene W. Leigh. The book examines the sensitive issues associated with cochlear implants emerging through an extensive analysis of qualitative research data from a questionnaire filled out by parents of children who have cochlear implants, and from follow-up interviews with a sample of these parents.

*Cochlear Implants in Children* begins with a history of their development and an explanation of how implants convert sound into electric impulses that stimulate the brain. The second section focuses on pediatric implants, starting with the ways parents initially coped with the discovery that their child was deaf. Parents share how they learned about cochlear implants and how they chose an implant center. They also detail their children’s experiences with the implants after surgery, and their progress with language acquisition and in school. The book contains many touching and informative quotes obtained during the interviews, comments that add human interest to the issue, such as the report about the child who was frightened at the sound of a garage door opening when arriving home after the first mapping session, or the child who panicked at the sudden loss of hearing, not realizing her implant magnet had fallen off. Christiansen and Leigh provide balance, too, including reports of negative experiences, such as when children were teased by their peers. The wide range of anecdotal data in this book provides a clear indication of the need for supporting the implanted child, especially during the first year after the surgery.

As with the more traditional issues hearing parents of deaf children face with regard to education and communication, the parents interviewed by Christiansen and Leigh encountered a spectrum of professional and personal opinions, especially at the pre-implant and adjustment stages. These parents also had to resolve conflicting views about the benefits and success rates among implanted children, and particularly about the ethics of having a child implanted without his or her consent. The authors delve into the cognitive, affective, and sociopolitical domains in discussing their findings. Wisely, they write that “Long-term outcome research covering linguistic, communicative, and psychosocial factors is critical to address further the issue of benefit as compared to risk.” Their own research provides a foundation volume for parents, teachers, and researchers, which examines a range of topics, especially logistical and bioethical issues.

Occasionally, however, the issues discussed in this book appear disjointed, lacking a clear organizing theme. Sometimes their data are difficult to interpret, such as when parents of college-age students implanted fifteen years ago are quoted along with parents of two-year-olds. I struggled to understand the generalizations when the authors often referred to “many” and “few” respondents. While cochlear implant technology is changing so rapidly that parts of this book may become outdated rather quickly, this seminal study nevertheless provides a thought-provoking summary of human experience in a twenty-first century context of a medical breakthrough.

Christiansen and Leigh candidly conclude that the results of their research, including analysis of more than 2,500 pages of interview transcripts, reveal much variability in the difference cochlear implants may make, not only in terms of a child’s overcoming the communication difficulties associated with deafness, but especially with regard to intellectual functioning and language development. They write that while most of the parents in this study realize that the implanted children “are still children who are deaf,” these parents generally “see the implant as enhancing their child’s quality of life.”

*Cochlear Implants in Children* identifies many needs which should be addressed over time. I especially liked the suggestion that parents remember that “deaf adults are their children grown up” and that the advice and wisdom these deaf adults may offer have the potential to positively influence self efficacy in children. Both deaf and hearing people need to be part of the collaborative teamwork supporting the implanted child, and ongoing research is essential in order to inform the field.
One thing is certain—educators of deaf children strongly agree that parent-infant communication and early intervention efforts are important predictors of academic success of deaf children. *Cochlear Implants in Children: Ethics and Choices* reinforces these critical needs—and provides a resource for parents that is both readable and informative.