

The Silenced Voice: Examining the Evolving Debate on Pediatric Cochlear Implantation

*Me: "What do you say to people who tell you 'I'm sorry' when they realize you're deaf?"
Sophia: (half-jokingly) "I'd tell them, 'I'm sorry you're hearing.'"*

In 1997, when she was three years old, my sister Sophia received a cochlear implant. I sat in the waiting room with my grandparents, swinging my legs on a chair, unaware of the changes that this surgery would suddenly cause. I have a fuzzy memory of the next day. My father is carrying her in his arms. She has a white bandage wrapped multiple times around her head and is crying. In the background, there is a little hospital bed, dim lighting.

In the next several years after the surgery, I tagged along with my mother and sister to various audiology and doctors' appointments. In the office, I would watch Sophia with a pair of headphones over her ears, a small, stuffed monkey in the corner, which would clap his two cymbals together in celebration when she correctly identified the mechanical tones. Every week, the speech therapist would arrive at our house with her notebooks and small wooden hoop with a black covering. She would hold it over her mouth and make sounds my sister struggled to distinguish. Sometimes, my mother and I would also practice with her in the kitchen. Sophia hated this exercise, but it was important to my parents, and so we all persisted. "Don't sign with her," my mother would say. "Let her learn to hear you."

A Brief History

Since its implementation, pediatric cochlear implantation has become one of the most controversial issues for bioethics, disability and Deaf¹ scholars. While the medical community espouses a pathological model (i.e. deafness is an individual defect or handicap, which must be remedied via the use of hearing aids or cochlear implants), those belonging to the Deaf world, or

¹ I will follow the distinction between D/deaf so prevalent in the current literature. The former denotes cultural/ethnic identity and the latter the pathological model, i.e. hearing impairment.

Deaf community, believe being Deaf is highly valued, and Deaf culture should be respected for its own set of experiences, history, and language.² In this cultural model, there is absolutely nothing wrong with being deaf, and it is the hearing community that has not been able to accept and embrace a new definition of normality and welcome this diversity. For a proud Deaf member, there is no need – indeed, it would be an insult – for someone to say, “I am sorry you are deaf.”

In 1990, the Food and Drug Administration approved cochlear implantation for children. Though funding had initially been difficult to obtain for researchers pursuing implant invention, (oftentimes exaggerated) media reports of “curing” the deaf, biotechnology industrial interest, and further developments generated much public excitement and led to widespread implementation of the procedure by the beginning of the twenty-first century. The U.S. government had originally required patients to be at least two years of age at the time of implantation, but that number dropped to twelve months in 2000, as studies suggested earlier implantation could lead to improved speech and literacy skills.^{3,4} Today, some countries allow patients as young as three months to undergo implantation surgery.⁵ Nevertheless, evaluations of pediatric cochlear implantation were, and are still, fraught with a number of issues, including variability of success rates, the need for a lengthy rehabilitation program, and a lack of standardized testing data.⁶

² Lane, H. & Grodin, M. (1997). Ethical Issues in Cochlear Implant Surgery: An Exploration into Disease, Disability, and the Best Interests of the Child. *Kennedy Institute of Ethics Journal*, 7(3), 231-251.

³ National Institute on Deafness and Other Communication Disorders. (2011). Cochlear Implants. *National Institutes of Health*. Retrieved from <http://www.nidcd.nih.gov/health/hearing/pages/coch.aspx>.

⁴ Henkel, G. (2013). History of the Cochlear Implant. *ENT Today*. Retrieved from http://www.enttoday.org/details/article/4550891/History_of_the_Cochlear_Implant.html.

⁵ National Institute on Deafness and Other Communication Disorders. (2011).

⁶ Blume, S. (2010). *The Artificial Ear: Cochlear Implants and the Culture of Deafness*. Piscataway, NJ: Rutgers University Press.

The Sound and Silence

My father writes, “While I can understand the point of view of some in the Deaf community with their opposition to the implant, I felt we needed to give Sophia the option of oral language and this needed to be done while she was young, the earlier the better. I remain convinced that we made the right decision and hope Sophia agrees.”

I have no knowledge of my sister ever answering this question directly: Was the right choice made? Honestly, I don’t know if she can judge fairly and conclusively. I don’t think anyone can. Instead, she tells me she probably would not be where she is today – an Ivy Leaguer, rugby player, and second-year chemistry major surrounded by a loving group of both deaf and hearing friends – without a cochlear implant. But at the same time, she identifies much more strongly with the Deaf community and feels most comfortable there. One evening, we drive to our local mall and unexpectedly run into a group of people signing in the food court. Even though they are strangers, they extend such warmth and welcome to her, and I know this, too, must be a kind of family. I watch from the sidelines as they laugh, their hands flying, their faces more expressive than mine could be while speaking. Even with a cochlear implant, she is still deaf and Deaf, and this seems to hold true for how many deaf children with implants and their families see them(selves).⁷

Sophia, in the meantime, shares stories with me about the Deaf experience. She tells me about one of her deaf friends, who had also received a cochlear implant. This friend had met a girl who had been taking an American Sign Language (ASL) class. Sometime later, he was walking across campus and heard his name called out from behind and turned around and saw

⁷ Lee, C. (2012). Deafness and Cochlear Implants: A Deaf Scholar’s Perspective. *Journal of Child Neurology*, 27(6), 821-823.

the girl. She said admiringly, “Wow, it’s like you’re not deaf!” Sophia sums it up for me: “He was offended.”

Understandably, most hearing parents hope their deaf children can share their culture and native language. Studies have shown that a strong majority of parents cite “desire for oral communication” (and similar motivations) as the top reason for why they chose pediatric cochlear implantation.^{8,9} Indeed, many parents believe that knowing spoken English and developing the child’s hearing will open up more academic, professional, and social avenues for him/her to pursue. In his article, “Refusing Cochlear Implants: Is It Child Neglect?” bioethicist Julian Savulescu strongly argues for pediatric cochlear implantation –

When a couple deny an existing child a cochlear implant, they deny that child the opportunity to hear speech, sound, music and to participate in the dominant culture, as well as being able to participate in a signing community. They make that child worse off.

This is analogous to a deaf couple with a hearing child who, wanting that child to be like them, deafen that child. That would be child abuse.

[...] To my knowledge, no hearing adult has ever freely chosen to become deaf. But it would be easy to achieve. So the cochlear implant affords the deaf child an extra option: to be deaf or hearing later in life.¹⁰

Like my mother and father, a number of ethicists have agreed with Savulescu, maintaining that parents have a duty to provide their children with “an open future,” a possibility that can occur most readily with pediatric implantation.¹¹ Though opponents have claimed it would destroy Deaf culture, another bioethicist Neil Levy concludes, albeit regrettably, that deafness is still a natural disability and that hearing parents have absolutely no obligation to Deaf culture: “To be

⁸ Hyde, M., Punch, R., & Komesaroff, L. (2010). Coming to a Decision about Cochlear Implantation: Parents Making Choices for their Deaf Children. *Journal of Deaf Studies and Deaf Education*, 15(2), 162-178.

⁹ Okubo, S., Takahashi, M., Kai, I. (2008). How Japanese Parents of Deaf Children Arrive at Decisions Regarding Pediatric Cochlear Implantation Surgery: A Qualitative Study. *Social Science & Medicine*, 66, 2436-2447.

¹⁰ Savulescu, J. (2009, July 19). Refusing Cochlear Implants: Is it Child Neglect? *Practical Ethics*. [Web log comment]. Retrieved from <http://blog.practicaethics.ox.ac.uk/2009/07/refusing-cochlear-implants-is-it-child-neglect/>.

¹¹ Ouellette, A. (2011). Hearing the Deaf: Cochlear Implants, the Deaf Community, and Bioethical Analysis. *Valparaiso University Law Review*, 45(3), 1247-1270.

born a potential member of a culture is not to be born a member of that culture...Deaf activists and their supporters have no right to impose the burdens of deafness on hearing-impaired children.”¹² Despite his acknowledgement of the unique values of Deaf culture, Levy ends his article on this verdict.

On the other hand, opponents of pediatric implantation have commonly argued that its implementation reduces self-esteem and confuses identity as it signifies the child must be *cured* and aspire to mainstream notions of normality. In fact, parents have expressed concern for their child’s possible identity crisis; in one study, a mother stated, “I told [a deaf mother] about our plan for our daughter to receive an implant and she called my child a ‘social outcast.’”¹³ Furthermore, implantation (especially coupled with a mostly oral education) could prevent the child from entering into Deaf culture, eliminating the child’s opportunity to participate in a supportive, vibrant Deaf community. Indeed, by engaging in the Deaf community, a deaf child gains access to a unique world of art, storytelling, humor, history, mentorship, etc., all features that could potentially boost the child’s sense of self-worth and make him/her a proud and contributing member to Deaf culture and, possibly, hearing society too. The issue of the child’s identity comes to the forefront when one considers the imperfect nature of the cochlear implant and the need for a lengthy rehabilitation period that requires extensive parental and professional involvement. At best, pediatric cochlear implantation provides the child with moderate to light hearing impairment.¹⁴ Of course, the fact that the decision to undergo implantation surgery must be made at a young age, often when the child cannot express his/her wishes, makes choosing or not choosing a cochlear implant difficult for parents as well. Parents of deaf children are

¹² Levy, N. (2002). Reconsidering Cochlear Implants: The Lessons of Martha’s Vineyard. *Bioethics*, 16(2), 134-153.

¹³ Okubo, S., et al. (2008).

¹⁴ Hawker, K., Ramirez-Inscoe, J., Bishop, DV., Twomey, T., O’Donoghue, GM., & Moore, DR. (2008). Disproportionate Language Impairment in Children Using Cochlear Implants. *Ear and Hearing*, 19(3), 467-471.

frequently not exposed to members of the Deaf community and their opinions. This consequently raises problems of informed consent, but gaining knowledge of Deaf culture, and thus being aware of the cochlear implant controversy, does not necessarily make the decision easier; if anything, that decision could be more difficult.¹⁵

Because entry into Deaf culture is so contingent upon learning sign language, the issues of rehabilitation and identity formation grow even more complex. The medical community has historically promoted speech and discouraged signed language use, so many pediatric patients have spent much of their childhoods developing oral and aural skills, time which, for at least some, may have come at the cost of developing actual *language* ability. In 1992, Professor Robert Ruben strongly emphasized this distinction between speech and language: “The cochlear implant could not provide a sufficient ‘flux’ of aural language input during the vital second and third years of the child’s life. Only sign language could do that.”¹⁶ In other words, given that cochlear implantation *may* allow the patient to develop almost normal speech but that there *is* a possibility of failure, how should, or could, one effectively divide efforts spent at learning speech or signed language, the much more fail-safe outcome? This is an important point, since even with today’s technology, it is impossible to predict accurate results for an individual’s success with cochlear implantation.^{17,18} Added to patients’ concerns are the risks associated with the surgery and recovery process itself, including increased risk of infection and meningitis, nerve disorder, and restrictions on daily activities (e.g. participation in some sports).¹⁹

¹⁵ Qtd in Hyde, M., et al. (2010).

¹⁶ Blume, S. (2010).

¹⁷ Hawker, K., et al. (2008).

¹⁸ Kermit, P. (2012). Enhancement Technology and Outcomes: What Professionals and Researchers Can Learn from Those Skeptical about Cochlear Implants. *Health Care Annals*, 20, 367-384.

¹⁹ Okubo, S., et al. (2008).

Lastly, Deaf scholars have argued deaf children have a right to Deaf culture due to their physical make-up and that it is the parents' responsibility to ensure the child has the means to access this culture.²⁰ Levy argues against this, stating that assuming one's culture solely off race, or some other physical aspect, is a form of racism (i.e. one cannot conclude every black person identifies with black culture just as one cannot automatically say a deaf child should belong to Deaf culture upon birth) and that parents "have no *special* obligations to a culture that has played no role in forming their identity, and to which their child only potentially belongs (after all, thanks to the availability of cochlear implants, they *also* potentially belong to the hearing world)."²¹ Nevertheless, even if parents have no such obligations, would not introducing the child to the Deaf community constitute a different form of limiting his/her options for an "open" future?

The Sharing and Preservation of Deaf Culture

In March 2011, my college hosted Hands Across the Water: An International Festival of Sign Language Poetry. Deaf poets from across the United States and United Kingdom arrived at our makeshift performance venue, sharing their experiences and memories in verse. Sophia and I sat off to one side, absorbing the beauty of the visuality, in both ASL and British Sign Language (even though neither of us knew BSL). We watched quietly as one metaphor melted seamlessly into another, one image into another, more fluid than any written or spoken language could achieve. Poetry became dynamic; it literally moved – back and forth, across the stage, arms opening and closing, hand shapes as rhymes and rhythm.

Deaf art and literature have gained much publicity in the last few decades, especially as the use of video technology to capture and share sign language became increasingly prevalent.

²⁰ Lane, H. & Grodin, M. (1997).

²¹ Levy, N. (2002).

Today, sign language poets, including Ben Bahan and Ella Mae Lentz, are well known in the Deaf community for their work. One year, Sophia even had her art exhibited at a local gallery in our hometown. Throughout high school, I watched my sister work on her numerous art pieces, so many of which showcase aspects of her Deaf identity: rubber stamps of the ASL alphabet, a painting of a figure reaching out for ASL letters, scissors cutting through a handicapped sign, a huge eye surrounded by ears. While I wrote my poetry, she sketched or painted, large sheets of paper spread out flat against the floor, fingers shiny black with graphite.

The extent of pediatric cochlear implantation in recent years has caused much concern for Deaf communities around the world. As children are consistently taught spoken language and implanted earlier and as technology improves, signed languages and Deaf culture may be relegated to the sidelines (or disregarded entirely) for new deaf generations and their (mostly) hearing parents. In 2006, researcher Trevor Johnston noted numbers of deaf people were declining and that Auslan (Australian Sign Language), if not used and passed on, could be considered an endangered language.²² Because the trends seen in Australia mirror those found in other developed countries, the plight of Deaf culture remains precarious, and steps should be taken to protect it.

The widespread implementation of cochlear implantation thus seems to counter this very goal. Bioethicists have long respected the wishes of legal guardians, and this holds true for both hearing parents of deaf children, who turn towards cochlear implantation and deaf parents, who reject it. Because of this desire to honor individual choices, banning the surgery seems pretty much impossible in the future. However, assuming implant technology improves to the point

²² Johnston, T. (2006). W(h)ither the Deaf Community? Population, Genetics, and the Future of Australian Sign Language. *Sign Language Studies*, 6(2), 137-173.

where it does provide perfect hearing, the size of the (potential) Deaf community would dwindle drastically (over 90 percent of deaf children are born to hearing parents), threatening the existence of Deaf culture altogether. Because of this endangerment, Sparrow questions whether public funding should be diverted to cochlear implant research,²³ especially since the United States tries to adhere to tenets of the United Nations Declaration of the Rights of Persons Belonging to National or Ethnic, Religious and Linguistic Minorities.²⁴ From the perspective of the cultural model, promoting cochlear implantation research would violate these principles.

The issue of Deaf culture preservation is more complex when the plight of deaf people in developing countries is taken into account. Johnston argues developed countries have an obligation to protect and encourage the growth of Deaf cultures in developing countries,²⁵ but would that come at the expense of the well-being of the individual deaf child? In a country where Deaf culture and sign language have not been as strongly established, a deaf child may not have many opportunities at all without participating, at least in part, in the larger mainstream. By providing the deaf child with oral/aural skills, cochlear implantation would assist this participation, and perhaps, denying him/her with the implant would be a very real form of neglect in this situation.

And yet even obtaining a cochlear implant in these developing countries raises an entire new set of issues. Parents are not always informed about the surgical process or the lengthy rehabilitation process (in one case, a parent said he would have strongly objected to implantation if he had known the true quality of sounds the implant provided his son),²⁶ and rehabilitation tests are not always up-to-date or applicable in these countries, especially when the spoken

²³ Sparrow, R. (2005).

²⁴ Lane, H. & Grodin, M. (1997).

²⁵ Johnston, T. (2006).

²⁶ *Voices of El Sayed*. Dir. Oded Adomi Leshem. Belfilms, 2009. DVD.

language is not similar to English (e.g. Arabic or Chinese).²⁷ Due to the high expenses associated with cochlear implantation (prices can readily exceed \$40,000, especially when rehabilitation and upgrade costs are included²⁸), many successful implant surgeries in developing countries have relied on donations from developed countries,²⁹ though there have been efforts to build cheaper multi-electrode implants.³⁰ However, the fact that these implants are so pricey could create a rift between those who can and cannot afford the surgery and rehabilitation. This is true even in the United States – though “lower-income children are twice as likely to be deaf as higher-income children,” nearly 75 percent of children who received cochlear implants lived in more affluent areas³¹ – and the discrepancy is likely to be even larger in developing countries. In other words, cochlear implantation could create its own disparities, compounding inequalities that already exist between hearing and deaf, high-income and low-income, families.

Moving Forward

On a cloudy, drizzling Sunday in early June, my friend and I find ourselves in the middle of the annual Rochester Deaf Festival. We wander slowly along the trails, walking from booth to booth and trying to communicate in our (work-in-progress) sign language to the vendors. I buy a bright blue t-shirt for Sophia as a souvenir; the front reads, “Can You Read My Hands?”, with the “Hands” part spelled out in the ASL alphabet. All around us, we see excited deaf people, who, if they do not know each other already, are eagerly introducing themselves.

Seeking familiar faces, we find the booth dedicated to the National Center for Deaf Health Research, the organization we are interning for that summer. We ask about how many

²⁷ Zeng, F. (1996). Cochlear Implants in Developing Countries. *Contact*, 10(4), 5-9.

²⁸ Cochlear Implant Frequently Asked Questions. (2013). *American Speech-Language-Hearing Association*. Retrieved from <http://www.asha.org/public/hearing/Cochlear-Implant-Frequently-Asked-Questions/>.

²⁹ Ibid.

³⁰ Ibid.

³¹ Stern, RE., Yueh, B., Lewis, C., Norton, S., & Sie, KCY. (2005). Recent Epidemiology of Pediatric Cochlear Implantation in the United States: Disparity Among Children of Different Ethnicity and Socioeconomic Status. *The Laryngoscope*, 115, 125-131.

people the researchers have been able to recruit for the deaf health survey, nibble on some of the candy they have scattered across the table, and joke, “How can you be serving candy when you are telling people to eat healthy?” Across the field, the performance for the festival is beginning; a charismatic deaf man in a suit stands on the stage, inviting people to participate in his trivia game. In the background, an interpreter voices over his signs. Standing there, watching a silence made alive, I realize I am the one who needs communication assistance; arguably, I am the one with a “handicap.”

Personally, I agree with bioethicists in that one should respect the choices parents and guardians make on the behalf of their children, but I also believe the medical and cultural models of deafness should be presented so that they may arrive at the most informed decision. After graduation from college, I am fortunate to be able to continue my studies in Rochester, New York, home to the largest deaf population in the United States. As an aspiring doctor, who one day hopes to work with deaf patients and families with deaf children, I will strive to be sensitive to differing sides of controversial ethical issues, including pediatric cochlear implantation. Having seen my sister’s experiences in the hearing and Deaf communities, I want to remain open-minded to public constructions and displays of normality and diversity.

As for the issues of funding cochlear implantation and the plight of Deaf cultures in the developing world, I honestly do not know how to effectively grapple with these dilemmas, though I realize these problems will probably grow more difficult in the future. The Western world places much emphasis on scientific advancement, and this has given patients hope and vastly improved our lives. Earlier this year, three pioneers of cochlear implantation, Graeme Clark, Ingeborg Hochmair, and Blake Wilson, were honored with the prestigious Lasker-DeBaakey Clinical Medical Research Award, reflecting the scientific community’s admiration for

their collaborative efforts to “cure” deafness.³² And yet, we would be losing something valuable and wholly unique in destroying Deaf communities and signed languages; to some, this would be a form of cultural genocide. I cannot imagine Sophia without her Deaf identity, and I do not know if she would have been able to find the same sort of understanding and friendship in hearing society as she did in the Deaf world.

In American Sign Language, there is a sign that translates roughly into “hearing-centric.” One uses his/her hands to signify a box around the ear, condemning the obsession with only seeing the deaf person’s loss of hearing and not the whole individual. To me, the sign seems to say, “Let me be the way I am, and accept me for it.”

The bioethical debate surrounding pediatric cochlear implantation (and, more broadly, the intersection of scientific advancement and societal values) has forced, and will continue to force, us to change the ways we think about multicultural societies, cultural preservation, and identity formation. Indeed, we should all learn to hear (or rather, see) the voices of others, including those from Deaf communities, even when that voice is silent – especially when it is silent.

³² O'Donoghue, G. (2013). Cochlear Implants – Science, Serendipity, and Success. *The New England Journal of Medicine*, 369(13), 1190-1193.

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