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# Cochlear Implants: A Multi-perspective Look at a Powerful Controversy

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### Cochlear Implants: A Multi-perspective Look at a Powerful Controversy

Ruth Tag Western Washington University Honors Program Senior Project Advised by Dr. Kimberly Peters Spring Quarter, 2015 Medical advancements have progressed to the point in which new organs can be printed from machines and placed in human beings giving them years more to live. Mechanical limbs are manufactured so that amputees can compete in the Olympic games. People who are born with a physical disability may be able to compensate through medical or surgical interventions, allowing for wider participation in society. These medical advancements challenge the way we define disability and more importantly how we define what is normal. For this paper, normal, or typical, will be defined as a person without a physical characteristic deviating from typical physiological development.

#### **Literature Review**

Cochlear implants are small devices inserted into the inner ear to stimulate dead hair cells, which are a cause of sensorineural hearing loss and sometimes deafness. The external portion of the device is made up of the microphone, speech processor, and transmitter. Sounds are detected by the microphone, "coded" by the external processor and turned into electrical impulses by the transmitter. Those pulses are then sent to the internal portion of the implant called the electrode array, which sends each impulse to the correct section of the membrane inside the cochlea. Early versions of cochlear implants had one electrode on the array whereas now there are many, vastly improving the performance of the implant. The hair cells in the inner ear are no longer functioning, so the implant stimulates the spiral ganglion of the cochlea and the VIII nerve. Information is then sent to the brain. An implant is different than a hearing aid, which simply amplifies sound. Cochlear implants bypass the outer and middle ear and go right to the source of the damage. This does not restore completely normal hearing, but provides the listener

with the sounds of speech and more auditory cues to understand spoken language (Schow & Nerbonne, 2012).

Cochlear implants are approved for infants 12 months of age and older. The earlier the child is implanted, the higher the success rate for acquiring and processing spoken language. For implantation, the patient must undergo surgery, followed by intensive therapy to familiarize themselves with the device and how best to use it. Without intervention after surgery, the child often will not able to make sense of new auditory signals coming into the brain and progression in spoken language acquisition will be hindered. Implantation is a process that needs tracking and attention to ensure success (Downs & Northern, 2012).

Language development in children is crucial to the acquisition of related communication skills, hopefully leading to a successful and diverse life. Children with cochlear implants tend to develop language later than normally hearing children, even when implanted at a very young age. Because language and communication are central to relationships and bonding, prior to surgery, parents of deaf children may embrace sign language as a viable choice. Signing gives the child a basis for language and the potential to be bilingual once spoken language is developed. The process of acquiring sign language introduces the child to a language-learning environment that brings together visual, tactile and auditory cues that give them the tools to process those stimuli in terms of spoken language (Humphries, Kushalnagar, Mathus, Napoli, & Padden et al, 2014).

The most successful combination for implanted children is early access to signing, and continued use of signs to help acquire spoken language. These children tend to follow the trajectory of normal developing children and are more likely to maintain their bilingualism well into adulthood. However, most hearing parents do not teach sign language to their deaf children,

and the children are exposed to signing only after they have begun to speak. This is significant because, along with language acquisition, literacy and theory of mind are skills that depend on the ability to understand patterns of language. Exposure to sign language early in life is a way of getting these patterns of morphology and syntax going in the brain, even if the signing is not perfect. Normally hearing parents who sign to their implanted children provide them with this access as well as auditory cues for spoken language (Lederberg, Schick, & Spencer, 2013).

Most of the decisions about first language are made in the home, and depend heavily on the preference and background of the parent. The quality of language acquisition also relies on parental modeling and encouragement. In some instances, parents feel the need to choose either sign or spoken and the child looses out on multiple tools to potentially increase language learning skills. The child also misses the opportunity to support one language with the other.

Often in bilingually implanted people, they speak and sign at the same time, giving themselves more expressional freedom and understanding for the listener (Humphries et al, 2014).

Deaf education is important in the schools for those children whose parents have normal hearing. Sign language skills of children born to hearing parents lag far behind those born to deaf or hard of hearing parents (Knoors & Marschark, 2012). Many implanted children enter school without being fluent in either sign langue or spoken language. This makes the provision of services hard because the school must decide how to support either or both. Putting deaf or hard of hearing children in a special setting or classroom is often hindering in their development in reading and language because of lack of proper interaction with peers (Marschark, Shaver, Nagle, & Newman, 2015).

A significant amount of deaf adolescents and adults seek out sign language that they were not exposed to as a child. Most of these people are the children of hearing parents and were

taught spoken language when they were implanted, resulting the in discontinuation of sign language. Later in life, the draw of the Deaf community contributes to the desire to re-learn signing (Knoors et al, 2012)

The situation of deaf or hard of hearing children learning language is complex and involves many sources of input. Family, self, school, and peers are just a few of the defining factors that shape a deaf person's language experience. When children are young, parents make the decisions and as a child matures, influences and priorities may change. Teenagers and adult may choose to affirm, rebel, or adjust their language and communication options. The tension between influences may create differing opinions on cochlear implants. This controversy is a real debate with real consequences. In the following discussion section, this paper will examine the feelings and experiences of both deaf and hearing people who are living within this debate.

### **Discussion**

People with common challenges, physical, intellectual, or social, have traditionally bonded together and formed communities. These collective groups support, advocate and advance public understanding and awareness of various conditions. The Deaf community is one of the oldest and strongest groups to fall into this category. Over the course of history this community has maintained that being Deaf is not a disability, but an opportunity to live a different but equally rich life.

Throughout history the Deaf community has been categorized by the hearing population as a disabled group. Often institutionalized along with the insane and criminal, the real root of this culture was the bringing of Deaf people together under the cloud of abuse and misunderstanding. Although hearing loss today is seen as much less hindering, the laws and

institutional bias often remains. The National Association of the Deaf was the first civil rights organization in the United States. After it was established in 1880, the organization fought for legal and social understanding of Deafness. Laws such as the Americans with Disabilities Act passed in the 1990 prohibited discrimination on the basis of a physical or mental disability. However, this law also placed deafness in the category of disabilities, falling in line with outdated and often uneducated policies of the past. The Deaf world sees state power and the institutionalization of cultural ideals as a main cause for the alienation and wrongful categorization of deafness (Teagle, 2007).

In 1957, two doctors accidentally restored the hearing of a bilaterally deaf patient after trying to reanimate his paralyzed facial muscles. This led to the development of the cochlear implant, a device meant to re-stimulate dead hair cells in the ear. For some, this may seem like a miracle realized. People who had no prior access to sound were able to hear and live what many might consider a normal life. From the perspective of a hearing-centered society, it is easy to assume that people want to be able to hear. However, members of the Deaf community do not necessarily share this view. This paper will take apart the main arguments for what has become a contentious issue, and attempt to educate the reader about the impact this controversy has on world (Teagle, 2007).

The majority of categorized deaf people become deaf after acquiring English and going through some schooling. This means that most deaf people do not use sign language, do not have Deaf spouses and are not involved heavily in Deaf culture. The small group that identifies with the Deaf culture consider themselves a distinct ethnicity. There are requirements that define an ethnic group as distinct, including a collective name, feelings of community, distinct values, and norms for behavior, knowledge and customs. Deaf culture fulfills these requirements. In

addition, there is a rich social, historical and artistic background to this group. Fundamentally, what the Deaf world undoubtedly has is an allegiance to their culture. Those within it identify themselves proudly and fully with this distinct group. National and international organizations support and help the advancement of Deaf communities all over the world, and encourage the education of other citizens about the legitimacy of this collective. Within this rich and varied cultural context, the resistance to cochlear implants as a repair for a diminished lifestyle or physical deficit becomes more understandable (McKellar, 2012).

The Deaf community has always been wary of government involvement in their affairs. American Sign Language, for example, drew resistance from the Deaf community when it was first proposed to be an official foreign language that could be taught in the public schools. The Deaf pride movement in the 1980's centered on the education of children in the Deaf community. In the absence of deaf children learning language and customs from their immediate and hearing family, Deaf people sought to be that support for infants and children. A hearing parent is very unlikely to encourage their child to immerse themselves in an unfamiliar culture from their own. These children were seen as lacking the opportunity to identify as Deaf, a service that only someone familiar with Deaf culture can provide (Mirus, 2007).

Since most deaf children are born to hearing parents, there is often little opportunity for them to be exposed to Deaf culture unless they meet other Deaf children at school or in a support group. Most deaf children born to hearing parents do not fully acquire sign language, or lose it once they are implanted (Sparrow, 2005). Parents often fail to encourage children to attain sign language, because they don't see it as an integral part of that child's cultural education. Education that is focused on learning and using English, instead of sign language, is another way to tell deaf children that the body they were born with is contradictory to the norm and they must

be rehabilitated until they function at a standard level. Cochlear implants are seen as the number one weapon used in this cultural war. Gallaudet University's president once said, when asked if he would rather be hearing, "That's almost like asking a black person if he would rather be white. I don't think of myself as missing something or as incomplete...It's a common fallacy if you don't know Deaf people or Deaf issues. You think it's a limitation" (Harlan, 2005).

Not only does the Deaf community reject the idea of deafness as a disability, there is also a pushback against the medical risks that cochlear implants present. Bacterial meningitis, long hospital stays and potential other infections overshadow the fix-all attitude that medical experts sometimes present. Also, although cochlear implants do provide access to sound, they do not produce perfect hearing. The implanted child will never have full access to acoustic cues. Members of the Deaf world argue that such risks, for what they define as so little real gain, do not outweigh the opportunity to be a part of a community like theirs. They also compare surgical repair such as this to experiments tried on people with perceived disabilities throughout history. The main argument is that if surgeries such as this needed consent from an adult who was also Deaf, they would hardly ever take place. In fact, the children of Deaf parents rarely get implanted (Gonsoulin, 2001).

Cochlear implants cannot be simply classified as a medical advancement for people suffering from deafness. This description ignores the belief within the Deaf community that the systematic changing of a deaf person's physiological auditory make\_up\_is the beginning of ethnocide against a culture. This tight-knit minority feels that the eradication of deafness through the use of medical procedures such as implantation is no better than the medical correction of other disabilities as defined arbitrarily by the majority population. Deaf children born to hearing parents are seen as not having the choice or opportunity to identify with their own culture as well

as their parent's culture. To deny them this right is one way the majority culture can wipe out Deaf culture and the support it provides to those with hearing loss (Gonsoulin, 2001).

Sign Language is perceived to be a secondary language, used by those who could not acquire English, and is less desirable than traditional spoken language. However, sign language is a rich and diverse language, with unique syntax, vocabulary, and grammar. Children who are implanted are much less likely to use and be taught sign language, because jobs and family require that they use spoken language. Medical professionals who hail cochlear implants as the cure for deafness show a lack of understanding of the perspective of those who are actually deaf. These engineers and doctors are also the individuals profiting the most from this invention, in the selling and developing of the product. They can therefore not claim all motivation as humanitarian. Resisters of the implant movement claim that children who are implanted will still face discrimination and hardships in their life simply because of their biological makeup and will then lack the support of a culture designed to stand behind them. If action is not taken to inform people about the depletion of Deaf culture, it will most likely slowly die out, as 90% of deaf children are born to hearing parents (Sparrow, 2010).

There is a common misconception that parents are fully informed about cochlear implantation. In reality there is very little information circulated to the general public about cochlear implants and the choices patients have regarding them. When a parent is faced with the choice of implanting their child, most of the information comes from the doctor, who is more than likely to be in favor of the procedure. There is little information about the Deaf community provided, or the opportunities and support the child could have without the use of technology (Gonsoulin, 2001).

Far fewer adults who become deaf post-lingually seek implantation. This is mostly because of the strong community that is more easily accessed by adults than children born to hearing parents. Individuals who participated in the Deaf community found little need for an assistive communication device like an implant because of the fully functional language that is sign language. In general, the medical field has shifted more towards convincing parents of deaf children to proceed with the surgery. They often feed off a parent's need to overcome their child's deafness and find a cure. The Deaf community sees this as a threat to Deaf culture and a gross misunderstanding of the power of life without hearing (McKellar, 2012).

The implantation of children is especially controversial because the children themselves do not have a full understanding or ability to consent. Since most deaf children are born to hearing parents, there is often a sense of urgency to bring the child into a world where the parents are comfortable and feel they can communicate with their child. A current movement within the Deaf community focuses around the idea that only legal adults should have the option of being implanted. Once a deaf child has grown up, he or she can be presented with both options and a choice can be made to either continue to live in Deaf culture, or to pursue spoken language and English as the primary choice of communication (Weisleder, 2012).

A poignant fear about imposing implants on deaf children is that they will fit into neither hearing culture nor Deaf culture. By altering their physical condition, the implants are wrenching them out of the possibility of community support. The variable and often less ideal performance of the implant ensures that these children will not fit in entirely into hearing culture. Children with cochlear implants require lots of rehabilitation and often face learning challenges in school. If later in life they decide for themselves to have implants, they will already have the base support of the Deaf community. Living in an in-between world will be a choice. Ethnocide, lack

of education and the inability for children to choose, all color the Deaf community's concern about the development of cochlear implants. The issue goes beyond the medical cure and impulse to fix a condition that does not take away the ability for an individual to flourish in society (Weisleder, 2012).

The medical community has been instrumental in supporting the development of cochlear implants and encouraging parents to implant their children. The Hippocratic oath specifies that physicians have a duty to "do no harm." Hearing loss is classified as a medical diagnosis, and deafness is the most severe level of this diagnosis. Cochlear implants as a cure for deafness are seen as very effective in helping patients regain hearing. Doctors often feel ethically responsible for helping patients have the quality of life that they desire and deserve (Harlan, 2005).

The first argument that the Deaf community uses to unite themselves against the curing of deafness is the claim that they are a culture. The American with Disabilities Act of 1990 defines hearing loss as a disability to which governmental benefits are applicable. A disability is most commonly defined as a failure to achieve a certain standard of function (Gonsoulin, 2001). Annually, upwards of \$120 million is spent on hearing impaired education in the United States. It seems hypocritical for a community so intent on displaying itself as a solid culture and proud of the bodies they were given to accept government funding. This argument rests on the idea that a hearing person can choose willingly to learn ASL and participate with Deaf culture, whereas a deaf person works from a deficit and cannot fully participate in the hearing world without full access to sound (Harlan, 2005).

The Deaf community maintains a claim over deaf children born to hearing parents. This community believes that these children should be taught about life by a Deaf adult who understands what it is like to live on the outside of a hearing worlda Deaf adult who understands

what it is like to live on the outside of a hearing world should teach these children about life. The opposition to this view points out that no one has legal or moral claim to a child's education and wellbeing outside of the child's parents. Implantation for deaf children is done overwhelmingly by hearing parents, in an effort to include them in the hearing world (Gonsoulin, 2001).

Developmental malleability of the brain is responsible for the effectiveness of implantation. The earlier a person is implanted, the more successful the procedure will be in terms of learning spoken language. This is often why it is up to the parents to choose whether or not to do the procedure, as the child is generally not old enough to make the decision. Those in the medical community maintain that the surgery is effective and safe. Children are able to hear and speak with audiologic rehabilitation after implantation. The complications involved with the surgery are minor, aligning with complications present in any surgical situation. The majority of the time, the surgery is successful in restoring sound to the deaf person, giving them access to auditory cues. This is an important step in engaging the implanted person in the hearing world. The notion triumphed by the Deaf community, that because the implant does not cure deafness it inflicts cruel and unusual physical pain on the patient, is simply not true. Even though cochlear implants are not a cure, medical research shows that surgery is effective in providing the listener with enough auditory cues to begin to understand speech with the aid of therapy (Cochlear Implants).

The president of the National Federation for the Blind, Marc Maurer stated that, "To assert that there is a culture of blindness would be to argue that this one characteristic alters an entire pattern of thought and behavior, which is to overstate the case. (Weisleder, 820)" This can be directly applied to the idea of Deaf culture, and the social bond that puts them in the same societal situation. However, it also disproves that Deaf culture needs to by politically protected

as a distinct ethnic group. Both of these physical impairments are isolated to one part of the body, and are not life-threatening in themselves. People in each group tend to gravitate towards others with the same disadvantage in life. The blind community faces harsh employment discrimination, and only about 15% of blind children are taught to read braille. This is similar to the failure to teach deaf children sign language at an early age. Like the Deaf community, organizations have risen up to help fight injustices and inequalities imposed on blind people. However, a shared experience does not constitute an entire culture that is under threat. The key is that cochlear implants are an assistive device meant to improve the quality of life and ease of maneuvering through a hearing world. They are not machines that threaten to take away everything from a certain group of people (Weisleder, 2012).

The benefits of sound go far beyond access to spoken language. Cochlear implants provide social and emotional cues that are vital to a child's development. Auditory cues also greatly impact other skills such as executive functioning, sensory-motor control and sequencing. The sensory deprecation that occurs if there is no exposure to sound inhibits this form developing on a normal trajectory. Fagan and Pisoni (2009), in their article about sensory inputs for implanted children, state "Attention to the various sounds and auditory effects in their environment, and to the auditory consequences of their own actions, provides hearing infants with the multisensory experiences they need to establish cause and effect relationships, and understand the links between perception and action, and acquire new concepts that depend on sound perception" (459). With this in mind, uncoupled sensory information often leads to altered neural development and impacts the perceptual organization parts of the brain in children. With implantation at a young age, auditory pathways being functioning relatively soon, giving the child access to multisensory input that can aid significantly in development. Even though

cochlear implants have varying degrees of quality, children respond well to limited amounts of auditory input and still tend to perform at the level of their peers. Quality of input can be altered due to the number of electrodes the device places in the cochlea as well as the age and wear of the implant. Regardless of the degrees of output by the electrodes, children who have access to both visual and auditory sensory input demonstrate better development along the normal trajectory in terms of neural and processing maturity (Fagan, 2009).

An important statistic in this debate is that 90% of deaf children are born to hearing parents (Teagle, 2007). Without a full understanding of each side of the issue, parents cannot make informed decisions about their child's well being. The Deaf community argues that these parents have little to no idea about the positive impact on a child resulting from being involved in Deaf culture, Deaf people are fully functioning in society, with jobs and college degrees and a mindset that they do not have a disability but an opportunity to see the world though a different light. Cochlear implants, according to many Deaf people are not worth the surgical risk and do not cure hearing loss well enough to be justified. Doctors and those in the medical community, on the other hand, maintain that the child is being denied the right to the auditory world, and that it might have a negative impact on the child's development if they are not implanted. Neural developments as well as psychological processes are impacted when a child is deprived of auditory sensations. The technology has advanced so that the cochlear implant can offer a wide variety of pulses to the brain, not just a single electrode. Another overarching issue is that children are not old enough to make their own medical decisions, but many feel that they are the only one who can truly determine what course their life should take. Although there have been several studies on post-implanted teenagers and their reaction to being implanted, each individuals experience is what shapes this debate. There is no overarching correct answer that

<u>eliminates the decision that must be made.</u> The most important part of this debate is that both sides disseminate factual information, in an effort to find the best for deaf people. No matter each individual's decision, they should feel supported and know that choice was best for them.

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