

Deaf is Dandy: Contrasting the Deaf and Hearing Cultures

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INTRODUCTION

Often ignored or stereotyped, the Deaf culture drifts in and out of the mainstream consciousness generally when issues such as cochlear implants surface. Most of the hearing culture consider the Deaf as handicapped or broken. They are regarded as not fully functioning people who need to be "fixed" so they can assimilate into the hearing world. However, the Deaf consider this as an inaccurate picture of their life. Members of the Deaf culture acknowledge that they are deaf, but do not see themselves as broken or impaired. They have their own culture. They are proud of it. They do not want to be a part of the hearing culture.

Our purpose in this article is three-fold: to describe the Deaf culture, to analyze the conflicting views on cochlear implants and to examine some of the arguments made in the Michigan implantation case.

THE DEAF AND DEAF WORLD

Although both are parts of a large community, deaf or hard of hearing people identify themselves as either deaf or Deaf. People who are impaired in their ability to hear well enough to rely on their hearing and use it as a means of processing information are deaf. These people may have been absorbed into the hearing society and do not see themselves as members of a separate culture. On the contrary, Deaf people identify themselves as members of a separate culture (Tucker, 1997). Padden and Humphries (1988) clarify that the lower case deaf is used when making a reference to the medical condition of not hearing, and the uppercase Deaf when referring to a certain group of deaf people who share a language – American Sign Language (ASL) – and a culture. Many individuals within the Deaf community consider being deaf more about their culture and their lives than about audiology (Bruegemann, 1999; Lane, Hoffmeister, & Bahan, 1996; Wrigley, 1996). Culturally Deaf individuals consider themselves a linguistic minority with a visual language, American Sign Language. The members of this group have inherited their sign language, use it as a primary means of communication among them and hold a set of beliefs about themselves and their connection to the larger society. The Deaf are separate from those who lose their hearing because of illness, trauma or age, and who do not have access to the knowledge, beliefs, and practices that make up the culture of Deaf people.

Hard of Hearing (HOH) people are those who have a mild or moderate hearing loss. Though HOH people can choose to be a part of or apart from Deaf culture, they typically do not wish to have any cultural connections with the Deaf community. However, they may have

more difficulty creating and maintaining a gratifying cultural and social identity away from the Deaf culture.

Deaf culture is distinctly different from the cultures of the hearing impaired, deaf community, and hearing society. It is clear that Deaf persons are proud to be Deaf when phrases such as "Deaf is dandy" are patented by the Deaf cultural community (Cherney, 1999).

Deaf culture has several facets, including Deaf attitude and Deaf organizations. Deaf attitude emphasizes the importance of Deaf culture, language, and supports its many groups and organizations. The groups include Deaf clubs, church services, and sports teams. Deaf organizations are social and political, and include "local, state, and national associations, such as Deaf Olympics, the National Association of the Deaf, and the World Federation of the Deaf" (Harris & Vanzandt, 1997, p. 4).

An important concern for the Deaf community is that they share the same values, experiences, and language. The most common communication used by Deaf Americans is American Sign Language (ASL). Cherney (1999), describing ASL as the language of the deaf, places it at the center of Deaf culture, more central than the loss of hearing. He states:

Researchers began to recognize the Deaf culture in 1965 when Bill Stokoe, Carl Cronenberg, and Dorothy Casterline published the Dictionary of American Sign Language. The dictionary made two important arguments: that ASL was a complete and sophisticated language and that the community of ASL users had developed a unique Deaf culture. While both ASL and the Deaf themselves had obviously existed prior to 1965, the dictionary sparked a shift in consciousness by declaring ASL a viable language and by identifying several of the cultural characteristics of its users. Until this time, ASL was mistakenly thought of as a signed version of English or a coded version of some other spoken language and was generally considered inferior to other languages" (p. 27).

Although sign language is not universal-Deaf people from different countries communicate with different signs-all sign language is organized in a linguistic way with specific markers: palm orientation (palms showing or not showing, and location of the hand), hand shape (sign being used), and movement of the hands (fast, slow etc.).

For grammatical signals, ASL users utilize eye movements, expressions of the face, and body and spatial agreement. For instance, a frowned eyebrow usually implies a question.

ASL differs from the English language in syntax, grammar, and word order. In spoken languages, the words are often put in a different order; the same is true of ASL. If an English speaking person would ask, "Have you been to San Francisco?" A Deaf person would sign "Touch San Francisco yet you?" (Tucker, 1997).

With their hands and body/facial expressions, Deaf people can communicate as many abstract and intangible ideas as the hearing can with words. The hearing, however, are reluctant to learn this form of communication. When hearing parents have a deaf child, they consider a cochlear implant because they believe this would provide the child with access to spoken language.

COCHLEAR IMPLANTS

The cochlear implant is a system of electrodes which directly stimulates the auditory nerve, by-passing damaged cells to provide the sensation of hearing. It consists of internal parts that are surgically implanted under the skin behind the ear and external parts that are worn on the body. About a month after implantation, a microphone and speech processor are provided, and these are tuned to meet an individual's needs. Several professionals then provide long-term support.

Essentially, an implant allows deaf people to hear environmental sounds, although it does not dramatically change their ability to hear. Research on the effectiveness of cochlear implants in language development is complicated by a variety of factors. Early research included very small samples with a wide range of characteristics related to hearing loss.

Recently, researchers have found that profoundly deaf children with cochlear implants were likely to process auditory information as good as children with lesser hearing losses using conventional hearing aids (Geers & Mong, 1994; Geers & Toby, 1992). Further, Blamey, et al. (2001) found that on tests of speech perception, reception, and expressive language tasks, profoundly deaf children using cochlear implants performed at levels comparable to that of children with severe hearing loss using hearing aids. The researchers suggest that the positive findings may be because of recent advances in implant technology and because the children had used the implants for a longer period of time.

Crouch (1997) however reported that in a study conducted three and a half years after implantation, only 40% of the words spoken by children were understood by a panel of three people. Swanson (1997) quotes Hartley Bressler, a deaf physician who points out that the successes of the cochlear implant are publicized; the negative outcomes are not. Other researchers (Christiansen & Leigh, 2002) have stated that most research emerges out of those places that perform implants and, often, is more focussed on their successes.

Researchers (Tucker, 1997) have also found that the most successful implants occur when the child is young, so s/he can learn to speak during the critical early years when language acquisition is easy.

Cochlear implants on deaf adults, described as very traumatic, have not been as successful. Deaf adults experience culture shock as they attempt to negotiate the two cultures – the hearing and the Deaf.

Cochlear implants are not cures

Hearing people view the implants as help, a treatment, and a way out of a life that might be difficult. To hearing people, cochlear implants help deaf people “fit” into a world that is more oriented towards the hearing.

The Deaf however, perceive this issue differently. The majority of Deaf people take offense when hearing people want to take being deaf away from them. They feel that cochlear implants are :

The ultimate invasion of the ear, the ultimate denial of deafness, the ultimate refusal to let children to be deaf. Thus, the Deaf culture advocates are strongly opposed to cochlear implants, particularly the implantation on children. A former president of the National Association of the Deaf has denounced cochlear implants as a form of assault ... by zapping the auditory nerve tissue electrically (Tucker, 1997, p. 31).

Neil Marshall, president of the Alberta Association of the Deaf calls the implants "useless" and "extravagant." He states that illnesses and life threatening diseases should be given priority. He also said, "Being deaf is not a health problem." (McGovern, 1994, p. 34).

Others are angered by the tendency of many medical professionals, the media, and the hearing parents of deaf children to focus on the implant as a way of enriching the quality of life as though deaf people's lives were inherently impoverished without the implant (Christiansen & Leigh, 2002). There were also occasions when the Deaf community was not consulted in evaluations of the implant. For example, there were no deaf organization representatives in the formal program during the 1995 NIH Consensus Development Conference on cochlear implants in adults and children policies.

It is pertinent to note here that the deaf community in the United States and elsewhere is not a homogenous one. Rather, they represent the cultural, religious, regional, racial and other variations that exist around the world. However, as a culture, they are aware of the majority culture's ignorance of or negative perceptions of their culture.

MICHIGAN CASE ANALYSIS

A recent case in Michigan exemplifies the contrasting views on cochlear implants held by the hearing culture and the Deaf culture. It involved Lee Larsen, the Deaf mother whose two boys - three-year-old Christian and four-year-old Kyron - were deaf since birth. The two boys were in foster care for about a year. While custody was being resolved, the government sought to give the children cochlear implants. The mother refused, and the case was taken to court, where the mother argued that she did not want her boys removed from the Deaf culture. She was the mother and had the ultimate say in the welfare of her children.

The court-appointed-attorney, Joseph Tevlin, argued on behalf of the children that cochlear implants would give them access to greater opportunities in education, and better employment and financial opportunities later. The mother's side argued that the implants often do not work, and that it takes several years, with therapists to learn to use them. Those critical years could be more usefully spent learning sign language. They also presented a notification issued by the Food & Drug Administration that 53 people, most of them children, had contracted meningitis after being implanted with the device.

David Gersch, the mother's attorney, aptly described the tension between the two cultures thus: "There's a division, for the most part, between hearing people and deaf people. Hearing people think, 'This is a no-brainer. You get the implants. The judge should order those implants'. And the deaf people are on a polar opposite side of this argument." The mother received strong support from the Deaf community from all over the country. The courts decided that the decision was the mother's to make.

When the hearing world argues for better opportunities, as they did in the Michigan case, they are arguing for beneficence. Beneficence, in the bioethical field, is one of the three principles used to evaluate medical decisions. The other two are non-maleficence and respect for autonomy. Christiansen and Lee, 2002, use bioethics to provide a detailed analysis of the implant choice from both the hearing and the deaf perspective. Beneficence states that the duty of the physician is to do good. Doing good, in this instance, is to correct hearing loss, an abnormal condition or pathology. However, the term also socially constructs hearing loss as a disability that must be cured in order to avoid the negative consequences of deafness (Cohen, 1995; Crouch, 1997; Tyler, 1993). The positive consequence of removing deafness through pediatric implantation is a better financial life.

The Deaf world, however, interprets beneficence very differently from the hearing world. Deaf people "do not see themselves as condemned to an inferior world of silence. Instead, they describe their lives as rich and fulfilling as part of a deaf world that is a vibrant cultural and linguistic community" (Christiansen & Lee, 2002, p. 299). Their interpretation challenges the medical definition of hearing loss as a disability that must be cured, and reconstructs deafness as a mode of living. The Deaf see cochlear implantation as forcing children from a natural way of life and communication into an unnatural, unknown way of life.

HOW PARENTS DECIDE: CULTURE IN ACTION

Researchers have found that since implants are given at very young ages when children cannot make the decision, it is the parents who decide whether or not the children are implanted. To understand the parental decision making from a cultural perspective, we heed the direction of Christiansen & Leigh (2002) and draw on the theoretical work of Ann Swidler (1986) whose focus is on cultures in action. She states that people or cultures go through "settled lives" and "unsettled lives." When people live settled lives, they "naturally know how to act" (1986, p. 280). That is, their cultural tool kit provides them with a repertoire of resources from where they can draw a range of strategies of action to meet various circumstances. They rely on cultural knowledge and past experience to function effectively in their everyday lives. If things progress smoothly, the knowledge base is unquestioned, and the cultural tool kit becomes a dependable source. However, when circumstances change, cultures or people go through "unsettled lives." People are compelled to come up with new strategies, separate from those they were socialized into, to deal with changing situations. Swidler contends that, even during unsettled periods, individuals are hesitant to leave their culturally developed strategies. Rather, they tend to hold on to strategies that were effective in the past.

Thus, when hearing parents are faced with a deaf child, they tend to think in "hearing" terms and depend upon their assumptions of the hearing life to come up with solutions for their deaf child. For instance, Christiansen and Leigh (2002) found that "much of the attraction that a cochlear implant has for hearing parents of deaf children is that it allows them to use strategies and resources that are already part of their cultural tool kit as they educate and socialize their child (p. 4). Hearing parents wish to make their child as close to hearing as they possibly can.

In the Michigan case, the mother chose to keep her children in her own culture - the Deaf culture. Using Swidler's premise, she used the familiar to deal with an unsettled period in her life.

When hearing parents choose to implant, they are implicitly constructing the deaf world as an abnormal one, implying that their child is incomplete without an implant. "Implanted children would end up trapped between two worlds; they can't live the way hearing people do and they won't have grown up in the deaf community, using ASL (Zimmer, 1993, p. 85). Without their own language, deaf children cannot communicate as well, and cannot fully adapt to the hearing world. Members of the Deaf culture believe the child is better off in the Deaf community where she is free to express herself. Instead of spending government funds on the implants, Deaf people would rather see the money go to deaf education.

Swanson (1997) explores some families who have considered cochlear implants for their children. She quotes Janice Springford, who has been deaf since age eight: "deaf is not bad, deaf is not wrong, deaf does not need to be fixed. What is between the ears is a lot more

important than what goes in the ears.” Her parents had saved money and when she was fifteen, they approached her about getting the implants.

She thought it odd, because she felt “normal” and “well-adjusted.” She declined her parents’ offer of the implants. Springford made the point that parents often times do not see all the possibilities with deaf children. They just see the negatives and the limitations.

CONCLUSION

The cochlear implant issue emphasizes the contrasting views of the hearing and the Deaf world. However, over the past few years, the two opposing views have given way to greater flexibility from both sides. In particular, the Deaf world is not as monolithic as it was once thought. Many Deaf people straddle both worlds, recognizing the advancements in implant technology.

However, they are opposed to media depictions of cochlear implants as miracle cures. In a Lexus Nexus survey of articles, we found that almost all the articles covering cochlear implantation referred to them as “miracles.” In reports about the Michigan case, a mother who had her children implanted, stated “It’s a miracle. I mean, my children are deaf, but yet they hear birds, they hear crickets, they can talk on the telephone. They hear, they understand, they communicate through spoken language. It’s just very natural, very normal. I mean, the sky’s the limit because of the opportunity they have with the cochlear implants” (Siegel, 2002).

But cochlear implantation is very expensive and it is unlikely that many Deaf people can afford it. Deaf culture will continue to be a rich environment for the Deaf. A statement from the National Association of the Deaf (quoted in Tucker, 1998, p. 25) is a fitting one: “Deaf people like being Deaf, want to be Deaf, and are proud of the Deafness. Deaf culturists claim the right to their own ethnicity, with their own language and culture, the same way that Native Americans or Italians bond together. They claim the right to cultural diversity. In short, they claim the right to their ‘birthright of silence’.” The hearing would do well to respect that right.

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