

Letting the Deaf Be Deaf Reconsidering the Use of Cochlear Implants in Prelingually Deaf

Children

Author(s): Robert A. Crouch

Reviewed work(s):

Source: The Hastings Center Report, Vol. 27, No. 4 (Jul. - Aug., 1997), pp. 14-21

Published by: The Hastings Center

Stable URL: http://www.jstor.org/stable/3528774

Accessed: 06/02/2013 04:36

Your use of the JSTOR archive indicates your acceptance of the Terms & Conditions of Use, available at http://www.jstor.org/page/info/about/policies/terms.jsp

JSTOR is a not-for-profit service that helps scholars, researchers, and students discover, use, and build upon a wide range of content in a trusted digital archive. We use information technology and tools to increase productivity and facilitate new forms of scholarship. For more information about JSTOR, please contact support@jstor.org.



The Hastings Center is collaborating with JSTOR to digitize, preserve and extend access to *The Hastings Center Report*.

http://www.jstor.org

Letting the deaf Be Deaf

Reconsidering the Use of Cochlear Implants in Prelingually Deaf Children

by Robert A. Crouch

In theory, cochlear implants hold out the possibility of enabling profoundly prelingually deaf children to hear. For these children's parents, who are usually hearing, this possibility is a great relief. Yet the decision to have this prosthetic device implanted ought not to be viewed as an easy or obvious one. Implant efficacy is modest and the burdens associated with them can be great. Moreover, the decision to forgo cochlear implantation for one's child, far from condemning her to a world of meaningless silence, opens the child up to membership in the Deaf community, which has a rich history, language, and value system of its own.

n the Country of the Blind the One-eyed Man is King." Or so thought Nunez, the protagonist of an H.G. Wells story who finds himself the sole person with sight in a community of people who have all been blind for fifteen generations.1 Surrounded by persons he considers disabled, Nunez sets out to convince the inhabitants of the country of the blind that they are missing out on a great deal because of their blindness. Despite his best efforts, however, the blind are not persuaded by his rhetoric, and Nunez, exasperated by their lack of understanding, shouts: "You don't understand . . . You are blind, and I can see." Broken, Nunez gives up his attempts to convince the blind of his superiority and in an interesting role reversal he himself becomes the subject of an attempt to be assimilated into the community of the blind. Convinced that all of Nunez's talk about such obvious nonsense as "sight" and "blindness" is due to the effect of Nunez's prominent eyes on his brain function, the community doctor proclaims: "And I think I may say with reasonable certainty

Robert A. Crouch, "Letting the deaf Be Deaf: Reconsidering the Use of Cochlear Implants in Prelingually Deaf Children," *Hastings Center Report* 27, no. 4 (1997): 14-21.

that, in order to cure him completely, all that we need do is a simple and easy surgical operation—namely, to remove these irritant bodies"—his eyes. To which a blind elder replies: "Thank Heaven for science!"

Wells's story of confrontations with difference is surprisingly relevant to a discussion about the permissibility of using cochlear implants on prelingually deaf children. Given that 90 percent of deaf children are born to hearing parents, it should not surprise us that hearing parents, upon discovering that their child is deaf, perceive the child as essentially different and seek out any means available to remove this difference. These parents have realized, after all, that they have a "disabled" child; a child who is "abnormal." And this designation of abnormality, far from being a neutral, descriptive category, carries evaluative import:2 the child will be perceived through the socially available constructions of normal functional ability and the attendant significance of deviation from the established norm. According to many among the hearing, the life of a deaf person is a priori an unfortunate and pitiable life, and is considered by some to be a full-scale tragedy. The hearing parents of the deaf child, themselves members of hearing society and well aware of the so-called abnormality of deafness, will naturally turn to the medical community in the hope that their child's disability will be "fixed."

In the hands of the medical professionals, the deaf child is put through a battery of auditory tests designed to uncover defects and, in fact, to "decompose" the child into "functions and deficits."³ The deaf child is then placed into one of many available categories: severe or profound hearing impairment, moderate hearing impairment, or some residual hearing present. One otologist invidiously categorizes such patients as being bronze, silver, or gold performers, respectively.4 If the hearing impairment is sufficiently severe, the child will be a potential candidate for a cochlear implant—a prosthetic device that can presumably correct deafness.

The parents discover in their interactions with the medical team that the socially available, culturally constructed views of difference are not limited to the general public: the medical community too conceptualizes deafness essentially as disability and abnormality. But it goes further than that, for the perils of deafness are great. Images of banishment and isolation abound. One writer claims that the deaf are "cut off from their families and other hearing people."5 Echoing this sentiment, an otologist writes that the deaf are "like foreigners in their own country." The medical profession, implicitly endorsing Samuel Johnson's remark that deafness is "one of the most desperate of human calamities," has adopted the goal of fixing the hearing loss of its young patients.7

Such an approach is clearly apparent in a recent editorial by the editorin-chief of an ear, nose, and throat journal. Referring to the world of the deaf as "a world of silence," the editor-in-chief writes, "There is in fact little reason to condemn anyone to be a prisoner of deafness," and goes on to conclude, "It is not only to the advantage of the child and his or her family to eliminate hearing loss, but also to society, which will see increased benefits from these productive individuals" (emphasis added).8

The implications are clear: the deaf serve no useful purpose in our society, and should be "cured" or "fixed" so that, among other things, we will all benefit from their newfound "productivity."

The Problem

The central concern of this paper I is the problematic use of cochlear implants in "prelingually" deaf children; namely, those who are born deaf or who become deaf before any meaningful acquisition of oral language has taken place (roughly, before three or four years of age). My arguments against the use of cochlear implants do not apply to postlingually deafened adolescents and adults. And while I will be principally concerned throughout with deaf children of hearing parents, my views are equally applicable to deaf children of deaf parents.

In theory, the use of cochlear implants holds out the possibility of giving hearing to profoundly prelingually deaf children. In this regard, the use of cochlear implants in prelingually deaf children may be conceived of as an intervention that can determine community membership. In other words, the cochlear implant is intended to help the deaf child ultimately learn an oral language and, in so doing, to facilitate the assimilation of the implant-using child into the mainstream hearing culture. When the child receives a cochlear implant, he or she is put on a lifelong course of education and habilitation, the focus of which is the acquisition of an oral language, and ultimately, a meaningful engagement with the hearing world.

Hearing parents, not surprisingly, almost always decide that it is in their child's best interests to be "like us"; that is, to be hearing. Of course, given our predominantly hearing society, parents are also likely to believe that being hearing is objectively better than being deaf. Regardless of the

parental motivation, these considerations underscore my claim that the intervention of cochlear implantation can be thought of as one that determines community membership. Struck by the otherness of the life that they imagine their child will lead-a life they imagine to be like their own lives would become if they were now suddenly to lose their hearing-parents will usually choose to provide their child with as much hearing as is medically possible either to prevent a chasm from opening up between them and their child (so that their child is in the same community as they are), or to avert what they believe will be the tragedies of a life bereft of sound (so that their child is in the "better" community).

The hope these parents have is made possible by the cochlear implant, an electronic device that consists of an externally worn speech processor and headset transmitter, and a surgically implanted receiverstimulator. Incoming speech is processed and transmitted through the skin to the implanted device, which then directly stimulates the auditory nerve of the child, thus bypassing the dysfunctional nerve endings within the deaf child's cochlea. Not all children who are born with profoundly impaired hearing, however, are potential candidates for cochlear implantation. The National Institutes of Health, in its consensus statement dealing with cochlear implants in adults and children, recently articulated a set of eligibility criteria to aid clinicians in identifying those who might reasonably be expected to benefit from a cochlear prosthetic. Prospective candidates must be older than two years of age; they must have profound bilateral sensorineural hearing loss with a hearing threshold greater than 90 dB (as a point of reference, the threshold of those without hearing loss is less than 25 dB)10; they must have used conventional hearing or vibrotactile aids and have received little or no benefit from such aids; the family and the child must display high motivation and appropriate expectations vis-à-vis the cochlear implant; and there must be no medical, financial, or psychosocial contraindications to implantation.¹¹

Once selected and implanted, however, what can the child and the family expect from the cochlear implant? The most basic aim of the cochlear implant is to help the child perceive sound, and in this limited capacity the implant does work. Ultimately, however, the pragmatic goal

We should rethink the policy of using implants in many prelingually deaf children and examine other options.

of the cochlear implant is to facilitate the entrance of the previously deaf child into the hearing community. To accomplish this end, the following three conditions must obtain. First, the implant-using child must learn how to perceive, not merely sound, but speech. That is, the child must be able to identify parts of speech-for example, that the word just spoken has two syllables and that the stress is on the second syllable. And the child must be able to identify spoken words-for example, that the word just spoken was "dog." Second, once the child can identify speech and its components, she must then learn how to produce intelligible speech herself; if one is to function in the hearing world, one must be understood. Finally, the child must be able to acquire an oral language, by which I mean that the child must be able to hear and understand speech and then be able to respond intelligibly in grammatically correct speech.

Given the above three necessary conditions for the possibility of becoming a fully functional member of hearing society, the idea behind the cochlear implant is simple: the more speech a child can perceive, the easier it will be for that child to understand speech, to produce intelligible speech, and ultimately, to function in oral English. As one enthusiastic otologist claimed, "cochlear implants can drastically alter the future for most hearing-impaired children and take them into the 21st century as productive citizens in the hearing community." 12

Has experience borne out such a proclamation? The results of longitudinal studies suggest that many deaf children who use and train with

> cochlear implants for extended periods of time do not improve their oral communication skills sufficiently to enable them to become functioning members of hearing society. In terms of

speech recognition, the gains afforded by cochlear implantation for many prelingually deaf children are modest, especially if we recall that these children are engaged in auditory training and habilitation every day, be it at home with the parents, in the clinic, or in the school.13 Similarly modest gains are observed when it comes to the speech production capabilities of implant-using children. A recent study showed that after five years of implant use the mean score for correct pronunciation of vowel sounds was 70 percent; although 70 percent is encouraging, this is a small benefit won only after five hard years of oral language habilitation, and a benefit that doubtfully brings the child closer to the ultimate goal of immersion in the hearing culture.14 Moreover, in another study that measured the speech intelligibility of prelingually deaf children who had used their cochlear implants for three and a half years or more, only approximately 40 percent of the words spoken by these children were understood by a panel of three persons.15

Of course, there will always be success stories among implant-using prelingually deaf children. Yet such successes are so infrequent that focusing on them would misrepresent clinical reality. Despite the limited successes of the few, and despite the successes of the many on audiological tests of lesser importance, the performance of the cohort of interest on speech perception, production, and intelligibility is quite poor. The oral language acquisition skills in many implant-using children is at this stage essentially nonexistent.

The vexing clinical problem presented by prelingually deaf children is that unlike postlingually deafened children or adults, the prelingually deafened child has no solid linguistic foundation in place prior to the onset of deafness to enable the learning of an oral language. While the postlingually deafened person, once fitted with a cochlear implant, can maintain his or her present speech production capabilities and relearn to hear, the prelingually deaf child using a cochlear implant must be intensively taught and trained to recognize and produce each vowel and consonant sound and each word from the ground up. For the implant-using prelingually deaf child, then, the path to oral language development is a long and arduous one beset with many pitfalls, where there seems to be no guarantee that the destination will be reached.

Overcoming the Narrative of Disability

The evidence suggests, then, that ■ the benefits of cochlear implantation in many prelingually deaf children are modest. A general problem with the information available is that it has only been a little over six years since the U.S. Food and Drug Administration gave pre-market approval to implant children with the Nucleus-22 multichannel cochlear implant. Longitudinal studies with longer follow-up periods would be needed to determine more clearly what the peak benefits of implant use can be in this population. Nonetheless, with the available information, we might reasonably ask whether the benefits associated with the use of

16 HASTINGS CENTER REPORT

cochlear implants outweigh the burdens of this procedure, and whether there are other reasonable options for deaf children. Although the cochlear implant works quite well in populations of postlingually deafened persons,16 the good results of those studies simply cannot be generalized to prelingually deafened children. I believe that given the current state of knowledge vis-à-vis cochlear implant efficacy, the burdens associated with cochlear implant use do indeed outweigh the benefits and we should rethink the policy of using implants in many prelingually deaf children and examine other options.

However, as with many newly introduced medical interventions, it is not unreasonable to expect that five to ten years hence, when more follow-up years have been observed and when possible improvements in technology have been made, otologists and audiologists will be able to claim greater successes for the cochlear implant in prelingually deaf children. Yet even if such were the case, I would invoke another, perhaps more fundamental critique. It is my contention that the predominant view of deafness-that the deaf are "merely and wholly" disabled¹⁷—is wrong and that we should quickly disabuse ourselves of this ill-begotten notion. Considered in the proper light, the decision to forgo cochlear implantation for one's child, far from condemning a child to a world of meaningless silence, opens the child up to membership in the Deaf community, a unique community with a rich history, a rich language, and a value system of its own.18 Thus, contrary to popularly held beliefs, the child who is permitted to remain deaf can look forward to acquiring a language, namely, American Sign Language (ASL), or whatever signed language is indigenous to the child's geographical area. And when the child has acquired such a language, she thereby possesses the language of an active cultural and linguistic minority group, which can then serve as the linguistic foundations upon which new written languages can be built, thereby ensuring access to the wider hearing society. Once we conceive of the Deaf as being members of a linguistic and cultural minority, our moral landscape should be altered. My beliefs regarding the value of Deaf culture, the richness of the lives of Deaf persons, and the importance of recognizing and overcoming our cultural biases regarding the Deaf would therefore be unchanged by a dramatic improvement in implant efficacy.

What I hope to demonstrate, then, is that parents of prelingually deaf children have a reasonable basis upon which to refuse a cochlear implant for their child, either presently, because of a mix of reasons, including poor implant efficacy, the burdens associated with ineffective implant use, and the benefits of membership in the Deaf community, or at some unknown point in the future when cochlear implants might work with greatly improved efficacy, because of the benefits of membership in the Deaf community. I do not endorse the view that the only reason it is acceptable to be a member of the Deaf community is that there is no way to treat one's impaired hearing. This paper represents, then, one response to a current medical and societal state-of-affairs. I ask: Given the efficacy of cochlear implants in prelingually deaf children, and given the authentic nature of signed languages and Deaf communities, what are some of the options available for prelingually deaf children, and which option might be reasonable to choose? While many may find the terms in which the debate is presently carried out philosophically uninteresting, preferring instead to examine a possible world where cochlear implants were significantly efficacious, the present moral problem as I see it seems sufficiently worthy of attention.

It is important at this point to understand why the goal of implantation and oral language habilitation has been pursued so aggressively. It is not, I would claim, being pursued simply because of the benefits that come with being able to hear in a predominantly hearing society, but more importantly it is also being pursued because of the perceived burdens associated with being deaf. Indeed, given the rather poor efficacy of cochlear implants in many prelingually deaf children, there seems to be an implicit belief that while implants may not work that well, surely some hearing and oral language, however rudimentary, is better than none. To take one example, supporters of cochlear implant use frequently recite the fact that by the age of five, a child with no hearing impairment will commonly have a vocabulary of between 5,000 and 26,000 words, while at the same age a deaf child will have a far inferior vocabulary of only 200 signed or spoken words.19 The implication of this line of thought is that deaf children should be fitted with cochlear implants and that exclusive oral language instruction should be pursued aggressively so that such tragic outcomes can be avoided. While this reasoning does display its own internal logic, it shows little sensitivity to the deaf child's educational context, and to the history of the education of the deaf, which has produced generations of deaf persons who have suffered from linguistic and educational neglect.20 Once we recognize that historically deaf children have been educated predominantly in an oral-only environment—despite their imperfect auditory systems and to the exclusion of ASL training-it should not surprise us that their vocabularies are often much smaller, and that their emotional and social development so often lags behind that of their hearing counterparts.

To be sure, the education of deaf children has improved somewhat in the last forty years, but the denial of the Deaf perspective chiefly remains. For example, legislation, in the form of the Individuals with Disabilities Education Act (IDEA-B) of 1975, mandated that the educational segregation of deaf children be stopped

July-August 1997 HASTINGS CENTER REPORT 17

and that the deaf be "mainstreamed" into regular hearing classrooms so that their oral skills would improve, and with them their emotional and social skills. However, with its emphasis on educational integration, the IDEA-B purchased increased access to oral education for deaf children at

The deaf child no less than the hearing child has all the requisite skills that will enable her to achieve a different, but no less human, expressive potential.

the cost of a dramatic decrease in the quality of their education.21 Often, the best that the deaf student can hope for is to be given access to an unskilled ASL interpreter, or to an interpreter in the classroom who knows no ASL and who works only in manually coded English—a manual form of English that follows the rules of English grammar, and that seems not to help deaf children learn English.²² The life of a deaf child in such a mainstreamed educational environment can also be very difficult socially. A boy in the eighth grade who testified before the U.S. National Council on Disabilities began by declaring, "I'm not disabled, just deaf," and went on to give an account of how it feels to be forced into an educational environment where the focus is on oral English acquisition. He testified: "Learning through an interpreter is very hard; it's bad socially in the mainstream; you are always outnumbered; you don't feel like it's your school; you never know deaf adults; you don't belong; you don't feel comfortable as a deaf person." Another boy, also attempting to learn oral English at school, put it more starkly: "I hate it if people know I am deaf."23

The perspective of the Deaf in creating educational policies for the Deaf has mostly been ignored, and consequently, the outcome of the "education" of deaf children by means ill-

suited, inimical in fact, to their needs, perpetuates the stereotypical view of deaf people as disabled and slower witted than their hearing counterparts. Against such an historical background, the proper response is not to maintain that deaf people will unavoidably lead impoverished and

fragmentary lives, but rather to start paying attention to the Deaf point of view and to realize that positive change can thereby be effected.

As with previous strategies for the deaf, the decision to pursue cochlear implantation

and auditory habilitation for one's child also has burdens associated with it beyond the failure to achieve oral language competence. The child whose life is centered upon disability and the attempt to overcome it grows up in a context that continually reinforces this disability, despite his or her own best efforts to hear and to speak and despite the diligent work of the educators of the deaf and hearing-impaired. These children are therefore always aware that they are outsiders, and not merely outsiders, but outsiders attempting to be on the inside. This narrative of disability within which the deaf implant-using child lives is not the only one available to her. There is an alternate narrative in reference to which the child may judge her own life and it is the one that exists within the Deaf community. Simply put, my concerns about the burdens of using cochlear implants in prelingually deaf children can be reduced to a cluster of considerations grouped under the heading of "opportunity costs." One of the main burdens of implanting a child and setting her on the course of auditory habilitation is that it deprives her of the alternate linguistic, educational, and social opportunities that the Deaf community can offer her, while (presently) offering a poor guarantee that functional membership in the hearing community will materialize.

Contrary to what many believe, the Deaf community has a distinct history, language, and value system that plays a central role in the lives of its members. Two prominent members of the American Deaf community have noted that the beliefs and practices that make up the culture of Deaf people should not be viewed simply as "a camaraderie with others who have a similar physical condition," but rather as "like many other cultures in the traditional sense of the term, historically created and actively transmitted across generations."24 Members of the Deaf community have their own language that, far from being merely a means of communication, is also, as are other languages, a "repository of cultural knowledge and a symbol of social identity."25 In contrast to Helmer Myklebust's claims that the manual signed languages of Deaf persons were "inferior to the verbal as a language" because they lacked "precision, subtlety, and flexibility," and that humans would not be able to achieve their "ultimate potential" through signed languages,26 Carol Padden and Tom Humphries have argued that

Despite the misconceptions, for Deaf people, their sign language is a creation of their history and is what allows them to fulfill the potential for which evolution has prepared them—to attain full human communication as makers and users of symbols. (emphasis added) (p. 9)

Thus, the deaf child no less than the hearing child has all the requisite skills that will enable her to achieve a different, but no less human, expressive potential.

The key point is that this narrative is a validating narrative; it is, in other words, a socially available story to which the child may refer when building his own life and making sense of that life and the lives of those around him. As the child learns about adult members of his Deaf community, or historic Deaf figures,

or the history of ASL, or Deaf poetry and theater he "gains ideas of [the] possible lives that he can lead and finds a basis for self-esteem in a [hearing society that insists he is inferior."27 But it does more than that: it also provides a basis for self-respect, that is, for the Deaf child's sense of dignity according to the community's acceptance and valorization of the Deaf way of being-in-the-world.28 Identification with the Deaf community is important, then, because it opens up a cultural space within which the Deaf themselves may establish their own norms, and within which one's sense of personal dignity is thereby engendered. Access to the validating narrative of the Deaf community will thus enable Deaf children to see themselves in a more positive light, while their peers and teachers will see them in this way and relate to them as similarly situated individuals in a shared story.

The implant-using child, although nominally within hearing culture, is, as I have claimed, virtually condemned to be an outsider—not only from the perspective of the hearing world, but also from the perspective of the Deaf world, which generally looks down upon those who attempt to be, as they say, ORAL. The child who embraces Deaf culture, on the other hand, *will* have a context, he will have a milieu in which to make sense of his life, and he will be an insider.

A key component of this view involves regarding members of the Deaf community as part of a linguistic minority. In my discussion of the goals of cochlear implants above, I claimed that the aim of the implant was to facilitate the entry of the hearing-impaired child into the hearing world. Two of the necessary conditions of entry were sufficiently competent speech production capabilities as well as the acquisition of an oral language. But as I claimed, intelligible speech production is virtually denied to many implant-using prelingually deaf children, and consequently, so too is oral language acquisition. Indeed, although intelligible *oral* language acquisition is only marginally possible, *language* acquisition need not be at all: "sign or speech can serve as the vehicle of language."²⁹

As with other signed languages, ASL is not a manual version of English; it is, rather, a distinct language with a syntax and a grammar independent of English.30 "Languages," as Harlan Lane has observed, "have evolved within communities in a way responsive to the needs of those communities. ASL is attuned to the needs of the deaf community in the United States; English is not."31 This point has important consequences for the issue at hand. For the prelingually deaf child, signed languages are acquired with far greater facility than spoken languages are acquired by those using cochlear implants, and there is no evidence to indicate that the use of ASL will interfere with the child's ability to learn written English, or any other written languages.32 On the contrary, the deaf children who perform the best on measures of educational and language achievement are the 10 percent who come from deaf parents and who learned ASL as a first language.33 Thus, learning ASL as a primary language will enable the learning of written English as a second language, and this familiarity with written English leads to further successes in the educational and occupational disciplines to which the written word gives access, thereby increasing the Deaf person's links with the wider hearing community.

Placing prelingually deaf children in an environment where they can only learn oral language through an imperfect auditory system (even with cochlear implants) disadvantages many of them because not only do they fail to acquire an oral language, but perhaps more harmfully, their exposure to ASL is delayed, thus making their acquisition of ASL (and written English) far more difficult and incomplete.³⁴ The delay in the acquisition of ASL caused by the implant-using child's attempt to learn an oral language will delay the child's

exposure to and engagement with the Deaf community, and is unlikely to help the child assimilate into the hearing community. Denying prelingually deaf children the opportunity to immerse themselves immediately in ASL puts them *between* two cultures and *within* neither of them, a situation we should strive to avoid.

Thinking Clearly about Deafness and Disability

began this paper with a story A about a dual confrontation with difference: a confrontation between vision and blindness. Just as Nunez's disbelief that the blind could actually be happy and fulfilled without vision was inappropriate, so have I argued that the belief that the Deaf need be cut off from the world is similarly inappropriate and shows a great lack of understanding on the part of the hearing. Medical professionals and the hearing parents of deaf children should be finely aware of the consequences of implanting a prelingually deaf child with a cochlear prosthetic. Cochlear implantation is, as I suggested above, a unique intervention in that it may rightly be conceived of as one that determines community membership. It is therefore all the more important for those who are touched by this debate to carefully consider the social context in which it takes place and to realize that it is an issue informed by many perspectives. Since cochlear implant technology is relatively new, it is therefore much more urgent to be aware of and responsive to the historical treatment of deaf persons. Many of our present ideas regarding the deaf are a direct result of the historical silencing of this population and the exclusively oral educational policies for the deaf that this silencing set in motion, the tragic results of which can still be witnessed today. Given this historical background and its social and educational legacy, it is not surprising that the idea of letting one's child be Deaf is met with shock and opposition. But if one has a more realistic view of

July-August 1997 HASTINGS CENTER REPORT 19

what cochlear implants can and cannot do, of what deafness is and is not, and of the richly rewarding lives Deaf people can lead, then it is by no means clear that the use of cochlear implants is justified in many prelingually deaf children, nor again is it clear that hearing parents of deaf children are aware of the options open to them when faced with the question of how to raise their deaf child.

The decision to forgo cochlear implantation for one's child is undoubtedly a difficult one for hearing parents to make. Not only must parents consider their child's future, they must also consider their own interests and that of other family members. What will it be like to have a deaf child? How difficult will it be to learn ASL? Will a deaf child adversely affect family dynamics? Although the child is the particular family member who is deaf, the family unit as a whole is undoubtedly affected by the deafness.35 Consequently, the attitude and commitment of the hearing family members toward the deaf child is of central importance to the child's emotional, educational, and social progress, as well as to the integrity of the family.36 Deaf children need not be estranged from their hearing families (as some have claimed) if the family members are willing to make the required social changes and if they commit to learning ASL with their child. Indeed, one might say in general that communication between hearing and Deaf persons is primarily about connection rather than sound. A recognition of this fact will make it clear to parents that they can, with sustained efforts to be sure, raise their deaf child in such a way that he or she can lead a fulfilling and complete life.

In my case for the legitimacy and importance of the Deaf community to the prelingually deaf child, I hope I have provided reasonable grounds upon which parents can refuse cochlear implants for their child. It is impossible, of course, to construct a convincing argument that will be applicable to all deaf children, given

the different expressive capabilities (sign or oral) that such children will invariably possess. But I hope to have avoided some of the problematic elements that come with, on the one hand, the arguments of those who maintain that all cochlear implantation is a form of cultural genocide, and, on the other hand, the arguments of those who believe that cochlear implants are a panacea.

Acknowledgments

I would like to thank the Fonds pour la Formation de Chercheurs et l'Aide à la Recherche (Quebec, Canada) for research funds while I was working on this project. I am thankful to the following people for their helpful comments and criticisms: Carl Elliott, Karen Lebacqz, Jamie MacDougall, Gilles Reid, Lainie Friedman Ross, Charles Weijer, Anna Zalewski, the editors of the Report, and three anonymous reviewers. I am also thankful to audiences at the 7th Annual Canadian Bioethics Society Conference in Vancouver (1995), at the McGill University Biomedical Ethics Unit in Montreal (1996), at the Montreal Children's Hospital (1996), at the Annual Meeting of the Society for Health and Human Values/Society for Bioethics Consultation in Cleveland (1996), and at the University of Virginia Health Sciences Center in Charlottesville (1997) who heard and commented upon earlier versions of the paper.

I would like to dedicate this paper to the memory of my first bioethics teacher, Benjamin Freedman.

References

- 1. H. G. Wells, *The Country of the Blind and Other Stories* (London: T. Nelson & Sons, 1911), pp. 536-68.
- 2. On the origins, circa 1835, of the idea of measuring different characteristics of a people in order to determine "normality," see Ian Hacking, *The Taming of Chance* (Cambridge: Cambridge University Press, 1990), pp. 107-8.
- 3. The view that certain medical tests "decompose" patients into "functions and deficits" is found in Oliver Sacks, *The Man Who Mistook his Wife for a Hat* (New York: Harper Collins, 1987), p. 181.
- 4. Richard T. Miyamoto et al., "Speech Perception and Speech Production Skills of Children with Multichannel Cochlear Im-

- plants," Acta Oto-Laryngologica 116 (1996): 240-43.
- 5. John C. Rice, "The Cochlear Implant and the Deaf Community," *The Medical Journal of Australia* 158, no. 1 (1993): 66-67, at p. 66.
- 6. Michael E. Glasscock, "Education of Hearing-Impaired Children in the United States," *The American Journal of Otology* 13, no.1 (1992): 4-5, at p. 5.
- 7. As quoted in Oliver Sacks, *Seeing Voices: A Journey into the World of the Deaf* (New York: Harper Perennial, 1989), p. 1.
- 8. Jack L. Pulec, "The Benefits of the Cochlear Implant," *Ear Nose and Throat Journal* 73, no. 3 (1994): 137.
- 9. Others have made similarly objectionable remarks regarding deaf persons. In his Presidential Address read before the American Society of Pediatric Otolaryngology, Robert J. Ruben draws the link between hearing losses and criminal behavior, and he warns us that those with "communications disorders"-such as those with hearing losses, and those who are deaf-present a threat to the progress and prosperity of America because they are "economically burdensome and destructive of the social fabric." See, Robert J. Ruben, "Critical Periods, Critical Time: The Centrality of Pediatric Otolaryngology," Archives of Otolaryngology-Head and Neck Surgery 122, no. 3 (1996): 234-36.
- 10. Thomas Balkany, "A Brief Perspective on Cochlear Implants," *NEJM* 328 (1993): 281-82, at p. 281.
- 11. National Institutes of Health, Cochlear Implants in Adults and Children. NIH Consensus Statement 13, no. 2 (1995): 1-30, at pp. 18-20.
- 12. Glasscock, "Education of Hearing-Impaired Children in the United States," p. 5.
- 13. Richard T. Miyamoto et al., "Prelingually Deafened Children's Performance with the Nucleus Multichannel Cochlear Implant," *The American Journal of Otology* 14, no. 5 (1993): 437-45; John J. Shea III et al., "Speech Perception after Multichannel Cochlear Implantation in the Pediatric Patient," *The American Journal of Otology* 15, no. 1 (1994): 66-70; Harlan Lane, "Letters to the Editor," *The American Journal of Otology* 16, no. 3 (1995): 393-99.
- 14. Bruce J. Gantz et al., "Results of Multichannel Cochlear Implants in Congenital and Acquired Prelingual Deafness in Children: Five-year Follow-up," *American Journal of Otology* 15, Suppl. no. 2 (1994): 1-7.
- 15. Miyamoto et al., "Speech Perception and Speech Production Skills of Children with Multichannel Cochlear Implants."
- 16. Noel L. Cohen et al., "A Prospective, Randomized Study of Cochlear Implants," *NEJM* 328 (1993): 233-37.

20 HASTINGS CENTER REPORT July-August 1997

- 17. The phrase "merely and wholly" disabled is inspired by Oliver Sacks (*The Man Who Mistook his Wife for a Hat*, p. 180), and is invoked to express the view that the deaf are disabled and nothing other than disabled people.
- 18. The convention in the literature is to put the word deaf in lower case when referring to the biological condition of not being able to hear, and upper case, Deaf, when referring to the cultural aspects of being deaf.
- 19. American Academy of Otolaryngology–Head and Neck Surgery Subcommittee on Cochlear Implants, "Status of Cochlear Implantation in Children," *The Journal of Pediatrics* 118, no. 1 (1991): 1-7; Balkany, "A Brief Perspective on Cochlear Implants."
- 20. The history of the education of deaf persons is indeed a tragic one, consisting of a series of ignorant and destructive decisions made by the hearing on behalf of the deaf. What runs through this history of the last two hundred years is a systematic suppression of the Deaf perspective. Of course, the great triumph for the Deaf is that despite the attempts of the hearing to do away with ASL, it survives to the present day largely unchanged from what it was, say, one hundred years ago. Two excellent accounts of this story are, Harlan Lane, When the Mind Hears: A History of the Deaf (New York: Vintage, 1984); Douglas C. Baynton, Forbidden Signs: American Culture and the Campaign Against Sign Language (Chicago: University of Chicago Press, 1996).
- 21. On this see, Sy Dubow, "'Into the Turbulent Mainstream'—A Legal Perspective on the Weight to be Given to the Least Restrictive Environment in Placement Decisions for Deaf Children," *Journal of Law*

- & Education 18, no. 2 (1989): 215-28; Kathryn Ivers, "Towards a Bilingual Education Policy in the Mainstreaming of Deaf Children," Columbia Human Rights Law Review 26 (1995): 439-82.
- 22. David A. Stewart, "Bi-Bi to MCE?" American Annals of the Deaf 138, no. 4 (1993): 331-37.
- 23. As quoted in Lane, *The Mask of Benevolence*, pp. 136-7.
- 24. Carol Padden and Tom Humphries, Deaf in America: Voices from a Culture (Cambridge, Mass.: Harvard University Press, 1988), p. 2.
 - 25. Lane, The Mask of Benevolence, p. 45.
- 26. Helmer R. Myklebust, The Psychology of Deafness: Sensory Deprivation, Learning and Adjustment (New York: Grune and Stratton, 1960), pp. 241-42. This passage was quoted in Padden and Humphries, Deaf in America, p. 59.
- 27. Lane, *The Mask of Benevolence*, p. 172.
- 28. I am relying on the distinction between self-esteem and self-respect articulated by Michael Walzer in *Spheres of Justice*. According to Walzer, while self-esteem is a relational concept—one dependent upon the relative standing of citizens—self-respect is an external, normative concept—one dependent upon the "moral understanding of persons and positions" within the community. See, Michael Walzer, *Spheres of Justice: A Defense of Pluralism and Equality* (New York: Basic Books, 1983), pp. 272-80, at 274.
- 29. David M. Perlmutter, "The Language of the Deaf," *The New York Review of Books* 38, no. 7 (1991): 65-72, at p. 72.

- 30. Edward Klima and Ursula Bellugi, *The Signs of Language* (Cambridge, Mass.: Harvard University Press, 1979); Schein and Stewart, *Language in Motion*; Perlmutter, "The Language of the Deaf."
- 31. Lane, *The Mask of Benevolence*, p. 125.
- 32. Heather Mohay, "Letters to the Editor: Opposition from Deaf Groups to the Cochlear Implant," *The Medical Journal of Australia* 155, no. 10 (1991): 719-20.
- 33. As noted in Lane, The Mask of Benevolence, p. 138. See, Abraham Zwiebel, "More on the Effects of Early Manual Communication on the Cognitive Development of Deaf Children," American Annals of the Deaf 132, no. 1 (1987): 16-20; Ann E. Geers and Brenda Schick, "Acquisition of Spoken and Signed English by Hearing-Impaired Children of Hearing-Impaired or Hearing Parents," Journal of Speech and Hearing Disorders 53, no. 2 (1988): 136-43; Stephen P. Quigley and Robert E. Kretschmer, The Education of Deaf Children: Issues, Theory, and Practice (London: Edward Arnold, 1982).
- 34. Mohay, "Letters to the Editor: Opposition from Deaf Groups to the Cochlear Implant."
- 35. William H. McKellin, "Hearing Impaired Families: The Social Ecology of Hearing Loss," *Social Sciences and Medicine* 40, no. 11 (1995): 1469-80.
- 36. Deborah Henderson and Anne Hendershott, "ASL and the Family System," *American Annals of the Deaf* 136, no. 4 (1991): 325-29; Debra D. Desselle, "Selfesteem, Family Climate, and Communication Patterns in Relation to Deafness," *American Annals of the Deaf* 139, no. 3 (1994): 322-28.

July-August 1997 HASTINGS CENTER REPORT 21