

Cultural and Infirmity Models of Deaf Americans

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Many deaf Americans are acculturated as hearing people and consider themselves incapacitated to some degree by the advent of their hearing loss. Another group of deaf Americans, frequently born deaf or early-deafened, become acculturated as members of the deaf community, a linguistic minority that is currently having a cultural renaissance. Otology has been expanding its traditional clientele beyond adventitiously deaf people to include children who are culturally deaf or likely to become so. The medicalization of cultural deafness has a long history, in which the latest development is cochlear prosthesis. When applied to children who are born deaf or early-deafened and likely to join the deaf community, the procedure is highly experimental and ethically problematic.

Many deaf Americans are acculturated as hearing people and consider themselves incapacitated to some degree by the advent of their hearing loss. Another group of deaf Americans, frequently born deaf or early-deafened, become acculturated as members of the deaf community; they learn American Sign Language, often marry other deaf persons, and insert in a complex social structure (Schein, 1989; Olsen, 1989). The indiscriminate use of the same label, *deaf*, for members of both groups has contributed to confusion; scholars are increasingly capitalizing the word *Deaf* when referring to culturally Deaf people.

THE CONTEMPORARY RENAISSANCE OF DEAF CULTURE

Culturally Deaf people in America are living in a unique era in Deaf history, a time that will be noted and discussed for decades to come, an era that will be recognized, I believe, as the renaissance of Deaf culture.

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There is a growing awareness of Deaf community and culture among scholars and laymen: there are courses around the nation and several recent books including Padden and Humphries' *Deaf in America* (1988), Wilcox's *American Deaf Culture* (1989a), and Lucas' *The Sociolinguistics of the Deaf Community* (1989). Last July, 5000 culturally Deaf people from around the world gathered in Washington at the Deaf Way congress to celebrate cultural Deafness with lectures, exhibits, media events and performances.

We have been witnessing the flourishing of Deaf arts; there was a spectacular display of those arts – mime, dance, storytelling and poetry in sign language, crafts, sculpture, video and fine arts – at the Deaf Way congress. Perhaps the best known example of a contemporary work of art concerning Deaf people is Mark Medoff's play, later a movie, *Children of a Lesser God*; but there are many plays by Deaf playwrights and many Deaf performers (Bragg, 1989) and performing groups, including the National Theater of the Deaf.

The field of Deaf history is thriving; to cite only a few works, there are: Gannon's *Deaf Heritage* (1981) and his recent *The Week the World Heard from Gallaudet* (1989); my own history of Deaf communities in the Western World, *When the Mind Hears* (Lane, 1984); *The Gallaudet Encyclopedia of Deaf People and Deafness* (Van Cleve, 1987); and Van Cleve and Crouch's *A Place of Their Own: Creating the Deaf Community in America* (1989).

We are witnessing the burgeoning study of sign languages; American Sign Language (ASL) is taught in over 750 post-secondary programs in the U.S. Recent laws affirm that ASL meets the high-school foreign-language requirement in numerous states across the nation, and the list grows longer annually (Wilcox, 1989b). Journals, articles, books, and conferences teach us about ASL structure, use, history, dialects, registers, poetry (see, for example, *Sign Language Studies*; Wilbur, 1987; Lucas, 1989; Sternberg, 1990). New and better materials are available to learn the language; books and videotapes abound (e.g., Baker & Cokely, 1980; Eastman, 1989).

Deaf people are increasingly assuming leadership roles in educational and social service programs for Deaf children and adults. There has been a surge of activism of organizations of Deaf people. Many states have established commissions on deafness to act with and for Deaf people. All America took notice of the courage of young culturally Deaf leaders at the time of the Gallaudet Revolution, a year and a half ago. The appointment of I. King Jordan to the presidency of Gallaudet University and Robert Davila as Assistant Secretary of the United States Department of Education are further signs of Deaf leadership, as are a spate of recent appointments of culturally Deaf superintendents of schools for the Deaf.

There is mounting hearing acceptance of the Deaf difference. Truly, Deaf Americans have much to celebrate. Yet there are those who say, "You cannot *celebrate* deafness – you can only regret it." These people approach deafness exclusively with an infirmity model. They measure all deafness, even cultural Deafness, only in terms of loss, not in terms of gain. I say to them: enough

audiograms, look at the art. Enough laryngology, learn the language. They say, "It's a hearing world." I have news for them: it's a Deaf world, too.

THE MEDICALIZATION OF CULTURAL DEAFNESS

To apply an infirmity model to members of a group is to regard them and interact with them particularly with respect to our cultural conception of bodily defect. This conceptual framework, which one normally acquires in the course of acculturation, is implicit; without trying fully to explicate it here, we can observe that such frameworks entail issues, values, and reference to societal institutions. Some of the issues that naturally arise when we construe a certain way of being or behaving as an infirmity are: how did that infirmity arise; what are the risks and benefits of the available treatments, if any; what can be done to minimize the disabling effects of the infirmity? The values invoked are largely negative; we may admire someone's accommodation to their infirmity or their courage in struggling with it, but the infirmity itself is generally considered undesirable. The institutions that are part of this conceptual framework include notably the biological sciences, and the health and social welfare professions.

To apply a cultural model to a group is to invoke quite a different conceptual framework. Implicit in this posture are issues such as: what are the interdependent values, mores, art forms, traditions and language that characterize this culture? How is it influenced by the physical and social environment in which it is embedded? Such questions are, in principle, value neutral, although of course some people are ill-disposed to cultural diversity while others prize it. The institutions invoked by a cultural model of a group include the social sciences, professions in a mediating role between cultures such as simultaneous interpretation, and the schools, an important locus of cultural transmission.

In a recent development, otology has been expanding its traditional clientele beyond adventitiously-deafened hearing people who seek treatment, for whom an infirmity model is appropriate, to include culturally Deaf persons, for whom it is not. To medicalize a group is to promulgate successfully an infirmity model of that group when such a model is inappropriate. There are various measures of the success of medicalization but one that is understandably important to the health professions is whether the medicalized group seeks their services. By this measure, there is no prospect of medicalizing the million or so culturally Deaf adults in our society – they reject the claim that they have a medical problem (Evans, 1989). This apparently came as a surprise and a great disappointment to the early manufacturers of cochlear implants (House, 1990). There is, however, the possibility of medicalizing culturally Deaf adults while they are still children. That is because of a remarkable fact about this cultural and linguistic minority: most members have hearing parents who do not transmit and may not share the linguistic and cultural identity of their Deaf children. The children themselves are too young to refuse treatment or to dispute the infirmity model of their difference. Their hearing parents, frequently beset by guilt, grief and anxiety, and largely ignorant of the Deaf community, commonly accept the

infirmity model uncritically, and consequently turn to the related social institutions, such as medicine, audiology, and special education.

As a reasoned position, the medicalization of cultural Deafness in children and adults faces several difficulties; here are five:

1. Adults with this putative medical problem insist they do not have a medical problem.
2. The putatively handicapped population has a common language and social organization; their shared culture puts us more in mind of, say, Hispanic-Americans than of, for example, blind Americans. History provides many examples of more dominant cultural groups labeling less dominant cultural groups as defective, but no example of an entire linguistic and cultural minority that is truly infirm.
3. The otologists and audiologists who apply the infirmity model to culturally Deaf people are often unaware of the language and mores of those whose way of being and behaving they consider infirm.
4. There is no medical treatment that will improve the quality of life of the putatively infirm population as a whole.
5. Some of the professions collaborating in the medicalization of this population have a financial and social stake in designating cultural Deafness as a medical/handicap problem.

Although these considerations weigh against the infirmity model of cultural Deafness, many hearing professional people hold tenaciously to that model. Surgical implantation of Deaf children with cochlear prostheses has grown in just a few years from a closely-regulated research procedure for a few children to 166 centers currently offering surgeon/audiologist teams who implant the device in the United States (Food and Drug Administration, 1990). Hearing teachers of Deaf children claim that large numbers of their pupils are "learning disabled," "emotionally disturbed" and otherwise "multiply-handicapped" and that they require specialized medical and paramedical services from hearing people, such as special education, counseling, rehabilitative services, psychology, psychiatry, and audiology (Wolff & Harkins, 1986).

The medicalization of deviance is part of a larger social phenomenon which is the individualization of social problems. The locus of the educational problem of Deaf children is not in the child. The forces at work have to do with language, community, power, and social groups. We tend to look for the solution in the individual, rather than in the complex social system. We seek to change the victim rather than the society. For example, a focal theme of the 1985 International Congress on the *Education* of the Deaf (italics mine) was not the failure of Deaf education, or the impasse in teaching reading, it was cochlear implants.

The medical treatment of overactive children may provide a term of comparison: instead of addressing the social forces in the family and the school, we administer drugs to the individual child. Medicalization is the tranquilizer we take to put our social problems out of mind (Conrad & Schneider, 1985). Deaf

children and the Deaf community in America today pose social challenges. It may be instructive to shift the focus from the person labeled infirm and his or her etiology to the social context in which the infirmity label was acquired.

If we ask culturally Deaf adults how they first acquired the label “handicapped, disabled, impaired,” we commonly learn that some circumstance of heredity, of birth or of early childhood, marked the child as different from its parents and created an initial breakdown in communication between parent and child. The parents then see this as deviant relative to their norms and take the child to the experts – the pediatrician, the otologist, the audiologist. It is they who legitimate the infirmity model. Why do they do it? That is precisely a core function of their profession, to diagnose infirmity.

How do the experts medicalize the child’s difference into deviance? First they characterize the difference in great biological detail and often only in stigmatizing ways. Much will be said about impairment of spoken language, little may be said about acquisition of sign language. Much will be said about hearing loss, nothing about gains in spatial cognition (Bellugi, O’Grady, Lillo-Martin, O’Grady-Hines, van Hoek, & Corina, 1990). Second, while pursuing the infirmity model, the experts may remain silent about the cultural model; they may not advert to the community of adults who were once children much like their client. If the professional person does describe the Deaf community, it is likely to be in terms that are so concise that the parents do not really grasp an alternative conception of their child’s status and destiny. The professional expert and the parents generally share the same hearing culture; they may evaluate and label the Deaf child solely from the perspective of their shared hearing culture.

HISTORICAL PERSPECTIVE ON MEDICALIZATION

The right to define a problem and to locate it within one social domain rather than another – to construe it as a problem of medicine, education, rehabilitation, religion, politics – is won by struggle and enterprise. The medicalization of cultural Deafness is marked by a long history of struggle between Deaf people and the hearing people who profess to serve them (Lane, 1984).

In the first stage of systematic medicalization of culturally Deaf Americans, in the late nineteenth century, hearing experts sought to undermine a thriving Deaf culture in America by banishing sign language and Deaf teachers from schools for the deaf. Deaf teachers were fired summarily. Children were punished for using ASL. The medicalizing forces succeeded in reducing the role of Deaf teachers in Deaf education from preponderant to a token presence in today’s schools.

In the second stage of medicalization of cultural Deafness, day schools were established on a large scale at the beginning of this century, so Deaf children could live at home in a majority-language environment. The hope was that they would not learn sign language and would not marry other Deaf people, but nearly all, then as now, learned ASL, took a Deaf spouse, and entered the Deaf community (Schein, 1989).

In the third stage, the dominance of English was reinforced by encouraging its use in all forms of classroom communication: fingerspelling, lipreading, written English, spoken English, spoken English accompanied by signs, signed English. With most Deaf children in the schools deafened before the age of three (nine out of ten nowadays: Brown, 1986), the effort to teach intelligible speech and lipreading characteristically failed and the child instructed orally was certain to be handicapped indeed. An increasing part of classroom time was devoted to the attempt at oralizing the children. Many schools became in effect speech clinics. Hearing educators of the Deaf commonly were not trained in specific academic areas because none could be truly taught to the children under the oralist regime (Moores, 1978, p. 257).

Oralism gave way to "total communication," in which English remains the language of instruction. In practice, while the teacher is speaking grammatical English, she (or he) will utter ungrammatical signs, citation forms from the lexicon of ASL lacking the complex grammar of ASL, which has its own rules of word order, uses spatial arrays, and modulates signs for inflectional and derivational morphology. Almost all American programs for Deaf children now use sign supported English and call it Total Communication. As their poor results testify, Total Communication communicates very little to very few (Allen, 1986; Lane, 1986). Unsuccessful education of Deaf children reinforces the need for special education, for experts in counseling of the Deaf, and in rehabilitation of the Deaf.

In the fourth stage of medicalization of cultural Deafness, the minority has been increasingly dispersed by closing specialized schools, where Deaf language and culture were transmitted by older students and some Deaf staff. Deaf children are placed instead in scattered local public schools, a practice called "mainstreaming." In larger communities, there may be special classes for deaf children in the local school; in smaller ones, the Deaf child is frequently isolated in the mainstream. Cut off from his or her Deaf world, unable to communicate substantively with parents, peers and teachers, the Deaf child has a greater need to be a hearing child than ever before in American history. The infirmity model has become more plausible applied to the young Deaf child; with academic integration, the medicalization of cultural Deafness gained major ground.

It is in this historical context that the latest stage of medicalization of cultural Deafness has developed – childhood cochlear implants. Note that otologists are recruiting a new population when implanting young Deaf children. There has been nothing they could do to or for most of these early-deafened children heretofore.

COCHLEAR IMPLANTS AND CULTURAL DEAFNESS

Consider an audiologist who is informed about Deaf culture and language, who is familiar with culturally Deaf adults, who recognizes the forces at work in the medicalization of cultural Deafness. Suppose some educated hearing parents come to this audiologist to inquire about an implant for their early-

deafened and profoundly deaf child (as stated above, most deaf children are early-deafened, and for the present only profoundly deaf children and adults are considered candidates for implants). "What are the risks and the potential gains?" the parents ask. Here is how I imagine the interview.

Environmental Sound

The audiologist might begin by discussing perception of environmental sound with an implant. To quote Elmer Owens, "Although most patients will hear sound that is useful to a varying extent, others will hear only noise, and a relatively small proportion will fail to hear any sound. At present no accurate description can be given to a prospective implant patient on the benefit he will receive" (Owens, 1989, p. 26).

It is difficult to assess the remaining nerve population to predict benefit, the audiologist explains (Owens & Kessler, 1989, p. 7; Jackler & Bates, 1989, pp. 159, 174), and the prospects of gain in environmental sound awareness may be less favorable for children who have never heard environmental sound patterns or who have had limited exposure to them. Peripheral auditory damage can delay or impair structures in the central nervous system of animals. Hence congenitally deaf or early-deafened children may have a handicap in interpreting electrical stimulation. For differentiating various kinds of sounds in the environment, a tactile aid may be an attractive alternative (Osberger, Robbins, Miyamoto, Berry, Myres, Kessler, & Pope, 1990).

Speech Perception

The parents interrupt: they have much higher hopes; they want their child to understand speech. The audiologist explains that there is a distinct possibility their child will have no material gain in auditory speech comprehension as a result of the implant. One extensive study of children who had received the Nucleus 22-channel implant (Staller, Beiter, Brimacombe, & Arndt, 1990) found reliable improvements in speech perception after using the implant for a year on only two of seven tests where words and sentences were chosen from a large pool ("open-set"). The children's average score on these tests were only 11 and 13 percent correct, even though many in the sample of about 30 children had been deafened after learning English. Another study (Osberger, Robbins, Miyamoto, Berry, Myres, Kessler, & Pope, 1990) tested the ability of a like number of children with the same implant to understand common phrases. They were accurate, on the average, on only one sentence in ten, although the task was so easy that profoundly deaf children wearing hearing aids averaged better than eight out of ten.

It is difficult to estimate directly the risk of no material gain in speech comprehension with pre- or perilingually deafened children – those deafened before school age (Owens, 1989, p. 44, states that age five is generally accepted as the upper limit of "perilingual"). In approving the marketing of the Nucleus 22-channel implant, the Food and Drug Administration (1990) stated: "A few

children demonstrate the ability to recognize speech without lipreading." It is hard to predict if your child will be one of the few. There are several reasons for our ignorance. Experimental reports are few and very recent (see reviews in Owens & Kessler, 1989 and Kveton, 1990). The longest experience of implant use in children is with single-channel implants but multichannel implants are coming into greater use. Reports on both types of device are on heterogeneous populations of children, measured in various laboratories, with various procedures and tests. So the available data are fragmentary at best. To make matters worse, early-deafened children comprise a small percent of those implanted and tested, even though they are the vast majority of the school-age deaf population. Their implant results are generally poorer than those of the late-deafened children but are commonly not presented separately from the global group results on various tests.

It is, moreover, difficult to test young children in a reliable and valid way, particularly if the experimenter and child do not have a common language, all the more so if the child has had limited access to a language up to the time of testing – the case with many early-deafened children. Different tests of the same perceptual abilities often give different results in children; convergent measures are more common in late-deafened adults using implants but even differing recordings of the same sentences can lead to differing results (Rabinowitz, Ed-dington, & Grant, 1988). There are large unexplained differences in the performances of implanted children who are highly similar in all measured respects. The few reports available on the effectiveness of the multichannel device, published by experimenters some of whom are employed by the implant manufacturer, present results in terms that make it difficult to gauge material gain in speech perception for your child – gains that will really change her oral communication with family, neighbors, peers and teachers. For example, these recent reports give the percent of children who can identify one or more words out of 50, or the percent of children who showed any improvement at all on any of five quite different perceptual tests. In short, cochlear implants for early-deafened children such as yours are still highly experimental; your child may not make any useful gains in speech perception.

It appears that one significant factor in predicting an implanted child's gain in auditory-only speech perception is the age at which the child became deaf. Only 4 of 27 congenitally deaf children using the Nucleus implant in one study demonstrated any improvement in open-set speech recognition (although 11 improved to some degree on closed-set speech perception; Staller et al., 1990). Of the 80 children in that study, the 53 that showed no open-set recognition had become deaf on the average at age one and a half, while the 27 that showed some open-set recognition had become deaf on the average at age five years, three months. Osberger, Todd, Berry, Robbins, and Miyamoto (1990) found that children deafened in the first few years of life were no more likely to profit from their implant than those born deaf. Likewise, most adults who were deafened prelingually or perilingually make very poor gains in auditory speech

comprehension after receiving cochlear implants (Owens, 1989, p. 45).

Even postlingually deafened adults, once fluent in English, frequently make small gains in open-set auditory recognition for monosyllabic words when using single or multichannel implants. Although there are striking exceptions, a majority cannot reliably engage in speech communication without lipreading skills. To quote Owens further, "Persons [who] have such marked reductions in clarity of hearing experience extreme communicative difficulty in everyday life." They are left out in ordinary conversations. They cannot use the telephone or the television (Owens, 1989, p. 44). In attempting to guess what is being said by sound, these postlingually deafened adults have the enormous advantage of having mastered the language previously. Hence the risk of no material gain in auditory speech comprehension is larger for pre- and perilingually deafened children.

Early-deafened children with sufficient hearing losses to make them implant candidates have enormous difficulty lipreading since they have not mastered the language (see the reviews in Evans, 1981; Mogford, 1987). Many of these Deaf children are no better able to lipread after years of training than untrained hearing viewers. So the likelihood seems small that your child will effectively combine visual information from lipreading with degraded auditory information from the implant, as late-deafened adults frequently do with success.

An extensive recent study comparing speech perception abilities of early-deafened children using single-channel implants, multichannel implants, tactile aids or hearing aids, concludes: "Children with pure-tone thresholds between 90 to 105 dB and residual hearing throughout the frequency range derive more benefit from conventional hearing aids than they would from a multichannel cochlear implant" (Osberger, Robbins, Miyamoto, Berry, Myres, Kessler, & Pope, 1990, p. 23). Indeed, some investigators believe that the decision to implant surgically should only be made after a few years' trial with conventional amplification (Brookhauser, Worthington, & Kelly, 1990).

English Language Acquisition

All in all, there's a substantial risk that your child will not come to understand spoken English under most circumstances. This augers ill for her acquisition of English as a native language. Suppose the implant reduced your child's hearing loss from profound to severe. A large study of the academic achievement of Deaf high school leavers finds that profoundly Deaf and severely Deaf students at the end of their schooling score quite similarly on reading achievement – about the level of a fourth grade hearing child. And the Deaf children in this survey with less than severe losses averaged only about a half a grade higher (Allen, 1986, p. 165). Likewise, another extensive study of deaf children in aural/oral programs found "low correlations between reading scores and measures of hearing acuity, speech perception, and speech production" (Geers & Moog, 1987, p. 34). It may be that even a modest amount of hearing-impairment during preschool years precludes English mastery for most children. In that case, the

implant is unlikely to offer your child appreciable gains in mastering the English language.

On the other hand, some scholars argue that an implant providing the Deaf child with some spoken-language input in childhood, such as hearing children have, could arrive during a "critical period" for language acquisition and might provide a matrix for English language learning. However, the scientific literature does not provide clear guidelines on when such a hypothesized period begins and ends; different estimates arise from examining different performances such as normal first language learning, delayed learning of a first language, second-language learning, deterioration of speech following deafening, and the effects of cochlear implant on speech perception and production. Cochlear implant is unlikely to take place before the age of two years, by which time the nervous system may have made a partially irreversible adaptation to the sensory milieu (Kessler & Owens, 1989, p. 325; Curtiss, 1989). Furthermore, an impoverished auditory signal such as the implant provides may not yield some of the same benefits for later language acquisition that normal hearing does. The parametrization of speech signals in some coding schemes for the speech processors of cochlear prostheses may work against the usefulness of the auditory input for language development. Since children who are deafened early but implanted some years later show such modest gains in speech perception, it is tempting to say, "Let's not wait, let's implant her now." That's the experimental spirit, but it would not be a decision grounded in research findings.

Speech Production

Let's talk about the impact of the implant on your child's speech. Listeners understand about one word in five from profoundly Deaf children (Stark, 1979). The more severe the hearing loss the less the child's rated speech intelligibility will be. However, among profoundly Deaf speakers there is no clear relation between hearing loss and intelligibility (Osberger, 1989, p. 261). It is not clear that a little hearing is better than none when it comes to a child being understood by others. Kessler and Owens conclude that the evidence from studies conducted with a single-channel implant "is still unclear, even after several years of concentrated observation, regarding the acquisition of intelligible spontaneous speech by those children who may have previously never heard sound or who had only minimal exposure to sound" (Kessler & Owens, 1989, p. 323). Therefore, even if your child were to derive substantial auditory benefit from an implant, that would not necessarily be associated with substantially improved intelligibility.

Turning to direct evidence of the effects of cochlear implants on speech of Deaf children, there are only preliminary data to guide us. These data indicate that the implanted children are better able to produce some speech features such as voicing (Osberger, 1989). However, it is too early to say whether the average implanted child speaks more understandably than he or she would have without the implant and, if so, by how much. Nor do we know which children stand to benefit more and which less in this matter (Osberger, 1989, p. 277). Osberger

states: "Given the limitations of any cochlear prosthesis at this time, it can be predicted that the performance levels of nonauditory children might match but not exceed those of profoundly hearing-impaired children with residual hearing who use hearing aids" (p. 279). Three-fourths of such children are judged by their teachers to be unintelligible (Wolk & Schildroth, 1986, p. 147).

To summarize the issues so far, I will quote from the conclusions of the National Institutes of Health Consensus Development Conference: "Children with implants still must be regarded as hearing-impaired [and] will continue to require educational, audiological, and speech and language support services for long periods of time" (Kohut, 1988, p. 16). I expect your child will gain in awareness of environmental sound, will not gain materially in ability to understand spoken English and therefore in mastering the language, consequently will have the same prognosis in education as if not implanted, and may be only a little more intelligible at best.

Medical Risks

Your child will run the usual medical risks associated with general anesthesia and surgery. About one child in 30 implanted develops complications such as "infection/extrusion, pain/inflammation, delayed wound healing/extrusion, skin flap complications, transient drainage, electrode displacement and/or misplacement, and facial nerve damage" (Kveton, 1990, p. 20). These complications are usually resolved. Reimplantation of your child will probably be necessary over the next 60 or 70 years because of device failure and because of design improvements. However, deeply inserted multichannel electrodes, which seem to provide the greatest auditory benefit currently, may be difficult to remove without serious structural damage (Loeb, 1989, p. 142). Indeed, to insert the electrode in the first place, the surgeon may have to permanently alter the structure of your child's inner ear and this may reduce or destroy any residual auditory function in that ear. The effects of damaging the ear through insertion and the effects of long-term electrical stimulation are unknown. However, some patients have been successfully explanted and reimplanted.

Social Risks

Since your child has sufficient hearing loss to be a candidate for an implant, it is likely she will rely on some form of manual communication for most of her adult life. Most of her education will be conducted using some form of manual communication from primary school through university. The chances are that she will learn American Sign Language, marry a Deaf person and become involved in the Deaf community. She may have Deaf children. Therefore, your child's mastery of sign language is of great importance.

motion and money to the implant process and the necessity of intensive aural rehabilitation, generally in special oral/aural educational programs, raises the risk that your child will start acquiring American Sign Language later than she might have without the implant. Thus your child's opportunity to master a

language and to use it for fluently exchanging messages and learning about the world may be delayed – and with that the normal growth of her intellect. We know that Deaf children of Deaf parents, who experience no such delay, have a substantial educational and psychosocial advantage over Deaf children with hearing parents (see, for example, Moores, 1987; Weisel and Reichstein, 1989). This is probably because of early language mastery but other factors may be interwoven, such as closeness between parent and child.

With respect to your child's developing a social identity, a partially successful implant may be worse than none at all. It is possible that your family's commitment to the implant process, the aural/oral program your daughter will likely be enrolled in, the auditory benefit the implant provides, its visual appearance, and a possible delay in acquiring ASL may all hinder your daughter's developing identity as a Deaf person. However, it is unlikely that she will be able to develop as a hearing person. Therefore, she may "fall between" two potential sets of friends and mates and two "worlds." "Hard-of-hearing adolescents . . . tend to be culturally homeless, belonging to neither the Deaf nor the hearing communities" (Evans, 1989, p. 312).

On the average, the later the age that your child acquires ASL, the less will be her skill (Mayberry & Fischer, 1989). There is some evidence that brain tissue involved in spoken language in hearing children is reallocated to visual language in Deaf people (Neville, Schmidt, & Kutas, 1986). There is therefore the possible risk that early sound awareness from the implant may block this mechanism and give your child a permanent sign language deficit.

There are no research findings to guide your decision that describe the impact of the implant on the Deaf child's quality of life. In general, thoughtful people favor wariness when considering the use of high technology for life enhancement – as opposed to life-saving. We know how poor our record is in predicting side effects – as in "a little radiation will get rid of this acne." The newer the technology, the more cautious we want to be for the less sure the results.

There are some risks that are peculiarly your own, the audiologist warns the parents. "With cochlear implantation, the desire to have the perfect child may be rekindled" (Evans, 1989, p. 310). If the implant does not live up to your hopes, you may have to suffer a new period of regret and acceptance. The implant process may also delay the time when you yourself improve your signing skills and therefore your ability to communicate with your child; that, however, is up to you.

Ethical Issues

The hardest issues to weigh are the ethical ones. No doubt the design of cochlear prostheses will continue to improve but it is not self-evident that implanting those much more perfected devices in your child, when they come along, is the right thing to do. It is important for you to weigh the views of culturally Deaf adults since your child may hold their views one day and since deaf people have privileged access to knowledge about deafness. Eighty-five percent of

early-deafened adults, when asked in a recent survey if they would chose to have an implant if it were possible that they would gain some hearing, declined to have one (Evans, 1989). The members of the American Deaf community commonly believe that what characterizes them as a group is their shared language and culture and not an infirmity. When Gallaudet University's Deaf president, I. King Jordan, was asked if he would like to have his hearing back, he replied: "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" (Fine, 1990).

The World Federation of the Deaf finds technical implant developments "encouraging for persons deafened after some years of hearing" but "experimentation with young deaf children is definitely not encouraged" (World Federation of the Deaf, 1989, p. 4). Because there is now abundant scientific evidence that Deaf communities constitute linguistic and cultural minorities, the British National Union of the Deaf has condemned oral education of deaf children as a violation of the United Nations Treaty on Genocide, which prohibits measures that tend to eliminate linguistic and ethnic minorities (National Union of the Deaf, 1982).

Scholarship does not provide reliable guides on where to draw the line between valuable diversity and treatable deviance. In the course of American history, health practitioners and scientists have labeled various groups biologically inferior that are no longer considered in that light; these include women, Southern Europeans, Blacks, gay men and lesbians and Deaf people. If medical procedures become available to alter gender, sexual orientation, or racial traits such as skin color, would you favor parents taking those initiatives in the hope of easing life's burdens for their child?

It is difficult to say, of course, whether you will conclude later that you have acted unethically. What scholarship does tell us is that there is increasingly the view in America, as around the globe, that the Deaf communities of the world are linguistic and cultural minorities and that where there are laws or mores protecting such minorities they do (or should) extend to the Deaf community. In America, this recognition of the status of the Deaf community, fueled by the civil rights movement, is leading to greater acceptance of Deaf people. Your child's interests and your own may best be served by accepting that she is a Deaf person, with a rich cultural and linguistic heritage which can enrich your life as it will hers.

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REFERENCES

- Allen, T.E. (1986). Patterns of academic achievement among hearing-impaired students: 1974 and 1983. In A.N. Schildroth & M.A. Karchmer (Eds.), *Deaf children in America* (pp. 161-206). San Deigo, CA: College-Hill.
- Baker, C., & Cokely, D. (1980). *American Sign Language: A teacher's resource text on grammar and culture*. Silver Spring, MD: TJ Publishers.
- Bellugi, U., O'Grady, L., Lillo-Martin, D., O'Grady-Hines, M., van Hoek, K., & Corina, D. (1990). Enhancement of spatial cognition in deaf children. In V. Volterra & C. Erting (Eds.), *From gesture to language in hearing and deaf children* (pp. 279-298). Berlin: Springer Verlag.
- Boothroyd, A. (1989). Hearing aids, cochlear implants and profoundly deaf children. In E. Owens & D. Kessler (Eds.), *Cochlear implants in young deaf children* (pp. 81-100). Boston, MA: Little Brown.
- Bragg, B. (1989). *Lessons in laughter: The autobiography of a Deaf actor*. Washington, DC: Gallaudet University Press.
- Brookhauser, P., Worthington, W., & Kelly, W. (1990). Severe versus profound sensorineural hearing loss in children: Implications for cochlear implantation. *Laryngoscope*, 100, 349-356.
- Brown, S.C. (1986). Etiological trends, characteristics, and distributions. In A.N. Schildroth & M.A. Karchmer (Eds.), *Deaf children in America* (pp. 33-54). San Diego, CA: College-Hill.
- Conrad, P., & Schneider, J. (1985). *Deviance and medicalization*. New York, NY: Merrill.
- Curtiss, S. (1989). Issues in language acquisition relevant to cochlear implants in young children. In E. Owens & D. Kessler (Eds.), *Cochlear implants in young deaf children* (pp. 293-306). Boston, MA: Little Brown.
- Eastman, G.C. (1989). *From mime to sign*. Silver Spring, MD: TJ Publishing.
- Evans, J.W. (1989). Thoughts on the psychosocial implications of cochlear implantation in children. In E. Owens & D. Kessler (Eds.), *Cochlear implants in young deaf children* (pp. 307-314). Boston, MA: Little Brown.
- Evans, L. (1981). Psycholinguistic Perspectives on Visual Communication. In B. Woll, J. Kyle, & M. Deuchar (Eds.), *Perspectives on British Sign Language and Deafness* (pp. 150-162). London: Croom Helm.
- Fine, H., & Fine, P. (Producers). (1990, March). *Sixty Minutes*. New York, NY: Columbia Broadcasting System.
- Food and Drug Administration, Center for Devices and Radiological Health. (1990). Cochlear implant for children ages 2 through 17 years. Press release dated June 28, 1990. Washington, DC: Department of Health and Human Services.
- Gannon, J. (1981). *Deaf heritage*. Silver Spring: National Association of the Deaf.
- Gannon, J. (1989). *The week the world heard from Gallaudet*. Washington, DC: Gallaudet University Press.
- Geers, A.E., & Moog, J.S. (1987). *Factors predictive of the development of reading and writing skills in the congenitally deaf: Report of the oral sample. Final report to NINCDs*. St. Louis, MO: Central Institute for the Deaf.
- House, A. (1990, January). Cochlear implants in children; past and present perspectives. Address to the Third Symposium on Cochlear Implants in Children, Indiana University School of Medicine, Indianapolis, IN.
- Jackler, R.K., & Bates, G.J. (1989). Medical and surgical considerations of cochlear implantation in children. In E. Owens & D. Kessler (Eds.), *Cochlear implants in young deaf children* (pp. 153-182). Boston, MA: Little Brown.
- Kessler, D., & Owens, E. (1989). Conclusions: Current considerations and future directions. In E. Owens & D. Kessler (Eds.), *Cochlear implants in young deaf children* (pp. 315-330). Boston, MA: Little Brown.
- Kohut, R.I. (Ed.). (1988). Cochlear implants. *National Institutes of Health Consensus Development Conference Statement*, 7, 1-25.
- Kveton, J. (1990). The status of cochlear implantation in children. Unpublished paper, Surgery

- Subcommittee on Cochlear Implants, American Academy of Otolaryngology, Head and Neck Surgery.
- Lane, H. (1984). *When the mind hears: A history of the deaf*. New York, NY: Random House.
- Lane, H. (1986). Taking deaf education into your own hands. In R. Rosen (Ed.), *NAD Forum 1986: Life and work in the 21st century: The Deaf person of tomorrow*. Silver Spring, MD: National Association of the Deaf.
- Loeb, G.E. (1989). Neural prosthetic strategies for young children. In E. Owens & D. Kessler (Eds.), *Cochlear implants in young deaf children* (pp. 137-152). Boston, MA: Little Brown.
- Lucas, C. (1989). *The sociolinguistics of the Deaf community*. New York: Academic Press.
- Mayberry, R., & Fischer, S. (1989). Looking through phonological shape to lexical meaning: The bottleneck of non-native sign language processing. *Memory and Cognition*, 17, 740-754.
- Mogford, K. (1987). Lipreading in the prelingually deaf. In B. Dodd & R. Campbell (Eds.), *Hearing by eye: The psychology of lipreading* (pp. 191-211). Hillsdale, NJ: Lawrence Erlbaum Associates.
- Moore, D. (1978). *Educating the deaf*. Boston, MA: Houghton-Mifflin.
- Moore, D. (1987). *Factors predictive of literacy in deaf adolescents with deaf parents. Final report to NINCDS*. Washington, DC: Gallaudet University.
- National Union of the Deaf. (1982). *Charter of the rights of the deaf*. London.
- Neville, H., Schmidt, A., & Kutas, M. (1983). Altered visual evoked potentials in congenitally deaf adults. *Brain Research*, 266, 127-132.
- Olsen, G. (1989). *A kaleidoscope of Deaf America*. Silver Spring, MD: National Association of the Deaf.
- Osberger, M.J. (1989). Speech production in profoundly hearing-impaired children with reference to cochlear implants. In E. Owens & D. Kessler (Eds.), *Cochlear implants in young deaf children* (pp. 257-282). Boston, MA: Little Brown.
- Osberger, M.J., Robbins, A.M., Miyamoto, R.T., Berry, S.W., Myres, W.A., Kessler, K.S., & Pope, M.L. (1990). Speech perception abilities of children with cochlear implants, tactile aids, or hearing aids. Unpublished report, Indiana School of Medicine, Indianapolis, IN.
- Osberger, M.J., Todd, S.L., Berry, S.W., Robbins, A.N., & Miyamoto, R.T. (1990). Effect of age of onset of deafness on children's speech perception abilities with cochlear implant. Unpublished report, Indiana University School of Medicine, Indianapolis, IN.
- Owens, E. (1989). Present status of adults with cochlear implants. In E. Owens & D. Kessler (Eds.), *Cochlear implants in young deaf children* (pp. 25-52). Boston, MA: Little Brown.
- Owens, E., & Kessler, D.K. (Eds.). (1989). *Cochlear implants in young deaf children*. Boston, MA: College-Hill Little Brown.
- Padden, C., & Humphries, T. (1988). *Deaf in America: Voices from a culture*. Cambridge, MA: Harvard University Press.
- Rabinowitz, W., Eddington, D., & Grant, K. (1988). Comparison of three sentence level tests for evaluating audiovisual performance of subjects using a cochlear implant. *Journal of the Acoustical Society of America*, 84, Suppl. 1, S45a.
- Schein, J.D. (1989). *At home among strangers*. Washington, DC: Gallaudet University Press.
- Staller, S.S., Beiter, A.L., Brimacombe, J.A., & Arndt, P. (1990). Pediatric performance with the Nucleus 22-channel cochlear implant system. Unpublished report, Cochlear Corporation, Englewood, CO.
- Stark, R. (1979). Speech of the hearing-impaired child. In L.J. Bradford & W.G. Hardy (Eds.), *Hearing and hearing impairment* (pp. 229-248). New York: Grune and Stratton.
- Sternberg, M.L. (1990). *American Sign Language: A comprehensive dictionary*. New York: Harper and Row.
- Van Cleve, J.V. (Ed.). (1987). *Gallaudet encyclopedia of Deaf people and deafness*. New York: McGraw Hill.
- Van Cleve, J., & Crouch, B. (1989). *A place of their own; creating the Deaf community in America*. Washington, DC: Gallaudet University Press.
- Weisel, A., & Reichstein, J. (1988). Parental hearing status, reading comprehension skills, and

- social-emotional adjustment. In R. Ojala (Ed.), *Proceedings of the Tenth World Congress of the World Federation of the Deaf*. Helsinki: Finnish Association of the Deaf.
- Wilbur, R. (1987). *American Sign Language* (2nd ed.). Boston: Little-Brown.
- Wilcox, S. (1989a). *American Deaf culture: An anthology*. Silver Spring, MD: Linstok.
- Wilcox, S. (1989b). Teaching American Sign Language as a foreign language. *ERIC Digest*, EDO-FL-8901.
- Wolff, A.B., & Harkins, J.E. (1986). Multihandicapped students. In A.N. Schildroth & M.A. Karchmer (Eds.), *Deaf children in America* (pp. 55-82). San Diego, CA: College-Hill.
- Wolk, S., & Schildroth, A.N. (1986). Deaf children and speech intelligibility: A national study. In A.N. Schildroth & M.A. Karchmer (Eds.), *Deaf children in America* (pp. 139-160). San Diego, CA: College-Hill.
- World Federation of the Deaf, Commission on Medicine, Audiology and Neuropsychiatry. (1989). Resolution on cochlear implants. Quoted in P. Courneyeur, Cochlear implants and children. *Vibrations*, 3-5.