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Ethical Issues in Cochlear Implant Surgery: An Exploration into Disease, Disability, and the Best Interests of the Child

ABSTRACT. This paper examines ethical issues related to medical practices with children and adults who are members of a linguistic and cultural minority known as the DEAF-WORLD. Members of that culture characteristically have hearing parents and are treated by hearing professionals whose values, particularly concerning language, speech, and hearing, are typically quite different from their own. That disparity has long fueled a debate on several ethical issues, most recently the merits of cochlear implant surgery for DEAF children. We explore whether that surgery would be ethical if implants could deliver close to normal hearing for most implanted children, thereby diminishing the ranks of the DEAF-WORLD. The ethical implications of eugenic practices with the DEAF are explored, as are ethical quandaries in parental surrogacy for DEAF children, and their parallels in transracial adoption.

CONVENTIONAL WISDOM IN MEDICINE assumes that deaf children have a serious sensory impairment that gives rise to a disability and to social, educational, and linguistic handicaps. From that perspective, childhood deafness should be mitigated or corrected as far as possible. However, the disability construction of deafness has been challenged by deaf communities in the U.S. and abroad for more than a century (Lane 1984).

This article explores the disputed issues in the context of a recent development in the surgical treatment of deaf children—cochlear-implant surgery. It is our thesis that there is something unique about childhood deafness that challenges the value-laden claim that growing up deaf involves a disability and that challenges, therefore, the appropriateness of surgical intervention to mitigate that disability. Since this deaf point of

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view is less well known and is counterintuitive for many hearing readers, we dwell on it more than the disability construction; however, our aim is not to advocate for either construction but rather to analyze the issues in a way that illuminates broad questions of interest to medical ethicists. Our discussion focuses primarily on the special nature of the deaf community and concerns about tolerance, diversity, and, ultimately, eugenics. While our analysis is theoretical, it has practical significance for contemporary medical (and other social) practices. The fundamental issue we will address is whether childhood deafness should be treated, even if the interventions were safe and totally effective. If there are significant ethical dilemmas associated even with medical interventions that would provide close to normal hearing, then present practices, which leave the deaf child "severely hearing-impaired," are open to more serious challenge.

The proper conceptualizations of disease, illness, and health comprise one of the grounding problems of medical ethics and the philosophy of medicine (Von Engelhardt 1995). How one understands normality, pathology, and disability impacts on how one demarcates the nature, scope, limits, and goals of medicine (Engelhardt and Wildes 1995; Webb-Mitchell 1995). The appropriate care, treatment, and respect for newborns with disabilities, for example, has served as a rich paradigm for the exploration of these substantive quandaries. Of particular concern is a fundamental standard of medical treatment that entails implementing, withdrawing, or withholding treatment only when it is in the best interests of the child (Grodin, Schwartz, and Todres 1982; Grodin 1995). How one determines interests is problematic, but primarily involves an analysis of burdens and benefits from the child's perspective. A major difficulty with implementing the best interests standard is its failure to take account of individual, family, and societal interests. A parallel dilemma is determining who the appropriate surrogate is to make the burden/benefit analysis on behalf of an incompetent patient. Historically, most of the bioethics literature concerning the treatment of what were called handicapped newborns has focused on various levels of mental retardation (e.g., Down syndrome), extreme prematurity, and major physical disabilities (e.g., spina bifida). All of the conceptual issues just cited, however—grounding definitions, appropriate care, best interests of the child, burden/benefit analysis, and parental surrogacy—also arise when considering medical intervention with deaf children. Moreover, as we shall explain, one additional issue in the bioethics literature is fundamental here: contrasting cultural beliefs concerning medical practice.

CONTEXT

The DEAF-WORLD

Some factual information provides the context for the ethical issues. American Sign Language (ASL) is the primary language of an estimated one million Americans (Schein 1989). Scholarly research, particularly in recent decades, has revealed ASL to be a full-fledged natural language, unrelated to English, with a complex grammar and art forms all its own (Valli and Lucas 1995). Research has also shown that the users of the language are members of a tight-knit social structure and share a culture with characteristic customs, values, and attitudes (Lane, Hoffmeister, and Bahan 1996; Padden and Humphries 1988). Hereafter, we will refer to the members of that culture as DEAF and to the culture itself as the DEAF-WORLD; these are glosses of the signs in ASL with which those people refer to themselves and their culture, respectively. We also follow DEAF-WORLD practices in referring to children of any age as DEAF who have, for whatever reason, the physical constitution characteristic of this minority—viz., they rely so much more on vision than on hearing that they would communicate most readily in a natural signed language. (The issue is examined further in a later section.) The English terms *deaf*, *hearing-impaired*, and *deaf community* are commonly used to designate a much larger and more heterogeneous group than the members of the DEAF-WORLD. Most of the estimated 20 million U.S. citizens in this larger group communicate primarily in English or one of the spoken minority languages (Binnie 1994); they do not identify themselves as members of the DEAF-WORLD, nor do they participate in its organizations, profess its values, or behave in accord with its mores; rather, they consider themselves hearing people with a disability.

DEAF people obtain information primarily through vision—they are "visual people." Some, usually the offspring of DEAF parents, start their acculturation to the DEAF-WORLD in infancy; some in childhood, often upon placement in an educational program for DEAF children; and some never. Once acculturated to the DEAF-WORLD, DEAF people know the language, customs, attitudes, values, and the like, of that culture, and they self-identify as DEAF. There is a "ninety percent" rule that captures four important statistics about the DEAF-WORLD: 90 percent of children born to DEAF couples have normal hearing; 90 percent of DEAF people marry another DEAF person; 90 percent of DEAF children have hearing parents; and 90 percent of children who might be candidates for cochlear implants

because of their inability to hear even very loud sounds were born that way or became DEAF before age one (Schein 1989; CADS 1992).

Being DEAF is highly valued in DEAF culture. DEAF people who espouse those cultural values are glad they are DEAF, and they reject the suggestion that they have an impairment or a disability. (The ASL sign that translates, roughly, as *disability* does not include being DEAF.) This contrasts with the predominant attitudes of people with disabilities (although there is diversity within both groups). Leaders of the disability rights movement call for ambivalence about their impairment. Individually they want it valued, as a part of who they are; at the same time, as the result of poverty, war, disease, or accident, they ask that we regret the impairment and try to prevent it (Abberley 1987; Lane 1995b). The DEAF-WORLD is not ambivalent; its members characteristically think it is a good thing to be DEAF and would like to see more of it. Unlike most expectant parents with disabilities, expectant DEAF parents characteristically hope to have children with whom they can share their language, culture, and unique experiences—that is, DEAF children. Whereas people with disabilities seek, above all, better medical care, rehabilitation services, personal assistance services—e.g., help with personal hygiene, dressing, and eating—integration into society at large and independence, DEAF people do not attach particular importance to any of these services. Nor do they have any more concern with autonomy and independent living than people in general; DEAF people cherish interdependence with other DEAF people. Integration of DEAF children into hearing schools and classes is anathema to the DEAF-WORLD. The specialized schools for the DEAF, especially the residential schools, were the setting in which most DEAF adults acquired fluent (manual) language and socialization. It has been those specialized schools and, after graduation, the DEAF clubs with their athletic, literary, political, and social programs that have provided most DEAF people in America, despite their having hearing parents, with the generational continuity that is essential for a rich culture.

What seems to lie at the heart of all these differences between the values of people with disabilities and those of the DEAF is that people with disabilities in the U.S. are acculturated to mainstream American values while DEAF views, although influenced by the hearing culture that engulfs the DEAF-WORLD, are also shaped by the unique culture of the DEAF-WORLD itself. Indeed, the political agenda of the DEAF-WORLD—highlighting such issues as education for DEAF children using the DEAF-WORLD minority language and the provision of interpreters—more closely resembles the agenda

of other language minorities than it does the agenda of any group of people with a disability. It may be objected that each disability grouping has its characteristic demands, so that the distinct concerns of culturally DEAF people, and even the fact that they do not see themselves as people with a disability, do not necessarily make it inappropriate to group DEAF people among people with disabilities. However, there is nothing inherent in DEAF people that requires them to be seen as people with disabilities, nor can any reason be given why they must be mistaken about their identity. When there are enough fundamental differences between the two groups, we are at liberty to revise our social construction. The social constructions of several other minority groups—Blacks and Gays, to name two—have shifted over the years in the direction of the group's own self-construction (Lane 1995b).

Cochlear Implants

The latest collision between the disability and cultural constructions of childhood deafness arose in 1990 when, after five years of clinical research trials, the U.S. Food and Drug Administration (FDA) approved surgical implantation of cochlear prostheses in children over the age of two. (The FDA had formerly approved this prosthesis for adolescents over age 12 and adults.) In the wake of the FDA approval, several medical, paramedical, and consumer groups also endorsed the practice; among them, the National Institutes of Health, the American Academy of Otolaryngology/Head and Neck Surgery, the American Speech-Language Hearing Association, and the Cochlear Implant Club International. An estimated 5,000 children in the U.S. and abroad have been surgically implanted with cochlear prostheses of the type approved by the FDA. Numerous national organizations of the DEAF around the world and the World Federation of the Deaf (with 110 member nations) have published position papers opposed to childhood implant surgery.[1] The single most recurrent criticism is that the surgery is unethical. For example, the National Association of the Deaf in the U.S. condemned the FDA decision as "unsound scientifically, procedurally and ethically" (NAD 1991).

In the surgical procedure under dispute, the hospitalized child is placed under general anesthesia for three to four hours. After preliminary surgery, a wire carrying electrodes is inserted into the inner ear. A receiver coil connected to the wire is sutured to the skull and the skin is sewn over it. A small microphone worn on an ear piece picks up sound and sends signals to a speech processor worn on a belt or in a pocket. The processor

sends electrical signals to the implanted receiver via a transmitter mounted behind the ear, and those signals stimulate the auditory nerve. The surgery normally is followed by very extensive speech and hearing therapy, administered by speech pathologists, teachers, and, frequently, parents. The research literature shows that the benefit in speech perception obtained by the minority of children, those who lost their hearing after acquiring English—an estimated 3 percent of children with profound hearing losses[2] (CADS 1992)—is similar to that obtained by patients deafened in adulthood: in many cases such children recover substantial ability to recognize words by ear. However, for the estimated 86 percent born with profound hearing losses who must *acquire* spoken language rather than recover some ability to perceive it by ear, the results are different. There has been no case reported in the scientific literature of a child acquiring spoken language as a result of implant surgery, although there are anecdotal reports. Several medical centers around the U.S. have investigated auditory word recognition in such implanted children. Their results converge in revealing that the majority of implanted children who were born DEAF are unable to follow instructions to take the test or get no words correct on the test (without prompting), even after five years of implant use and habilitative therapy (Lane 1995a). A few children do much better, however, for reasons that are unclear.

There is a consensus among audiologists (who evaluate the children's ability to hear speech, provide training, and "fit" the prostheses) and otologists (who perform the surgery) that children with cochlear implants remain "severely hearing-impaired" (see, e.g., Horn, Noza, and Dolitsky 1991; Boothroyd 1993). This leads to a variety of concerns. For example, the decision to have the surgery and habilitation may promote delays in the child's acquisition of ASL and therefore may delay the time when that child has any full language at his or her command. Developmental milestones for signed languages are similar to those for spoken languages, and the later the acquisition of ASL, the poorer its mastery on the average (Petitto 1993; Mayberry and Eichen 1991). If implanted children become fluent neither in English nor in ASL, their intellectual, social, and psychological development may be compromised. However, we wish to explore the ethical dimensions and arguments that arise in the dispute over childhood implants, to point out important considerations in the debate rather than to advocate for or against implant surgery, and to examine what light is shed on this issue by examining parallel cases. For these purposes, it is helpful to consider whether the surgery would be ethical if, contrary

to the present facts, implants could deliver close to normal hearing for most implanted children, and the children then proceeded to acquire spoken language.

ETHICAL ISSUES RAISED BY COCHLEAR-IMPLANT SURGERY ON CHILDREN

Parents have an ethical duty to act in the reasonable best interests of their DEAF child, and the surgeons have an ethical obligation to provide their patients, given their consent, with a safe and potentially effective treatment. Both groups see implant surgery as promising at least an increased responsiveness to sound, and in particular to speech. At best, the hope is that surgery will allow the DEAF child to acquire spoken language. That, in turn, would provide the child with easier communication with parents, peers, teachers, and others. Moreover, the child would not be subject to the stigma of being DEAF. With a "perfect implant," the child would acquire English not ASL (assuming the parents are English speakers) and become acculturated to his or her parents' culture and not that of the DEAF-WORLD. If this surgery were performed on a large scale, many children who would have learned ASL and who would have become acculturated to the DEAF-WORLD would not do so. Some 60,000 school-children in the U.S. receive special services for the hearing-impaired, and, with a perfect implant available, most would be candidates for the surgery. Thus, the population of the DEAF-WORLD in the U.S. would decline drastically—although most DEAF children of DEAF parents would presumably continue to enter it. The presently thriving culture would diminish as well, and possibly die. If so, the program of cochlear implantation in children, and the parental decisions that implemented it, would have as one effect the diminution of a minority culture. It would also reinforce the belief that those remaining in the DEAF-WORLD suffer from an impairment, a belief that the DEAF-WORLD finds erroneous and inimical to its interests.

Let us assume then that it is in the best interest of the DEAF child to receive a perfect implant and not in the interest of the DEAF-WORLD for substantial numbers of DEAF children to do so, as that would lead to a diminution of the DEAF-WORLD and its culture. Let us further assume that preservation of minority cultures is a good. We would argue—but will not do so here, for it would take us too far afield—that the variety of humankind and cultures enriches all cultures and contributes to the biological, social, and psychological well-being of humankind. Laws and covenants, such as the United Nations Declaration of the Rights of Per-

sons Belonging to National or Ethnic, Religious and Linguistic Minorities (1992), are founded on a belief in the value of protecting minority cultures. Programs that substantially diminish minority cultures are engaged in ethnocide (Diamond 1970), and may constitute crimes against humanity. The United Nations Convention on the Prevention and Punishment of the Crime of Genocide (1948) defines as genocide "any of the following acts committed with intent to destroy in whole or in part a national, ethnical, racial or religious group, [including] measures intended to prevent births within the group." While surgical programs that implant large numbers of DEAF children do not have as their intent the destruction of DEAF-WORLD culture, both the U.N. Declaration and the Convention express humankind's interest in preserving and fostering minority languages and cultures and thus, once the minority language and culture of the DEAF-WORLD is recognized, alert us to the conflict of values arising from those surgical programs.

Clearly, there is a tension, then, between concern for the individual DEAF child who would benefit from a perfect implant and concern for the DEAF-WORLD, which would be harmed by the widespread use of implants. Granted that the parents of that child have a primary duty to pursue their child's reasonable best interests, do the hearing parents of the DEAF child also have an obligation to consider the destructive effects on the DEAF-WORLD of parental decisions for childhood implant surgery? If the parents do not have that obligation, does society at large have such an obligation? Consider a different case of tension between concern for the individual and concern for the minority group. How should parents act if they endorse busing for school desegregation in their town but believe that their own child would be adversely affected by being bused? Suppose we respond that parents must, in the end, weigh the consequences for their own child more heavily than those for the minority culture, whether the DEAF-WORLD or African Americans. How would this calculation be affected by recognizing that the DEAF child's physical constitution would otherwise have made him or her a member of the DEAF-WORLD? Does this oblige the parents to place more value on the welfare of that particular minority culture than the value that our common humanity leads us to place on the protection of all minority cultures?

Consider white foster parents who have a Black child and hearing parents who have a DEAF child. Both sets of parents have physical attributes markedly different from their children, and in both cases the children would become members of minority groups different from their parents'

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culture if no special measures, such as surgery, were undertaken to change that. Are white foster parents of a Black child, then, obliged to consider not only the interests of their town and their Black child in the busing issue but also the views of the Black community? Suppose the white foster parents believe that Black parents might give even more weight than they do to desegregation. Should they allow that to tip the balance in favor of busing their child? In short, does having a child that would normally be a member of a distinct minority culture oblige the child's parents, whether foster or not, to give more weight to acting in the best interests of that minority culture than they would have otherwise? Or is the parents' sole duty the reasonable best interests of their child, leaving to social institutions the responsibility for defending the interests of minority cultures? Relegating the responsibility to society does not provide an entirely satisfactory solution since: (1) hearing parents are members of the larger society to which the responsibility for defending the DEAF-WORLD would be left and (2) if hearing parents elected in large numbers to have their DEAF children surgically implanted, it is hard to see what measures a concerned society might take to ensure the survival of the DEAF-WORLD that would not trammel the primary authority of the parents' decision.

Consider a further case of tension between concern for the individual and for the minority group. Some Black leaders and organizations have condemned transracial adoption practices on the ground, among others, that they promote "cultural genocide" (see Simon and Altstein 1992). This issue is a closer parallel than desegregation to the fundamental interest of the DEAF-WORLD in its very survival in the face of widespread cochlear implantation. Suppose a white couple wishes to adopt a particular Black infant whose quality of life would, let us assume, then improve. Does the couple have an ethical obligation, grounded in the value we place on other cultures, other ways of life, to weigh the negative views of the Black minority since the child they propose to adopt is Black and, even if not yet acculturated to African-American culture, would normally acquire that minority culture if they did not intervene? Suppose that the couple agrees that preservation of Black culture is a good and that the policy of transracial adoption is inimical to that good; is the ethically right course for them to decline to adopt the Black child? Since they are not the child's parents, they would have no preexisting parental obligation to benefit the child. Should they decline to adopt even if there are no Black foster parents available and the child is languishing in an orphanage?

Perhaps the couple will respond that they can satisfy their concern for the Black minority by doing all in their power to raise their child biracially and biculturally. Hearing parents of a DEAF child cannot attempt to resolve the tension in this way since, if their child had a perfect implant, he or she would no longer have the physical constitution that is necessary to be DEAF. Moreover, the parents would have little reason to ensure that their child learns ASL, especially since he or she could never be a full-fledged member of the DEAF-WORLD, which would, in any event, be moribund. Consider instead then, a large-scale program that resettled in the United States children from a culture whose survival is threatened by war or disease or famine. Would such a program be ethical if it enhanced the lives of the children at the expense of hastening the demise of their culture? If not, should government permit such a program? Should citizens agree to serve as foster parents under those conditions?

The Congress and the courts of the U.S. seem to have held both values dear—the best interests of the child and those of the minority culture—in legislating and adjudicating cases under the Indian Child Welfare Act of 1978. Passed at a time when the survival of Native American cultures was considered threatened by very high rates of transracial adoption, the act was designed to prevent the undermining of Native American tribes, stating that "it is the policy of this nation to protect the best interests of Indian children and to promote the stability and security of Indian tribes . . . ." The Supreme Court has ruled that lower courts must consider the best interests of the particular Indian tribe as well as the best interests of the child (Simon and Altstein 1992).

WHICH CHILDREN ARE DEAF?

The extent to which analogies from transracial adoption are helpful in examining the case of DEAF children depends on how we analyze the relationship between the parent and the child. If we see as the defining characteristic of the relationship the biological ties between parent and child, then it is not illuminating for the issue of DEAF children to conclude, for example, that foster parents of a Black child have an obligation to defend the interests of the Black minority. Hearing parents of the DEAF child object that they, unlike foster parents, are the child's biological parents; this child belongs not to another culture but to their own culture. Since it has not yet made any ties to the DEAF-WORLD, they need not be concerned about that world any more than any other person. In contrast, where there are cultures whose members have a characteristic physical constitution, all the children with that constitution tend to be seen as the rightful recipients of that culture to some degree.

Clearly, Black leaders believe that African-American children, for example, have an African-American heritage from the day they are born, regardless of whether they are allowed to take possession of that heritage. Accordingly, the National Association of Black Social Workers came out opposed to transracial adoption on the grounds that it will deprive such children of their heritage. We need not decide at this juncture whether it is more important for these Black children to be adopted as quickly as possible or to take possession of their heritage; the relevant point is whether they do have such a heritage at birth. Likewise, does a visual child—one who relies primarily on vision—however raised, have a DEAF heritage. For members of the DEAF-WORLD, the answer is clearly "yes." They feel a strong bond with that child; they may note that it has "DEAF EYES," and, after all, that the child's life trajectory, given its constitution, will likely cause him or her to become fully acculturated to the DEAF-WORLD. The DEAF child can be deprived of the opportunity to acculturate to that world, as can the Black child or the Native American child, but the child's potential for acculturation to that world, which is rooted in his or her physical difference, remains, so we consider the child with that difference DEAF, Black, or Native American right from the start, whether they are in fact able to enter their respective cultures or not. This would explain why adult DEAF, Black, and Native Americans, for example, feel a strong emotional investment in the welfare of, respectively, DEAF, Black and Native American children, and identify and empathize with them, even when they are not related to them.

Although some children are DEAF for hereditary reasons, others become DEAF as a sequel to illness prenatally or in childhood. Children in other cultural minorities do not acquire their distinctive physical constitution as a sequel to illness or in childhood, so an examination of the cultural norms for membership in the DEAF-WORLD is particularly interesting. The reasons for which the DEAF constitution arises are irrelevant for those norms, but the constitution itself is essential. Hearing children of DEAF adults, called "codas," are not considered DEAF despite their fluency in ASL and acculturation to the DEAF-WORLD, a situation that is perhaps comparable to Caucasians who are occasionally raised in a Native American culture but are not considered Native Americans. However, as with other language minorities, the characteristic constitution is important in that it predisposes the person to communicate in the language and thus to participate

in the life of the culture (Bahan 1994). If that predisposition is undermined by long acculturation to spoken language and culture, as it would be in a hearing adult who later is deafened, it seems that that person is not considered DEAF on constitutional grounds alone and must acquire signed language fluency and DEAF-WORLD cultural norms before the DEAF-WORLD will view him or her as DEAF.

Consider a contrasting view, namely that children who are so much more reliant on vision than on hearing that they have severe difficulty with oral communication nevertheless start out in mainstream hearing society and become part of the DEAF-WORLD only when they are "placed in that community by their parents or voluntarily decide to enter it" (Cohen 1994, p. 1). From this vantage point, if the child is fitted with the perfect implant early enough, the DEAF-WORLD is utterly irrelevant, and the child should be considered formerly deaf not DEAF. However, we would not say of, for example, Hispanic-American children that they start out in the mainstream society and only become members of the Hispanic minority culture when placed there by their parents or their own decision; rather, we would say that the child "is Hispanic" and has an Hispanic heritage at birth. Is that because Hispanic children normally have Hispanic parents—is it the parents' culture that is criterial in ascribing a cultural heritage to the child? No, since an Hispanic-American infant adopted at any age into an English-speaking foster family is still viewed as an Hispanic-American child. Likewise, a Native-American infant who is transracially adopted is still considered a Native-American child. Suppose an embryo formed by the union of two Native Americans were implanted in the womb of a Caucasian woman, would the child to which she gave birth be considered Caucasian or Native American? It seems that the cultural membership ascribed to the child is not based on its parents' culture, but rather on the culture the child would enter given its physical makeup. What makes the DEAF case unique among minorities, and therefore challenging for our ethical reasoning, is that these two criteria—the culture of the parents and the culture that the child's constitution predisposes him to enter—have separated.

THE EUGENICS DISPUTE

DEAF children and the DEAF-WORLD are not the only groups whose interests are affected by a policy authorizing cochlear implantation. The interests of parents, professionals, and the wider society are also at stake. This becomes clearer in the dispute between hearing and DEAF cultural values

in the realm of eugenic measures aimed at avoiding the birth of DEAF children in the first place. The underlying reason, we submit, that doctors and parents want cochlear prostheses for DEAF children is that their construction of those children's reality is based on disability. The underlying reason that the DEAF-WORLD is at odds with them is that its cultural construction of the reality of DEAF children is based on the children's potential for sharing the language and culture of the DEAF-WORLD and identifying with it (Lane 1992, 1995b). It follows from the disability construction that being DEAF is not a good thing and that efforts will be undertaken not only to eradicate the underpinning physical difference in the individual child with prosthetic surgery but also to prevent more children with that disability from being born through genetic counseling and genetic engineering. More than half of all children who are DEAF in the U.S. are DEAF for hereditary reasons (Reardon 1992).

The DEAF-WORLD seems to have a favorable view of genetic research and counseling under two conditions. First, some DEAF adults seek genetic counseling when considering a mate, in order to enhance the possibility that they will have DEAF children (Jordan 1991). Second, while DEAF adults welcome the birth of DEAF children, they commonly support measures that would reduce the numbers of DEAF children that are born with what are seen as disabilities in DEAF culture—e.g., motor impairments. However, genetic counseling and research aimed at reducing the numbers of children born simply DEAF and eugenic proposals, such as gene therapy, with that same goal are considered highly unethical (Jordan 1991). The former chairman of a National Institutes of Health planning group recently acknowledged this conflict in an interview with *The New York Times*: "I am dedicated to curing deafness. That puts me on a collision course with those who are culturally deaf. That is interpreted as genocide of the deaf" (Pride in a Silent Language 1993).

If it is unethical for the majority culture to aim to reduce the numbers of children born DEAF because measures intended to prevent births within a cultural group constitute genocide, is it also unethical for a DEAF couple to seek genetic counseling to reduce the chances of having a hearing child? Davis (1997, p. 14) concludes that it is: Even "if Deafness is considered a culture, . . . then deliberately creating a Deaf child who will have only very limited options to move outside of that culture also counts as a moral harm." On the other hand, many members of oppressed cultures put great weight on marrying someone from their own culture so that their child will be a member of that culture—even if marrying outside of the culture

would potentially give their child a more open future. What is more ethically disquieting than people coupling to have children like themselves are eugenic social policies that favor some cultural groups—especially majorities—over others.

Contemporary efforts to regulate childbearing by DEAF people have a long history. Alexander Graham Bell was the leading figure in the last century in efforts to stop DEAF reproduction through model sterilization laws, campaigns to dissuade DEAF adults from marrying and procreating, and efforts to discourage DEAF socializing and education in the company of other DEAF people (Lane 1984). In 1992, Boston University researchers announced that they had identified the "genetic error responsible for the most common type of inherited deafness" (BU Team 1992). The director of the National Institute on Deafness and Other Communication Disorders (NIDCD) called the finding a "major breakthrough that will improve diagnosis and genetic counseling and ultimately lead to substitution therapy or gene transfer therapy" (BU Team 1992, p. 6). Thus a new form of medical eugenics applied to DEAF people was envisioned, in this case by an agency of the U.S. government.

The primary characteristics of DEAF people with this genetic background are numerous DEAF relatives, facial features such as widely spaced eyebrows, and coloring features such as differently colored eyes, white forelock, and freckling. For such characteristics to be viewed as a "genetic error," rather than normal human variation in physiognomy, coloring, and the like, some of the common features must clearly be construed as signs of a disease or infirmity. In fact, according to a leading medical geneticist, the "sole detrimental feature" of the syndrome described is that some of these people have the physical constitution of DEAF people (Fraser 1987). Within the culture of the DEAF-WORLD, then, this cannot be and is not a disease. In its National Strategic Research Plan, the NIDCD states: "The insertion of genetic material into cells to prevent or ameliorate hereditary hearing impairment may soon become a possible treatment option." (NIDCD 1992, p. 34.) The Institute acknowledges that "many deaf individuals believe that deafness is not a disorder but a *culturally defining condition*" (1989, p. 40; original ital.). Because the statement makes this a matter of individual belief among DEAF people, rather than the tenet of DEAF culture that it is, and because the statement makes no mention of what hearing people believe, the implication is that the authors of the statement and other such authorities have a different and perhaps more objective view of the matter. The statement goes on to say,

however, that the NIDCD (1989, p. 40) respects "the cultural integrity of deaf society." What construction of DEAF people would allow the Institute logically to support eugenic measures for limiting the membership of the DEAF-WORLD, all the while respecting the cultural integrity of DEAF society? Elsewhere in the report, the Institute calls for genetic research to improve diagnosis, counseling, and gene therapy, all with a view to reducing the numbers of children who are born deaf. Is it ethical to seek to prevent a "culturally defining condition"? Would it be ethical to offer genetic counseling to other groups with culturally defining conditions with the aim of avoiding children with those conditions, groups such as mixed-race couples or homosexual prospective parents?

Suppose we say that it is unethical to take measures aimed at reducing the number of births of children who will populate a given language and cultural minority. Once again, a unique property of the DEAF-WORLD probes our ethical reasoning. For not only do most DEAF people have hearing parents, but also some DEAF people, albeit a small percent, acquire the defining physical makeup that leads them into the DEAF-WORLD as a sequel to illness, such as meningitis, and not as a result of heredity. Is there an ethical dilemma in providing prenatal care whose effects are to reduce the likelihood of a hearing parent having a DEAF child? Is it problematic to treat a child for an illness that, untreated, might very well lead to that child becoming DEAF? If we presume that doctors should treat children to avoid their becoming DEAF, then why is it unethical for the doctors to try to avoid DEAF births in the first place by, for example, genetic counseling?

CULTURAL DISAGREEMENTS ON MEDICAL PRACTICE

Mainstream American culture is generally well-disposed to attempts to mitigate disability with high technology, and cochlear implants in particular have been presented in the media as a very positive development (Lane 1994). Many people see such measures aimed at giving a DEAF child hearing as beneficent. However, speech and hearing are not valued in the culture of the DEAF-WORLD, which resists efforts to inculcate them in DEAF children and adults. Suppose we grant the earlier argument that the DEAF infant is a member of the DEAF-WORLD and therefore that DEAF-WORLD values have standing along with the values of that child's hearing parents. Let us further assume that the implant surgery is not a matter of saving life or of alleviating great suffering. (Although membership in the DEAF-WORLD undoubtedly brings disadvantages as well as advantages, there are countless happy and successful DEAF adults.) Is there a way to choose

between the opposing cultural views of what constitutes proper medical practice in this case? Is it unethical for the surgeon in our hearing culture to proceed to operate on the DEAF child? Is it ethical for a plastic surgeon to reduce the Negroid features of a Black child, assuming the operation entails low risk and the parents request it? If the ear surgeon has an ethical obligation to provide prostheses to DEAF children, supposing the surgeon believes them to be a potentially effective treatment, is it unethical for DEAF parents to refuse such a treatment for their DEAF child, as they assuredly do? If it is ethical to change the makeup of a child born DEAF so the child has a makeup more like its hearing parents and considered better in hearing culture, is it ethical to change the makeup of a child born hearing so that the child has a makeup more like its DEAF parents and considered better in DEAF culture?

Consider the argument of some hearing parents who favor implant surgery for their child that the surgical procedure is readily reversible—the external equipment could simply be put aside—so their child could always choose to be DEAF at a later date. Therefore, in approving the surgery, they maintain, they are not choosing for their child, they are creating the conditions that will allow their child to choose. However, with a successful implant it seems likely that most users would not become acculturated to the DEAF-WORLD, so in choosing implant surgery the parents have indeed chosen their child's cultural membership. Moreover, the family's evident embrace of the disability model combined with their child's late, and therefore impaired, mastery of ASL would create further barriers to a true choice. True, given the present imperfect implants, implanted DEAF children are more motivated to acculturate to the DEAF-WORLD, although therapeutic efforts aim to avoid that by favoring speech over ASL and mainstream classes over education with other DEAF children. In seeking to give their children the choice of two worlds, parents may place them in the predicament of many hard-of-hearing children, too hard of hearing to move readily in their parents' hearing culture, but too hearing in their values and communication to move readily in the DEAF-WORLD. It seems as problematic to raise a child in two different "worlds," with two opposed constructions of the child's fundamental nature, as it is to raise a child in two contrasting religions simultaneously, aiming to allow the child to exercise choice later as an adult.

DEAF people live in a hearing society and American society makes special allowance for their fuller participation—allowances such as provision of interpreters, cash payments for disability, special education pro-

grams, and more. When the DEAF-WORLD opposes childhood implantation in principle—i.e., presumably, even with perfect implants—does it undermine its moral claim to the provision of interpreters and other special provisions? Indeed, if it insists there is no disability in being culturally DEAF, is it ethical to accept benefits provided under legislation such as the Americans with Disabilities Act? What should any minority do if its means for fuller participation in the society are provided by laws that classify it in ways it opposes? Does the DEAF-WORLD have particular claim on interpreting services since, unlike other non-English speakers, most of its members cannot in principle acquire spoken language? Similarly, does the DEAF-WORLD have a special claim on bilingual education (in English and ASL), which it strongly favors. If so, is the claim flawed that to be culturally DEAF is not to have a disability?

PARENTAL SURROGACY

Parents are given great, but not unlimited, moral and legal authority in the U.S., when it comes to making decisions that affect their children. Not only do parents normally have the reasonable best interests of their children at heart, but also they likely will be affected more than any other adult by their parental decisions, and their children's values as competent adults are likely to resemble their own. However, it is open to question whether a DEAF child's values as an adult will closely resemble those of its hearing parents, and it is arguable whether others do not also have an important stake in the rearing of the child. On the first count, is it ethically troubling that in choosing the implant surgery for their child, hearing parents are making a choice that their child probably would not make if the choice were postponed until the child were old enough to judge? Of course, we cannot be certain that a particular DEAF child would refuse implant surgery if mature enough to express an informed choice, nor can we even be totally certain that the child will enter the DEAF-WORLD. However, we do know what most people believe who were once DEAF children but are now old enough to make a considered decision, and they are overwhelmingly opposed. Is the parents' surrogacy also weakened by the fact that the surgery promises a solution to their own communicative impasse with their child? It is extremely rare for parents who have a good command of a signed language to consent to cochlear implant surgery for their children.

Finally, the parental commitment to the best interests of the child flows not only from biology but also, as with foster parents, from rearing. Does

parental commitment also flow from a genuinely concerned community to which the child will ultimately belong—absent any special intervention? Does a Native American tribe have parent-like moral authority when it comes to the proper rearing of a transracially adopted child from that tribe? Does the DEAF-WORLD have such authority with respect to the rearing of DEAF children? No one has proposed transferring legal authority from the hearing parents to DEAF adults (Balkany, Hodges, and Goodman 1996, notwithstanding). The question is, rather, how great is the parents' obligation to consider these voices that emanate from a culture more connected with their child than with themselves?

CONCLUSION

This paper has examined some features of the DEAF-WORLD as a paradigm to explore the grounding questions of disease, disability, and what constitutes the best interests of the child. We have shown the parallels and discontinuities of comparing people in the DEAF-WORLD to people in mainstream society who have disabilities. We have raised serious questions about the appropriateness of a disability model and surgery based on that model in view of DEAF people's membership in a specific cultural group. Ultimately, how we treat this problem will say a great deal about what kind of society we are and the kind of society in which we wish to live. Difference and diversity not only have evolutionary significance but, we would argue, are a major part of what gives life its richness and meaning. We have examined ethical tensions that arise even when positing a perfect cochlear implant, leaving to other fora the debate about burdens and benefits of the present prostheses, which are far from perfect. Ultimately, addressing ethical quandaries surrounding the use of cochlear implants in children will require not only a commitment to continued open and explicit dialogue, but also attention to the requisite concern for the respect and dignity of all who contribute to that discourse.

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NOTES

1. Illustrative position papers are available from: National Association of the Deaf, 814 Thayer Avenue, Silver Spring, MD 20910; Les Sourds en Colère, BP 322, 75122 Cedex 03 Paris, France; Canadian Cultural Society of the Deaf, #144, 11337 61 Avenue, Edmonton, Ontario T6H 1M3; Danske Doves Landsforbund, Postboks 704, Fensmarkgade 1, DK 2200 Kobenhavn, Denmark; Sveriges Dovas Riksforbund, PO Box 300, S-79327 Leksand, Sweden; Norges Doveforbund, PO Box 6850, N-0130 Oslo, Norway; Deutscher Gehorenlosenbund, Paradeplatz 3, 2370 Rendsburg, Germany; World Federation of the Deaf, Proceedings of the XII World Congress of the World Federation of the Deaf, Vienna, Austria, 10–15 July 1995: World Federation of the Deaf, 13D Chemin du Levant, F-01210 Ferney-Voltaire, France; National Institutes of Health Consensus Development Conference Statement, Cochlear Implants in Adults and Children, 15–17 May 1995: Federal Building, Room 618, 7550 Wisconsin Avenue, Bethesda, MD 20892; American Academy of Otolaryngology-Head and Neck Surgery, One Prince Street, Alexandria, VA.
2. Persons with hearing losses termed "profound" require at least 90 dB greater sound pressure level than the norm in order to detect pure tones at selected frequencies. Those with "severe" losses require 70 to 89 dB more. Children with losses that place them in either category routinely receive special class placement and speech, hearing, language, and educational assistance.

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Dena S. Davis

Cochlear Implants and the Claims of Culture? A Response to Lane and Grodin

ABSTRACT. Because I reject the notion that physical characteristics constitute cultural membership, I argue that, even if the claim were persuasive that deafness is a culture rather than a disability, there is no reason to fault hearing parents who choose cochlear implants for their deaf children.

LET ME BEGIN BY expressing my gratitude to Harlan Lane and Michael Grodin (1997) for their provocative and hard-hitting article. By positing a situation in which cochlear implants are risk-free and effective, they have constructed the strongest case possible for the use of such implants and thus have challenged themselves to make the most robust and uncompromising argument for the position that DEAF people are not disabled, but rather are members of a linguistic/cultural minority, and that parents act wrongly when they seek to convert deaf babies into hearing ones.

I will respond under three headings.

IS DEAFNESS IS A DISABILITY?

I cannot accept the claim that deafness is not to be perceived as a disability. The DEAF-WORLD of which the authors speak has created a rich and unique culture, and I am happy to assent to the claim that that culture is qualitatively, though not quantitatively, equal to that of the hearing world. It also is true that a great deal of what "disables" the deaf in our present world is socially constructed and could be substantially ameliorated by a more caring majority. But there is a difference between valuing the culture that the DEAF-WORLD has built and equating deafness *with* culture.

One of the defining differences between culture and disability is the option that human adults have to choose the extent to which they iden-

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tify with and participate in their culture. As the authors state, many people who are physically deaf are not members of the DEAF-WORLD (p. 233). Some hearing people are more at home in the DEAF-WORLD and more fluent in American Sign Language (ASL) than are many deaf people (Cohen 1995). Despite the many positive aspects of the DEAF-WORLD and despite the fact that DEAF and deaf people may, on average, lead lives as happy and productive as those of hearing people, I maintain that the inability to hear is a deficit, a disability, a lack of perfect health. A hearing person has a choice about whether to participate in DEAF culture, by learning ASL, attending social and cultural events, and so on. A nonhearing person, however, is irrevocably cut off from large areas of the hearing world. Even if I were to follow Lane and Grodin's generous example and posit an ideal educational environment for the deaf, most prelingually deafened persons would not be able to communicate effectively orally, with obvious social and vocational consequences. (I can anticipate an obvious response, that hearing people are equally disadvantaged because they can never be fully accepted in the DEAF-WORLD. But if that is true, it is because DEAF people are prejudiced against them, not because they are disabled from learning the necessary skills.)

IS CULTURAL MEMBERSHIP PHYSIOLOGICALLY DETERMINED?

I reject the notion that physical characteristics, hereditary or congenital, constitute cultural membership. Culture, the "body of customary beliefs, social forms, and material traits constituting a distinct complex of tradition of a racial, religious, or social group" (Webster's International Dictionary 1993), is passed on by people, not by genes. A child born into an Ashkenazic Jewish family, for example, partakes of that culture because her parents pass it on to her, *in exactly the same way* as they would pass it on to a child whom they adopted at birth (or as an embryo). Should this couple happen to have both a biological child and an adopted one, they would not consider one child to be "more" Jewish than the other. This is as silly as saying that Madeleine Albright is "really" Jewish. The opposite notion seems to me deeply racist and genetically determinist.

There are, of course, some counterexamples to my claim, as Lane and Grodin point out. In one type of counterexample, one acknowledges that a white couple raising an African-American child has an obligation to give the child a clear and proud sense of her black identity because, whatever they do, the child will be treated by others as a black person and therefore she needs a proud racial identity as a buffer against racism. In

another type of counterexample, one might argue that a child with, say, an Italian genetic ancestry should know something about his parents' and grandparents' culture, feel proud of the accomplishments of his ancestors, and so forth. But neither of these arguments fits the situation of a deaf child born to hearing parents. Deaf children who are fitted with perfect cochlear implants will not be treated by others as deaf, and children of hearing parents obviously do not have deaf ancestors.

My point is that even if I were to accept the claim that deafness is a culture rather than a disability and even if there were *no* downsides to being deaf, there is no reason to fault hearing parents who, reasonably enough, prefer to have children who share their language and culture—and those of their siblings—and who do not require huge investments of parental resources to learn sign language, to pay for special schools and equipment, and so on.

PRESERVATION OF MINORITY CULTURES

Lane and Grodin raise the question of whether, since the "preservation of minority cultures is a good," parents have an ethical obligation not to choose cochlear implants for their nonhearing child, because converting their child from deaf—and therefore potentially DEAF—to hearing diminishes the population strength of the DEAF-WORLD. I perceive three arguments against this claim.

First, even if deafness is a culture rather than a disability, I think that the authors are, quite simply, asking too much. Raising a DEAF child well requires an enormous commitment of time, money, and energy. Parents who usually are not expecting their new baby to be deaf, must learn ASL quickly in order to communicate with their child early so that language is mastered at the appropriate developmental stages. In addition, they may need to pull up stakes and relocate to a community that can offer the appropriate services. If they adopt the DEAF values that the authors describe, integration of their child into hearing schools will be "anathema," and they probably will have to send their child to a residential school at a much earlier age than they would normally contemplate. If cochlear implants in the first year of life present a risk-free alternative, it seems unrealistic to expect parents to choose this enormous burden for reasons unrelated to the welfare of their child. (Especially since, as the authors suggest, it is not wrong to seek to cure such deafness-causing diseases as meningitis even if doing so will reduce the DEAF population.) Furthermore, hearing parents might plausibly worry that they will not be successful i

raising a happy and productive DEAF or deaf child; how much simpler, then, from the perspective of the child's own well-being, to choose the implants.

Second, as the authors point out, there are many more "deaf" people than there are "DEAF" people since many "visual" people fail to become successful members of the DEAF-WORLD or choose not to do so. Thus, there is no certainty, perhaps not even a likelihood, that the child in question will make that step, and without that likelihood all of the arguments about not diminishing minority cultures fall flat.

Third, against the authors' positive depiction of the DEAF-WORLD, one needs to think seriously about the limited opportunities that exist for even the most positively acculturated DEAF person. Marriage partners, conversation partners, vocations, and avocations are severely limited. Yes, one can think of cultural minorities about whom the same could be said—e.g., the Amish or very Orthodox Jews—but these children can change their minds as adults and a significant percentage do so. As I have argued elsewhere, every child has a "right to an open future" (Davis 1997; the concept is Joel Feinberg's) in which she can choose her mate, her vocation, her religion, her reading material, her place of residence, and so forth. Because deafness severely limits the child's future *in an irrevocable fashion*, I cannot agree that parents act wrongly in "curing" a child's deafness.[1] Furthermore, if deafness is not a culture but a disability, then the authors' claim becomes even harder to sustain, even if that disability were the entry ticket to a rich and happy culture.

Against these arguments, the authors suggest that the parents of a deaf child have a special connection to the DEAF-WORLD, which grounds a unique obligation to be concerned for the continuing strength and flourishing of the DEAF population. They suggest that this special concern may be powerful enough to tip the balance when parents are weighing their obligations to the child's best interest against their moral concern for the flourishing of minority cultures. This suggestion seems false. We all have obligations to be concerned about the situation of vulnerable minorities. Those of us in the majority group who have family members in the minority population arguably have a special awareness of the minority situation, but not therefore a unique obligation. It is not, after all, considered a valid moral argument to say, "Why should I care about the flourishing of the DEAF population? No one in my family is DEAF!" Some years ago, when my only child was quite young, I would occasionally—mostly to be provocative—respond to persons who questioned my active commitment to gay rights by saying that, after all, my son had approximately a 10 percent chance of turning out to be gay, and I needed to enhance his chance of having a just and pro-gay society to live in. But in retrospect, this seems nonsensical; now that my child has turned out to be heterosexual, I certainly do not think that I have any less reason to continue my work for gay rights.

In conclusion, I cannot accept the foundational claim that deafness is primarily to be understood as (potential) membership in a cultural and linguistic minority, rather than as a disability. But even if I were to be persuaded to that claim, I do not agree that the needs of that culture for continuing population strength trump a hearing family's plausible assumption that by giving their baby normal hearing, they have increased his chances for a happy life and also for a much more open future.

Like the authors, I end with more questions. By limiting myself to Lane and Grodin's challenge, I have made only a very narrow claim: that hearing parents do not act wrongly when they choose (safe and effective) cochlear implants for a deaf baby. Questions abound for future dialog. Do hearing parents therefore act wrongly if they *decide against* implants? Ought this to be considered neglect and grounds for the state to step in and insist on implants? What about parents who are deaf or DEAF? Is it wrong for them to choose implants for their children? Wrong for them to refuse implants? Wrong for them to seek genetic counseling to maximize their chances of having deaf children? Wrong for them deliberately to expose themselves to rubella, for example, in order to change a hearing fetus to a deaf one? If we accept the disability premise, these will be tough questions with which to grapple.

The author of this article is hearing.

NOTE

1. Lane and Grodin note that most DEAF adults are opposed to the notion of cochlear implants and infer from that that DEAF children would refuse implant surgery if they were old enough to be consulted. But, of course, in my view, children are not born DEAF, merely deaf. Further, it makes as much sense to ask ordinary hearing people now if they would have wanted implants had they been born deaf as it does to ask DEAF people that question.