

## Defending Deaf Culture: The Case of Cochlear Implants\*

ROBERT SPARROW

*Philosophy and Bioethics, Monash University*

“COCHLEAR implants” are a technology which attempts to “cure” deafness by bypassing the outer ear through electrical stimulation of the auditory nerve. In the last two decades, these implants have been offered as treatment options not only for adults who have lost their hearing as a result of accident or disease in later life, but also for children who were deafened as infants or who were born deaf. An increasing number of operations are being undertaken on children as young as two years old to install these implants in order to allow them to begin hearing and learning spoken language.<sup>1</sup> While the existing technology is at best only partially successful in allowing the deaf to hear, if the technology continues to improve then one day we may live in a world in which no-one needs to be deaf.

It comes as a great surprise to most people in the hearing community to learn that a sizeable section of the deaf community has reacted with hostility and dismay to the development of this technology. Throughout the 1980s and the early 1990s, Deaf people mobilized to protest the use of cochlear implants.<sup>2</sup> In particular, they objected to the choice being made on behalf of young children to insert the implant. These critics reject the very idea of trying to find a “cure” for deafness. Indeed they have compared it to genocide. They argue that deaf people should not be thought of as disabled but as members of a minority cultural group.<sup>3</sup> The search for a cure for deafness represents the desire of a

\*I wish to thank Catherine Mills, Kate Crawford, Jeremy Aarons, Lyn Gillam, Neil Levy, Jacqui Broad, and the participants of the Victorian Council of Deaf Persons State Conference, Melbourne, 2002, for comments and discussion which have improved this article.

<sup>1</sup>Because deafness early in life makes it extremely difficult for individuals to acquire speech, there are powerful incentives to provide deaf children with the implant at a very young age.

<sup>2</sup>For accounts, see: H. Lane, “The Cochlear Implant Controversy,” *WFD News*, July 1994, pp. 22–8; E. Dolnick, “Deafness as Culture,” *The Atlantic Monthly*, September, 1993, pp. 37–53. I will follow other writers in the area by using capital D “Deaf” to indicate a cultural identity and lower case “deaf” to refer to those whose level of hearing does not allow them to live easily in a spoken-language-oriented society.

<sup>3</sup>B. P. Tucker, “The ADA and Deaf culture: contrasting precepts, conflicting results,” *Annals of the American Academy of Political and Social Science*, 549 (1997), 24–37; Dolnick, “Deafness as Culture”; H. Lane, and M. Grodin, “Ethical issues in cochlear implant surgery: an exploration into disease, disability, and the best interests of the child” *Kennedy Institute of Ethics Journal*, 7 (1997), 231–51.

majority culture to impose its language and values on the Deaf rather than modify its institutions to take account of the perspectives and needs of members of another culture.<sup>4</sup> Cochlear implant technology represents an attack on the culture of the Deaf, because it seeks to ensure that deaf children grow up to use a spoken language rather than the signed languages of the Deaf. Success in this project adversely affects the interests of individual members of Deaf culture by reducing the size of the community with whom they can communicate in their first language.

The cochlear implant controversy therefore involves questions about the nature of disability and the definition of “normal” bodies and also raises arguments about the nature and significance of culture and the rights of minority cultures. My purpose in this paper will to be defend the claim that there might be such a thing as “Deaf culture” and then to examine how two different understandings of the role of culture in the lives of individuals can lead to different conclusions about the rights of Deaf parents in relation to their children, and about the ethics of public funding for research on cochlear implants.

## I. DEAFNESS, DISABILITY AND THE DEFINITION OF “NORMAL” BODIES

When talking to hearing persons about the cochlear implant, the single biggest barrier to their understanding the hostility of many Deaf persons towards it is an inability to comprehend that deafness could be perceived as anything other than a tragic loss and a disability. Arguments about the purported rights of the Deaf to preserve their culture will most likely be perceived as perverse if we understand deafness as a disabling medical condition. Thus, even though the implications of adopting a “cultural” understanding of Deafness will be the main focus of this paper, it is important to briefly explain why many Deaf persons do not feel that their deafness is best understood as a disability.

Our first response to those who would insist that deafness is a disability should be to note that this is not an opinion shared by many of those deaf persons who identify with Deaf culture. According to the testimony of many individuals who

<sup>4</sup>See, for instance, H. Lane, *The Mask of Benevolence* (New York: Knopf, 1992) and “The Cochlear Implant Controversy.” There is a small but growing literature on the ethics of the development and use of the Cochlear Implant technology. As well as the sources cited above, see: A. E. Brusky, “Making decisions for deaf children regarding cochlear implants: the legal ramifications of recognizing deafness as a culture rather than a disability,” *Wisconsin Law Review*, 1995 (#1), 235–70; R. A. Crouch, “Letting the deaf be Deaf: reconsidering the use of cochlear implants in prelingually deaf children,” *Hastings Center Report* 27 (#4) (1997), 14–21; D. S. Davis, “Genetic dilemmas and the child’s right to an open future,” *Hastings Center Report*, 27 (#2) (1997), 7–15; M. D. Garretson, ed., *Viewpoints on Deafness* (Silver Springs, Md.: National Association of the Deaf, 1992); C. Newell, “Access to opportunity or oppression: an Australian policy analysis of the ethics of the cochlear implant,” *Interaction*, 13 (#3) (2000), 16–23; B. P. Tucker, “Deaf culture, cochlear implants, and elective disability,” *Hastings Center Report*, 28 (#4) (1998), 6–14; N. Levy, “Reconsidering cochlear implants: the lessons of Martha’s Vineyard,” *Bioethics*, 16 (2002), 134–53.

are members of Deaf culture, it is perfectly possible to lead a happy and productive life without hearing or spoken language. A sizeable proportion of Deaf individuals say that they would not want to be granted hearing even if it were possible.<sup>5</sup> Striking anecdotal evidence of the strength of Deaf individuals' attachment to their condition—or as they would have it, their culture—is recounted in several articles about the CI controversy. According to several reports, Deaf couples have been known to seek genetic counselling and testing in an attempt to ensure that their children will be born deaf.<sup>6</sup> Other sources suggest that Deaf parents may celebrate in neonatal wards upon learning that a child will be unable to hear.<sup>7</sup> Unless we insist, in an entirely ad hoc fashion, that these parents do not have the best interests of their child at heart, we must admit that they do not believe that their child will be harmed by being born deaf. In the face of such evidence and testimony from those who *experience* deafness, it is problematic for hearing persons to continue to insist that it constitutes a disability to be avoided if at all possible.

Of course it remains true that deafness can result in tremendous disadvantage in this society. But as disability rights activists have argued, the key phrase in this sentence is “in this society.”<sup>8</sup> Many of the “disadvantages” faced by people who are deaf turn out to have social and institutional causes and could be rectified by changes in the way society is organized. The replacement of all telephones with teletext machines would, for example, go a long way towards removing the difficulties that deaf people currently face in gaining access to social services. More radically, the problem of personal communication between the Deaf and the hearing could be solved by all members of the community, both hearing and Deaf, learning sign language. The purpose of these examples is not to argue for this institutional change or that, but to highlight the fact that the claim that deaf people are disabled relies on assumptions about prevailing institutional arrangements that are themselves part of what is under contestation in arguments about who is to count as disabled.

Yet it still seems as though some of the disadvantages associated with being Deaf cannot be overcome through reordering society. To many, it seems as though there are things that the Deaf cannot do that “normal” people can, and

<sup>5</sup>See, for instance, the views attributed to Meg Aumann in D. O'Brien, “On Deaf Ears,” *The Big Issue*, 122 (2–17 April, 2001), 16–17. See also Dolnick, “Deafness as Culture,” p. 38.

<sup>6</sup>Tucker, “Deaf culture, cochlear implants, and elective disability,” p. 7; Davis, “Genetic dilemmas and the child's right to an open future,” p. 7; Lane and Grodin, “Ethical issues in cochlear implant surgery.” As I write this paper, a vigorous controversy is raging in the press about the decision of two Deaf lesbians to deliberately seek out a deaf sperm donor for an IVF procedure in order to maximise their chances of having a deaf child. See L. Mundy, “A world of their own,” *Washington Post*, March 31, 2002, p. W32.

<sup>7</sup>H. Lane, R. Hoffmeister and B. Bahan, *A Journey into the Deaf-World* (San Diego, Calif.: DawnSign Press, 1996), pp. 18, 24–5. Dolnick, “Deafness as culture,” p. 38.

<sup>8</sup>C. Barnes, G. Mercer and T. Shakespeare, *Exploring Disability: A Sociological Introduction* (Oxford: Polity Press, 1999). S. Wendell, “Towards a feminist theory of disability,” *Hypatia*, 4 (1989), 63–81.

that these incapacities place them at a disadvantage in a normal environment regardless of any social changes we might make to accommodate the deaf. One might argue, for example, that deaf people are disabled because they cannot respond to aural cues that indicate the presence of various environmental dangers.

Arguments of this sort fail for two reasons. Firstly, the condition of “deafness” involves the development of new or enhanced sensory modes as well as the absence of more familiar modes. There is a tendency in our society to think of human variation solely in terms of deviation from some imagined perfection. In particular it is easy to think of disability as a merely negative phenomenon; as the loss of capacities only. But a loss of capacities in one area is often accompanied by a gain in capacities in another. People who are deaf often have skills and abilities that hearing people lack. First and foremost of these is the ability to communicate in Sign as a natural first language. But deaf persons may also have a superior consciousness of subtlety of gesture and of the movement of bodies through space than do hearing persons.<sup>9</sup> More generally, the differences which in existing social contexts appear to us as disabling may sometimes be better thought of as constituting a different way of being, and one which is not necessarily inferior. In certain environments (such as those with high levels of environmental noise) deafness will be an advantage and people who are deaf will have *greater* ability to act. As a consequence, the stipulation of the environment will always be question-begging. In some environments, it will be those who can hear who are “disabled.”

Secondly, arguments of this type founder on our reluctance to single out a “normal” human body from the range of variation that we currently recognize. It would be easy, for instance, to construct an example where either men or women are disadvantaged in relation to some aspect of a given environment. Yet we would be hesitant to conclude that members of either of these groups are disabled as a consequence of such an argument. Instead we would quite rightly point out the stipulative nature of the example.

Perhaps one way to avoid the difficulties of adjudicating who is normal and who is not might be to draw up a list of paradigmatically human capacities and then decide the matter with reference to that list? Deafness is a disability because hearing is one of the six senses that humans characteristically possess (including proprioception). But a moment’s thought reveals how question-begging any such attempt must be. The limits of normal human capacities will be the result of who we consider to be part of the range of normal variation amongst persons. If we include the deaf, then hearing will not be something that all normal people

<sup>9</sup>See O. Sacks, *Seeing Voices: A Journey into the World of the Deaf* (London: Pan Books, 1991); R. Rettenbach, D. Diller and R. Sireteanu, “Do deaf people see better? Texture segmentation and visual search compensate in adult but not in juvenile subjects,” *Journal of Cognitive Neuroscience* 11 (#5) (1999), 560–83.

have. It will instead become a less important mark of difference, like hair or eye color, and our account of what it is to be normal will not mention it. Further difficulties appear when we consider the range of bodies, capabilities and experiences amongst persons that we currently recognize as normal. Our account of normal bodies is at the very least significantly bifurcated with regard to sex. It admits significant variation in height, weight, skin color and sexual preference. What this suggests is that the route whereby we decide on the nature of normal bodies actually runs the other way. Normal bodies are those that normal people possess and it is our intuitions about who is normal that are doing all the work here. The question of normal human capacities comes after the question of the range of normal human variation.

Thus, if critics want to insist that deaf people are disabled because they do not have the full range of normal human capacities, it is appropriate to ask whether they think that it is men or women who are disabled? If they insist that both men and women have normal human bodies despite the fact that they have different bodily capacities, then the question arises as to why they are not prepared to admit that this range might include deaf persons as well?

It is also timely here to emphasize how far the boundaries of the “normal” have already shifted. For much of the history of Western culture the “normal” person was white, male and propertied. Women, non-whites and working class people were thought to be inferior examples of the human form.<sup>10</sup> Science—and in particular medical science—was a central discourse in the theorisation of difference.

Of course the fact that we have been wrong to draw the bounds of the normal as we have in the past does not establish that we are wrong to draw them at any point. But my purpose in this observation is to suggest that it is conceivable that we are wrong again and thus to reduce our confidence in our intuitions about who is normal and who is not. The ignoble history of such intuitions suggests that their strength is often a consequence of a failure of imagination of those who possess them.

## II. AN ALTERNATIVE MODEL

### A. DEAFNESS AS CULTURE

But if deafness is not a disability, what is it? At the heart of elements of the Deaf community’s objection to cochlear implant technology is the claim that Deaf people constitute a minority culture rather than merely a group of people who share a disability.<sup>11</sup> How plausible is this claim?

<sup>10</sup>Despite constituting the majority of the population—which should serve to remind us that the category of the “normal individual” is far more normative than it is descriptive.

<sup>11</sup>O’Brien, “On deaf ears,” pp. 16–17; Dolnick, “Deafness as culture”; Crouch, “Letting the deaf be deaf”; Lane and Grodin, “Ethical issues in cochlear implant surgery.”

The definition of culture is a vexed question in the literature on minority rights. It seems that the possession of a shared history, a unique language (or perhaps dialect), a distinctive art, music, literature or cuisine, are all important in establishing whether or not a group constitutes a “culture.” The extent to which a group maintains or has evolved its own institutions to serve its “cultural” needs is also important.<sup>12</sup> But the precise weighting and relative importance of these factors in determining when a group becomes (or possesses) a culture remains controversial. It is well beyond the scope of my paper to resolve this question. For my purposes here it will suffice to suggest that social groups may appear on a continuum of candidates further from and closer to the ideal type of a culture, extending from aggregations of individuals, to interest groups, to subcultures, to ethnic, and then, perhaps, national or societal cultures.

What is clear is that on this continuum “Deaf culture” falls closer to the paradigmatic cases of ethnic and national cultures than do many other proposed candidates for the appellation. Unlike subcultures, or even some ethnic cultures, Deaf people possess their own distinct language(s), each with a unique vocabulary and grammar.<sup>13</sup> Deaf people also have a shared set of experiences, relating to the consequences of deafness in a hearing culture, a shared history and distinct set of institutions. They have their own schools, clubs, meeting places and even sporting competitions. The combination of the possession of a language and a set of institutions makes the claim of Deaf culture a particularly strong one.<sup>14</sup>

## B. CULTURE AND COCHLEAR IMPLANTS

Unfortunately, recognizing Deafness as a cultural identity rather than a disability does not resolve the debate about the ethics of cochlear implants. There are two reasons for this.

Firstly, there are genuine and difficult questions about the rights of parents to choose a cultural identity for their child which may substantially reduce the opportunities available in later life.<sup>15</sup> These questions are especially urgent in the case of Deaf parents making a decision about bringing up their child without an implant, because without the implant it is highly unlikely that their child will be able to learn the spoken language of the majority culture in later life, and is therefore likely to be severely restricted in their ability to participate in it.

<sup>12</sup>See W. Kymlicka, *Multicultural Citizenship* (Oxford: Oxford University Press, 1995), p. 76.

<sup>13</sup>There are many distinct signed languages, just as there are many spoken languages.

<sup>14</sup>For an excellent introduction to the rich world of Deaf culture, see: Lane, Hoffmeister, and Bahan, *A Journey into the Deaf-World*; C. Padden and T. Humphries, *Deaf in America: Voices from a Culture* (Cambridge, Mass.: Harvard University Press, 1988).

<sup>15</sup>R. J. Arneson and I. Shapiro, “Democratic autonomy and religious freedom: a critique of *Wisconsin v. Yoder*,” in I. Shapiro and R. Hardin (eds), *Nomos XXXVIII: Political Order* (New York: New York University Press, 1996), pp. 365–41; D. S. Davis, *Genetic Dilemmas: Reproductive Technology, Parental Choices and Children’s Futures* (New York: Routledge, 2001); J. Feinberg, “The child’s right to an open future” in W. Aiken and H. LaFollette (eds), *Whose Child? Children’s Rights, Parental Authority, and State Power* (Totowa, N.J.: Littlefield, Adams, 1980), pp. 124–53. N. Levy, “Deafness, culture and choice,” *Journal of Medical Ethics*, 28 (2002), 284–5.

Secondly, there are some important differences between the case of Deaf culture and other cultural groups. These stem largely from the fact that one seems to be born into Deaf culture in a more literal sense than is the case for other cultural identities. Arguably, an important criterion of membership of Deaf culture is actually being deaf.<sup>16</sup> While hearing persons may enter some way into the life-world of the Deaf by learning Sign and through contact with the Deaf, they remain to some extent outsiders.<sup>17</sup> The experiences stemming from being unable to hear, in a hearing world, are central to the cultural identity of the Deaf. Yet, as the role played by Sign in the Deaf community makes clear, being unable to hear is not sufficient for membership of Deaf culture. One must also use Sign and participate in the cultural institutions of the Deaf. There is a social as well as a biological aspect to Deafness.

However, some 90 per cent of deaf children are born to hearing parents.<sup>18</sup> This means that Deaf culture cannot rely on the most familiar mode of cultural transmission, wherein a culture is passed on from one generation to the next within the family, from parent to child. Instead, cultural transmission of Deaf culture occurs primarily in the other cultural institutions of the Deaf, and through contact with cultural role models other than parents. Children who are born without hearing or who lose their hearing at an early age are *potential* members of Deaf culture only.<sup>19</sup> Without some significant proportion of them learning to Sign and participating in the cultural institutions of the Deaf, Deaf culture will eventually die out. As we will see below, it is this disjunction between the biological and social basis of membership of Deaf culture that is responsible for some of the most difficult questions surrounding the development of cochlear implant technology.<sup>20</sup>

<sup>16</sup>Lane and Grodin. "Ethical issues in cochlear implant surgery."

<sup>17</sup>The boundaries of membership of Deaf culture are, unsurprisingly, contested. In particular, the status of children of Deaf adults (CODAs), who have grown up with signed language but who can also hear, in the Deaf community is controversial. For different accounts of the boundaries of Deaf culture, see J. Roots, *The Politics of Visual Language: Deafness, Language Choice and Political Socialisation* (Ottawa: Carleton University Press, 1999). The extent of disagreement about the boundaries of Deaf culture is especially apparent in Garretson, *Viewpoints on Deafness*.

<sup>18</sup>Lane and Grodin, "Ethical issues in cochlear implant surgery," p. 233.

<sup>19</sup>As reported in Tucker, "Deaf culture, cochlear implants and elective disability," p. 8, some Deaf culturalists argue that Deaf culture is the "birthright" of these children. This claim is thrown into doubt once cochlear implant technology becomes available.

<sup>20</sup>The nature of the relation between the biological and social components of Deafness also renders Deaf culture a unique case in the typology of cultures. While the Deaf constitute a distinct minority culture, members of Deaf culture are not immigrants who have entered our society. Nor have they left another culture (the exceptions here are those who became Deaf later in life after they had previously been inculcated in another spoken language culture). Instead potential members are generated within each national culture by accident of birth and individual history. The cultures of the Deaf may therefore be thought of as a type of immanent "indigenous" culture. (See the European Parliament's, Resolution on Sign Language for the Deaf, 17 June 1988, and Resolution on Sign Languages, 18 November 1998.) Like indigenous cultures in the New World, Deaf cultures have always existed but have been denied recognition of their status by majority cultures that have persecuted and institutionalised their members. See H. Lane, *When the Mind Hears: A History of the Deaf* (New York: Random House, 1984).

### III. TWO MODELS OF CULTURE

What I want to do in the remainder of this paper is show how two different models of culture, and its role in both constraining and making possible the choices of individuals, have different implications for our understanding of both of these issues.

#### A. THE “LIBERAL” MODEL

The first understanding of culture that I wish to discuss is what I shall call a “liberal” account of the role and importance of culture, which I identify with the work of Will Kymlicka.

According to Kymlicka, membership of a secure culture is an important good because it is essential to the self-respect of individuals.<sup>21</sup> As a rule, individuals are only capable of achieving the self-respect which flows from the faith that the choices they have made and the activities in which they are engaged are valuable ones if they live in a culture that affirms the values of those choices and activities. Furthermore, cultures provide the “context of choice” in which individuals make their choices about the good. For my purposes here, it is important to note that to a large extent this role is fulfilled by a culture’s language. Languages reflect the form of life, beliefs, practices and values of a culture and transmit these to each successive generation.

On this account culture is essentially an *instrumental* good; it is good by virtue of its role in securing other goods, namely self-respect and a context of choice that allows individuals to pursue their own notions of the good. Driving the liberal account is a concern for each individual’s ability to decide for themselves how they wish to live their life. In order for them to be able to do this to the fullest possible extent they must be able to choose between as many different ways of life as possible. This also means that it is possible to rank cultures against one another, according to the extent to which they secure a wide range of possible life options for their members.<sup>22</sup>

Finally, these assessments are supposed to be ones upon which people can agree regardless of their own cultural commitments. Such agreement is only possible if it is possible for members of different cultures to abstract away from their particular commitments and assess the range of opportunities within another culture independently of the values of their own culture.

#### B. THE “COMMUNITARIAN” MODEL

The second model of the role and significance of culture is one that I shall call a “communitarian” account. The label “communitarian” is one which has been

<sup>21</sup>W. Kymlicka, *Liberalism, Community and Culture* (Oxford: Oxford University Press, 1989), pp. 163–6.

<sup>22</sup>B. Parekh, “Dilemmas of a multicultural theory of citizenship,” *Constellations*, 4 (1997), 54–62.



applied to and adopted by a wide range of different authors and political agendas, not all of whom would agree with the use I make of it here. The account that I sketch below owes most to the early work of Michael Sandel.<sup>23</sup>

The communitarian account of culture also holds that cultures are important because of the role they play in grounding the self-respect of their members and in providing them with a “context of choice” within which to make their own choices. But communitarians are likely to hold that part of the value of a culture is that it grounds self-respect in realizing *specific* cultural roles and that it provides a context of choice in which particular choices appear attractive and others are discouraged.<sup>24</sup> The communitarian account emphasizes that what we desire for ourselves (and others whom we care about) are not opportunities *per se* but valuable or important opportunities. The mere multiplication of opportunities does not increase our chances of leading a meaningful or worthwhile life. Judgements about the content and worth of opportunities are inevitable and they are necessarily made with reference to our existing values, which themselves are influenced by our culture.

According to the communitarian, then, although culture remains an instrumental good, the good that it is instrumental in achieving is a particular conception of how a human life is best lived. Each culture therefore makes possible (a) different good(s). This means that it will not be possible to straightforwardly rank cultures against each other according to the extent to which they provide these goods. Instead members of each culture will judge the matter differently, with reference to the standards contained in their own culture.

#### IV. APPLYING THESE MODELS TO THE COCHLEAR IMPLANT CONTROVERSY

My aim now is to show how these two models of culture give different results when applied to the cochlear implant controversy. The differences between these two accounts can be usefully highlighted by considering two cases, one real—the existing cochlear implant—and one hypothetical (but not that far-fetched)—a future “bionic ear,” that can guarantee perfect hearing for those who use it.

##### A. THE COCHLEAR IMPLANT: AN IMPERFECT TECHNOLOGY

Both a liberal and a communitarian account of the value of culture are capable of grounding a serious objection to the use of the existing cochlear implant in pre-linguistically deaf children. The danger with existing cochlear implants is that they risk depriving such children of full membership of *any* culture. Implantees may end up trapped “between cultures,” unable to function

<sup>23</sup>See M. J. Sandel, *Liberalism and the Limits of Justice* (Cambridge: Cambridge University Press, 1982) and Sandel, ed., *Liberalism and its Critics* (Oxford: Blackwell, 1984).

<sup>24</sup>C. Taylor, “Can liberalism be communitarian?” *Critical Review*, 8 (1994), 257–62.

effectively in a hearing context but also lacking the facility with sign language available to those who grow up with it as their first language.

This risk exists because of the imperfect nature of the current technology and because the attempt to hear and communicate in a spoken language is often made at the cost of an early education in Sign. Existing implants fall substantially short of guaranteeing that implantees will be able to participate fully in hearing interaction. It is widely acknowledged that the majority of persons who receive the implant will remain deaf to some extent.<sup>25</sup> A significant percentage of early childhood implantees are unable to communicate effectively even with those close to them, without the benefit of Sign, lip reading, or other hearing aids. Moreover, ease of communication in a signed language removes the incentive for the child to learn to speak and for this reason communicating with the child in Sign, and the child's own use of Sign, may sometimes be discouraged.

If this occurs and the child's attempt to learn to hear and speak with the aid of the implant fails then she will have been deprived of the early contact and experience with Sign that allow those who learn it from birth to use it as a natural language. She may grow up unable to use any language fluently and suffer a host of cognitive, developmental and educational problems that flow from this. Furthermore, lacking effective language skills, she may also be deprived of full membership of either the hearing *or* Deaf community.

The outcomes for deaf children fitted with the implant may therefore sometimes be worse than if they had been allowed to grow up using a signed language, and if resources had been devoted to removing the social causes of the disadvantages that the Deaf face in a society oriented around spoken language.

The argument up to this point is one that could be made using a liberal account of culture. It is the risk of the loss of opportunities to the child that has concerned us so far, without reference to what these opportunities consist in. In so far as the decision to provide a child with the implant risks leaving the child with fewer opportunities than if they had learned to sign, liberals can agree that the use of existing implants is unethical.<sup>26</sup>

<sup>25</sup>Lane and Grodin. "Ethical issues in cochlear implant surgery," p. 236.

<sup>26</sup>It might be thought that this argument only establishes that children should not be deprived of the benefits of Sign while learning to use the implant. However there are three reasons to be suspicious of this "bi-cultural" solution to the question of the ethics of the implants. The first is practical/educational and concerns whether such bi-cultural education is likely to be pursued by parents and institutions that have invested a significant amount of effort, time and money in procuring an implant, and also whether it is likely to succeed in its intent. Cochlear implants are expensive devices; the many hours of speech therapy and other specialist assistance required to use them effectively are costly. Having made such a large commitment to this project, parents may be reluctant to spend time teaching their children Sign as well, especially if they feel that doing so is likely to distract their child from the task of learning to use the implant. Conversely, the more facility a child and their parents develop with signed language, the less incentive there is for them to persist in using the implant. There is thus an unstable tension in the project of teaching a child both to sign and to use the implant. The existence of this tension suggests that attempts to teach children to use both a signed and spoken language may incur a cost to their fluency in one or the other. However, these are empirical matters and it may prove that my concerns are ill-founded. My second and third reasons for concern are theoretical ones, which raise issues that will only have force for Deaf communitarians, and they will be discussed below.

The communitarian account of culture will also ground criticism of the use of the implant in these circumstances. But the route to this conclusion is slightly more complex as we cannot determine the effect of adopting a communitarian account without also considering who it is that is making the assessment. Nonetheless it seems that both a Deaf and a hearing person must agree that the outcome in the case where a child ends up with *no* secure membership of *any* culture is a disaster. In so far as the existing implant technology carries a substantial risk that this may occur, both Deaf and hearing people may be opposed to the use of the implant in young children.

Note, however, that Deaf and hearing persons are likely to judge the *threshold* for success in use of the implant very differently. A Deaf critic may not be impressed with even a high level of success in learning to hear and speak, if she is strongly committed to her own Deaf culture and does not value the opportunity to participate in hearing culture. A hearing person though is likely to judge *any* ability to speak and hear as a fantastic outcome. The full implications of this difference in judgements becomes clear when we move to consider the case of a perfect cochlear implant technology—the bionic ear.

## B. THE BIONIC EAR—A PERFECT TECHNOLOGY OF CULTURAL ASSIMILATION

What if cochlear implant (or indeed some other) technology improves to the point that it does become possible to cure deafness? If scientists manage to create a genuine “bionic ear”?<sup>27</sup>

Once such a perfect technology exists then the argument set out above using the liberal account of the value of culture collapses. The danger that children will be left between cultures disappears. The decision whether to proceed with implantation or not now becomes a decision about which culture a child will grow up in.<sup>28</sup> Without a bionic ear, and given access to Sign language and the opportunity to participate in the institutions of the Deaf, the child will grow up as a member of Deaf culture. If a bionic ear is installed then the child will grow up a fully participating member of the spoken language culture of the wider society.

If we adopt a liberal account of the role and importance of culture, we should seek to ensure that the child grows up in the culture that offers them the most opportunities. It also seems clear that this will be the spoken language culture of the dominant majority. While participation in Deaf culture may offer the child an environment that provides the conditions for self-respect and a context of choice, merely because of its smaller size it is unlikely to offer the same range of opportunities as the spoken language culture.

<sup>27</sup>New genetic technologies pose an equal if not greater threat to the survival of Deaf culture. See J. Kelly, “Chosen one: designer baby to have perfect hearing,” *Herald Sun* (Melbourne), September 21, 2002, pp. 1–2.

<sup>28</sup>Contra Lane and Grodin. “Ethical issues in cochlear implant surgery.”

Because freedom to choose between different life plans is the most important good according to liberalism, depriving a child of the widest possible range of opportunities is a grave wrong. To trap a child in a culture with reduced opportunities is to risk consigning them to a life that they would not have chosen if they had had the wider range of options.<sup>29</sup> Thus, depending on how large we judge the difference in opportunities available to Deaf and hearing children to be, it may even count as a form of child abuse to deprive a child of a bionic ear. Furthermore, on the liberal account, this is a judgement that even the Deaf parents of a deaf child should be capable of agreeing with. A failure to reach this conclusion, that is available to all reasonable persons, can only be due to a failure of reason on behalf of the parents, or perhaps a failure to have the best interests of their child at heart. The implication that people who would deny their child access to the technology must be unreasonable or uncaring may serve to strengthen support within the hearing community for legal or state intervention to grant the child a bionic ear against their parents' wishes. The universalism of the liberal account therefore has the unexpected result of placing pressure on the choices available to Deaf parents of deaf children.<sup>30</sup>

But note the implicit subject position from which this assessment is made. The judgement that the child will be better off as a member of a hearing culture presumes that the person making it has no allegiance to the cultural identity of the Deaf.

From the perspective of a member of Deaf culture, the opportunities that are made available by a bionic ear, and which seem so valuable to the hearing person, may not appear as such. The main opportunities at stake here are opportunities to hear, to speak and to communicate with the majority of members of the broader society in their language. These will in turn open up a wide range of opportunities that result from participation in a much larger community, including important social and economic opportunities. But a Deaf person with a strong identification with their own culture may feel that it is more important to participate in Deaf culture than to communicate with those outside it. More fundamentally, because they do not identify with the way of life of another culture, they may not value opportunities which exist within it. Moreover, the cost of gaining access to these opportunities in this case is the loss of the opportunity to experience the unique and rich culture of the Deaf and to pursue all the ways of life that *it* makes possible.<sup>31</sup> If one is deeply committed

<sup>29</sup>Davis, "Genetic dilemmas and the child's right to an open future."

<sup>30</sup>Notice also that once such implants exist, deafness becomes an "elective disability" and therefore, it might be argued, society has less obligation to provide social and institutional support for the deaf. This argument is actually endorsed in Tucker, "Deaf culture, cochlear implants, and elective disability."

<sup>31</sup>Again it might be thought that the argument here only establishes that the Deaf have a reason to want children taught Sign *as well as* spoken language. Surely even Deaf persons should agree that it is better for a child to have access to the opportunities made possible in *both* cultures? Once more, it is not my place to make this judgement. Nonetheless I can think of a number of reasons why a Deaf person might reject this conclusion. It is not uncommon for cultures to be defined *against* other

to Deaf culture then one may believe that a life lived as a member of Deaf culture offers a wider range of valuable opportunities than membership of a hearing culture.

I must emphasize that, as a hearing person, this is not a judgement that it is my place to make. Indeed it is a consequence of the communitarian account of culture that it is not a judgement I *could* make. My own cultural commitments make it impossible for me to occupy the place of a Deaf person considering the question.

It may also be that it is not a judgement that many Deaf persons would make.<sup>32</sup> But as I noted earlier, at least some Deaf persons claim that they would not choose to hear even it became possible for them to do so. Such persons presumably do *not* believe that they would have more valuable opportunities in a hearing culture; instead they place a greater value on the options and choices that Deaf culture contains for them. But if this is the decision that *they* would make then it follows that they should also hold that others, including children, are better off within Deaf culture.<sup>33</sup> The reasons for their own decision should generalise.

If we accept a communitarian account of the role and value of culture, therefore, we can see that Deaf persons may have good reasons to resist even the “perfect technology” of the bionic ear. But again, we must remember that according to the communitarian account, any assessment of the value of cultures depends on the cultural commitments of the person making it. Thus when we turn to consider the likely response of hearing persons to the development of the bionic ear, we get a very different result.

Once the risk that children might be trapped “between cultures,” which exists in the case of the cochlear implant, is overcome by the development of the bionic

cultures, with membership of a culture being predicated on rejection of the goods available in another culture. Members of a minority culture may draw together and reaffirm their commitment to each other and their culture by renouncing participation in the institutions and activities of a surrounding dominant culture. Where a culture defines itself in this way, it will not be possible to be a full member of the culture while affirming the worth of opportunities made available in another culture. There is some evidence that Deaf culture may be defined in this way, in the debate over whether or not CODAs are full members of Deaf culture. To the extent that a lack of ability and/or desire to participate fully in hearing culture is a condition of membership of Deaf culture, Deaf persons may have reasons to prefer that children be educated only in a signed language.

But more generally, I do not believe that such bilingual education succeeds in “summing” the cultures available to a child. If cultures are defined by the opportunities that they value and make available, then a person who attempts to be a member of two cultures is not a member of both, but is strictly speaking a full member of neither. To put this another way, in so far as members of each culture do not recognise and value the opportunities made available in the other, we cannot expect them to judge that a person who is “bicultural” has more opportunities than a member of their own culture.

<sup>32</sup>For a useful survey of Deaf attitudes on these matters, see Roots, *The Politics of Visual Language*.

<sup>33</sup>Note that I am not claiming here that a Deaf person would be justified in arguing that it would be better for a child to grow up Deaf even if this meant that they had fewer opportunities in life. From the perspective of such a Deaf parent, a child would have *more* opportunities to participate in those activities that they judge to be most valuable available to her, if she were to grow up in Deaf culture.

ear, it will appear self-evident to hearing persons that deaf children should be provided with the bionic ear so that they can grow up in hearing culture. Just as Deaf individuals may judge that children will have the widest range of valuable opportunities if they grow up in Deaf culture, so too will hearing persons judge that they should be brought up in a hearing culture.

Given this difference of opinion as to the best decision to make in relation to the cultural identity of a child, which perspective should be respected in relation to decisions about the use of bionic ears/cochlear implants? It is tempting to hold that children who are born deaf should be left alone, to grow up as members of Deaf culture. But once bionic ears are available, a child's deafness does not mean that she is a potential member of Deaf culture any more than any other child. The child will only grow up as a member of Deaf culture if she grows up in close proximity with other Deaf persons, in a Deaf residential school or through participation in the other institutions of Deaf culture. But with the benefit of a bionic ear, she need do none of these things. We therefore cannot settle the question of the proper cultural identity of a deaf child by reference to their deafness once a bionic ear technology has been developed.

So how to proceed? It seems sensible to allow that parents should be granted the right to make this decision on behalf of their own children. We should trust that parents are best placed to consider the best interests of their own children. Furthermore there are important practical reasons to think that children will be happier and more likely to grow up with a secure cultural membership if they share the culture of their parents.

Hearing parents of deaf children should therefore be allowed to employ the bionic ear to bring their children up as members of their hearing culture. But equally well, the right of Deaf parents to bring deaf children up as members of Deaf culture, without the use of the bionic ear, should also be respected.

The adoption of a communitarian account of the value of culture therefore allows the right of Deaf parents to bring up Deaf children to be defended even in the case where cochlear implant technology has improved to the point where deaf children could be made to hear perfectly. This is a significant conclusion because it means that Deaf objections to cochlear implant technology need not rest on the fact that it is currently an imperfect technology.

Unfortunately, however, establishing the right of Deaf parents to bring up Deaf children will not be enough to protect Deaf culture from the corrosive influence of cochlear implant technology. As I noted earlier, some 90 per cent of deaf children are born to hearing parents. It seems likely that the vast majority of these parents will choose to bring their children up in their own hearing culture with the benefit of the bionic ear. The realisation that Deafness is a cultural identity rather than a disability has little effect at the level of these parents' decision whether to provide their child with a bionic ear or not. What matters to them is that their child should grow up as a member of *their* culture. If the deaf children of hearing parents are all "cured" of their deafness in this way,

then this will reduce the size of, and opportunities available within, deaf culture to such a degree that eventually even Deaf parents are likely to judge that their children would be better off growing up in a hearing culture. Thus, once the technology exists to offer the hearing parents of deaf children this choice, it seems that an inevitable consequence in the long term is the destruction of Deaf culture.

## V. PUBLIC FUNDING FOR IMPLANT RESEARCH AND RESPECT FOR DEAF CULTURE

Yet, at a broader social level it does seem as though the conclusion that Deafness is an alternative cultural identity rather than a disability is important. It is at this level that the Deaf communitarian case against cochlear implant technology is best made. While it may be reasonable for hearing parents to employ this technology to ensure that their child grows up as a member of their culture, it is less clear that it is reasonable for society as a whole to fund the development of a technology that makes such a choice possible. The ethics of the decision to develop and maintain a technology is significantly different from the ethics of the individual decision to make use of it once it exists. Further, while we may feel that no individual has a duty to respond to the fact that the consequence of widespread use of bionic ears will be the extinction of Deaf culture, we may feel that society as a whole (or the government, as its representative) does.

A full account of the consequences of the communitarian account of the role and value of culture for the structure, institutions and politics of a multicultural society is well beyond the scope of this paper. Yet it is not unreasonable to suggest that, as far as possible, the government of a multicultural society should refrain from taking a position on matters of dispute between the cultures that exist within it. If it is inevitable that the government must adopt a policy that will have some impact on a dispute, it should endeavor to demonstrate respect for the cultures of which its citizens are members in doing so. At the very least, in the case where what is at stake is the destruction or survival of one of these cultures, it seems clear that the government should be extremely reluctant to side with those who would destroy a culture. Should it do so, it could expect no loyalty from members of the culture under threat.

Yet it seems as though the destruction of a culture is precisely what is at stake in the debate about the use of cochlear implants in pre-linguistically deaf children, especially if, as we can expect, this technology continues to improve. Any state support for the development of these implants should therefore be extremely controversial. When the government decides to devote substantial resources to the development of a technology that will allow some parents to ensure that their children avoid growing up as members of a particular culture (and which will thereby lead to the extinction of this culture), this clearly demonstrates a hostility to the values of the culture and a lack of respect for its members. Public funding for cochlear implant research attacks the self-esteem of

the Deaf directly by communicating the idea that their way of life is not valued by the broader society and that they are unfortunate victims of a disability rather than members of a unique culture. It also threatens their interests by jeopardizing their long-term projects in so far as these refer to the continued existence of a flourishing Deaf culture.

The negative consequences for Deaf culture if a bionic ear should be developed, and the message conveyed to Deaf people by public funding for cochlear implant research provide *prima facie* grounds for the conclusion that the government should not fund any further research into cochlear implant technology designed for use in pre-linguistically deaf children.<sup>34</sup> It is inappropriate for the government of a multicultural society to fund research into a medical technology, the intended purpose of which is to move persons from one culture to another, and the likely outcome of which is the destruction of a culture. Furthermore, given the tightly interwoven nature of privately and publicly funded research science, and the extent to which private research often “piggybacks” on public research, through making use of techniques and results developed in publicly funded institutions and by employing researchers educated and trained in them, this conclusion may also have substantial implications for the future of any research into a “bionic ear.”<sup>35</sup>

It may be objected here that a refusal to fund further research into the cochlear implant appears to elevate the desires of Deaf parents of deaf children above those of the much larger group of hearing parents of deaf children, who would like to use the technology to bring up their children in their own culture. This seems especially problematic as a communitarian account of culture also affirms the moral weight of hearing parents’ desires.<sup>36</sup>

I have already conceded that once such a technology exists there would be scant grounds to resist its use. But until it does, the balance of considerations may be quite different.

Firstly, in the absence of the technology, the Deaf claim about Deafness being the birthright of deaf children has some plausibility.<sup>37</sup> If children of hearing parents who are born deaf are educated alongside Deaf children, they will grow

<sup>34</sup>Continued development of implants for the post-linguistically deaf arguably does not convey the same disrespect for Deaf culture as those who lose their hearing later in life are less likely to be able to develop the fluency in signed language to enable them to participate as full members of Deaf culture.

<sup>35</sup>There is also a similar, although weaker, argument for prohibiting research into cochlear implant technology even by private associations. Society’s toleration of such research *may* be understood as condoning it. By refusing to prohibit research into the bionic ear, a society suggests that it is a matter of indifference whether or not Deaf culture is threatened by the success of such efforts, and this may be thought to demonstrate a profound disrespect for the interests and wellbeing of its members.

<sup>36</sup>In fact, this will depend on the commitments of the person making the judgement. What is true is that my suggestion above that the state should, as much as is possible, not take a position on the relative merits of the cultures within it is naturally interpreted to suggest that the government should accord moral weight to the desires of parents from all cultures to bring their children up within their own culture.

<sup>37</sup>Lane and Grodin. “Ethical issues in cochlear implant surgery.”



up speaking a signed language as their natural first language. They will have unfettered access to Deaf culture and to the goods available therein. Recognizing Deafness as a cultural identity rather than a disability may allow hearing parents to understand that their child can lead a rich and satisfying life despite—indeed because of—being Deaf. Moreover, it is not clear that hearing parents are being denied a right to bring their children up in their own culture, if it is not possible for them to do so, because the technology is unavailable. They may believe that their interests are being neglected if the government does not seek to develop a technology that might serve them, but their claim for positive action from the government is weaker than the claim they would have against government interference if the technology was available.

Secondly, as I noted above, any decision to research the technology has a public character that parents' decision to use it once it exists does not. This public character raises the question of the relation between Deaf and Hearing culture(s). Unlike that facing individual Deaf or hearing parents, the situation facing the Deaf and hearing cultures is very different. Deaf culture is clearly threatened with destruction if a bionic ear is developed. Hearing culture(s) face no threat if it is not. Any public funding for research into a bionic ear therefore expresses a lack of respect for the Deaf, in a way that a refusal to fund it does not express a lack of respect for hearing culture(s). Furthermore, the threat to the continued existence of Deaf culture posed by bionic ear technology negatively affects all Deaf persons, who have a clear interest in the survival and strength of their culture.

This means that there is a larger group of persons than just Deaf parents of deaf children whose interests are counter-posed to those of the hearing parents of deaf children who would like the bionic ear to be developed. Against the desires of hearing parents to have the bionic ear made available must be weighed the desires of those members of Deaf culture who wish to live in a society that respects their culture and to continue to be able to participate in a cultural community that would be threatened by the likely consequences of the existence of the implant. How we judge the relative weight of these factors will depend both on how much weight we accord these desires, and on the relative sizes of the these two groups. In societies in which there exists a large and flourishing Deaf culture, this judgement may well go in favor of the survival of the cultural group.

Finally, the presumption that the state should, as far as is possible, remain neutral in relation to disputes between cultures may be interpreted as requiring it to grant equal consideration to the interests of cultural groups, without reducing these to the interests of the individuals who comprise them. That is, the argument might proceed directly from the observation that Deaf culture would be threatened by the existence of a bionic ear technology, while hearing culture(s) are not threatened by its absence, to the conclusion that a “neutral” state would not fund the development of the implant. Granting equal

consideration to the interests of Deaf and hearing culture(s) favors a course of action that allows them both to flourish rather than one which leads to the destruction of Deaf culture.

Arguments which refer to the interests of groups without understanding these as merely the sum of the interests of their members are controversial. I have space only for two observations about them here. Firstly, despite the controversial nature of arguments of this sort, they are far more widely accepted and drawn upon than is usually recognized. Many forums, at all levels of contemporary politics, involve the representation of groups rather than individuals and often treat the interests of these groups as being of roughly even weight, regardless of how many members they have. It would therefore not be unprecedented to rely on an argument from the interests of Deaf culture, considered as a group, to motivate the conclusion that public funding should not be dedicated to the development of a bionic ear. Secondly, consideration of the interests of the group in this controversy is an important factor to which the communitarian perspective draws our attention. This argument *might* tell against public funding for the development of the bionic ear even in those cases where the Deaf culture that would be threatened by its development is quite small.<sup>38</sup>

There are obviously many and difficult questions that would need to be addressed and resolved before we could say with confidence that the *prima facie* case against funding for the bionic ear set out here translates into an all-things-considered conclusion that such research should not be funded. In particular, a more extended discussion of the proper role of the state in a multicultural society, the extent and significance of individuals' interests in the survival of their culture, and the nature and weight of groups' rights than I have been able to provide here, would be required. What I have tried to indicate briefly is how the *prima facie* case might be defended and developed. Any defence of Deaf culture from the potentially corrosive effects of any future "bionic ear" must focus on the ethics of the decision to fund the development of the technology, rather than on the ethics of its use once it exists, and emphasize the public nature of this decision and its implications for the relations between Deaf and hearing culture(s). An argument asserting the rights of minority cultures to equal respect and consideration within a multicultural society, informed by communitarian political philosophy, offers the best prospect for the defence of the unique culture(s) of the Deaf.

<sup>38</sup>Obviously, there must be a limit on how small a cultural group can be to demand respect from the state on this account. At the very least, in this case, a Deaf culture must be of sufficient size that it could sustain its culture in the absence of the threat posed by the existence of a bionic ear technology.