

# In One's Own Image: Ethics and the Reproduction of Deafness

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The ethics of the use of genetic screening and reproductive technologies to select against and for deafness is presented. It is argued that insofar as deafness is a disability it is ethical to act in such a way as to avoid the conception or birth of children with genetic or congenital deafness. The discovery and recognition of signing deaf communities as cultural and linguistic communities (minorities) does not alter this basic ethical position, although the consequences of widespread application of this technology appears destined to lead to the eventual disappearance of these communities. The argument that acting to avoid deafness is unethical because it will lead to the elimination of a linguistic or cultural group (genocide or ethnocide) or conversely that acting to ensure deafness is ethical, if not praiseworthy, can only be sustained if deafness is not regarded as a disability at all. I argue that the premise that deafness is not a disability of some sort is false and thus the claim that genetic selection against deafness is unethical is untenable.

The project to map the human genome has triggered a great deal of discussion in recent years on ethics and biotechnology—in particular, genetic and reproductive technologies. This was especially so in 2002 when there was a much publicized case of a deaf American couple acting to increase the chances of having a deaf child through donor insemination (Maryland) and when there was the first recorded instance of genetic screening being used with in vitro fertilization treatment to select against

deafness (Melbourne, Australia). Given these developments it was no surprise that early in 2003, at the time that the human genome project was completed, a conference was held at Gallaudet University on *Genetics, Disability, and Deafness* (see van Cleve, 2004).

The impact of genetic screening and/or reproductive technologies on the future size and viability of the Australian deaf community was discussed in Johnston (2004). Special attention was paid to the fact that the impact may be much more serious and rapid given that the actual size of the Australian deaf community appears to be much lower than previously thought.

In this article I want to make clear my position on the ethics of the use of genetic science to select against (or even for) deafness and to respond to positions that have been advanced by some deaf advocates and social theorists. Their claims concern me almost as much as do the potential nightmare scenarios that the use of reproductive technologies may lead to. For example, many people are surprised if not confused to learn that some deaf advocates and social theorists criticize the desire of parents to ensure the birth of children without deafness or actually praise those parents who intend the opposite. Most people's natural and laudable desire to help the disadvantaged or the disabled has been called into question and undermined by suggestions that one is at best misguided and, at worst, evil for entertaining this course of action.

I am not convinced it is ethical to do nothing to avoid the likelihood that one's children might be deaf, let alone intend one's child to be deaf. In other words,

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I do not oppose recent developments regarding genetic screening and reproductive technology in which action is taken to select *against* deafness.

Of course, I am not naive. It is a sad paradox of the human condition that great harm can be perpetrated by those intending to do good, so it is not impossible that the position I elaborate here is actually reprehensible. However, I would ask the reader to not forget that there is a greater moral paradox: unintended harm is also produced by people whose primary aim is to stop the actions of others that they perceive as doing harm (i.e., they are not actually trying to do an intrinsically good act themselves). It is thus not impossible that those who wish “to protect unborn children,” “to save the deaf community from annihilation,” or (I would be remiss in not conceding) “to maximize the health and well-being of future children” may have badly misconstrued the moral calculus according to many of their fellow citizens.

Thus, neither am I naive enough to think that this ethical debate will be resolved in one single collective act of reflection. There will be no quick and easy solutions. Rather, it is likely to take decades for our societies to develop a legal and ethical framework in which we are able to deal with these technologies in a way that is workable and acceptable to the majority of people. The dilemmas posed by this technology are likely to become a permanent feature of medical ethics, public policy, and moral philosophy as each newly discovered possible link with disease or disability in our genetic inheritance presents itself to us individually or collectively for consideration: is intervention justified?

In this article I examine three major questions in turn: (a) is deafness a disability? (b) is it ethical to knowingly or intentionally have children who are deaf? and (c) is there an ethical use of genetic screening and/or reproductive technology to avoid deafness? In addition, a number of other issues that relate to each of these questions are raised in their turn.

### Is Deafness a Disability?

I was one of the first people in Australia to point out that deaf people constituted a linguistic and cultural minority (Johnston, 1989a, 1989b). Contrary to the deficit model of deafness then prevalent, especially

among educators and linguists, it was argued that deafness was not *just* a disability. From this perspective, the dominant medicalized pathological model was revealed to be inadequate, and when it was the primary or only way to understand the experience of deafness, it was not only clearly false, but detrimental to the interests of deaf people. Of course, I was drawing on and citing observations first made by American scholars on the American Sign Language-using deaf community in the United States, scholars such as Lane (1984), Markowicz (1980), Padden (1980), and Stokoe, Casterline, and Croneberg (1965). Even though my observation was thus not original, I can say that I had always felt this was the case from my own life experience: hearing myself, I have deaf parents and a number of other deaf relatives. I have 11 living uncles, aunts, cousins, and children of cousins who are deaf. In all, there have been 21 deaf people in the extended family over five generations (including grandparents and their siblings).

However, in saying that signing deaf people constitute a linguistic and cultural minority I, for one, never meant to imply that deafness was not itself a disability *of some kind* or that deaf people were not disabled *in some way*, nor do I think did the original American scholars, such as William Stokoe. In recent years, on the other hand, it has been said that deaf people do not consider themselves as disabled at all or, more strongly, that deafness is simply not a disability (Branson & Miller, 2002; Dolnick, 1993; Ladd, 2003; Lane, 2005; Lane & Grodin, 1997; Lane, Hoffmeister, & Bahan, 1996). More precisely, rather than the bald statement “deafness is not a disability,” one is more likely to read something along the lines of “deaf people do not consider themselves as disabled.” However, this is usually done so without citing any particular person or study or the context in which the statement may have been or is likely to have been made.

Insofar as saying “I’m deaf but not disabled” relates to the common everyday understandings of the English words *disabled* and *disability* and Auslan signs with similar meanings that imply in their form some kind of motor or mobility impairment; deafness is indeed not disabling and deaf people are not disabled. From the extended deaf family and deaf community I grew up in, it was always made plain to me that deaf

people had long claimed a special status in this regard. They simply were not like other disabled people. In this sense, the comment is not at all controversial and it is no surprise to see it reported in descriptions of other deaf communities (Padden & Humphries, 1988).

However, to the extent that the more recent claims that deafness is not a disability are linked to the recognition of its cultural and linguistic character, it is an extension, if not a misunderstanding, of the discovery of deaf communities and deaf identities. In other words, it is not a valid basis upon which to claim that deafness is not a disability and that this is the attitude or belief of most deaf people (contra Lane, 2005). The claim has only been made by relatively few deaf advocates or social theorists, and it is moot whether this sentiment is actually shared by the majority of deaf people themselves. For example, a survey conducted for the Deaf Studies Trust (Centre for Deaf Studies, Bristol University) of over 200 signing deaf people in the United Kingdom showed that a slight majority of deaf people agreed that they were disabled (Dye, Kyle, Allsop, Dury, & Richter, 2001). It is certainly not part of my life experience growing up with a lot of deaf people around me that deaf people did not regard deafness as disabling *in some way*. Indeed, I wonder if the percentage agreeing to the proposition might not have been higher if ambiguities in the word *disabled*, mentioned above, were carefully distinguished or identified.

Whether it refers to deafness at birth or at some other stage of life, most people (including deaf people?) would say that deafness is undesirable insofar as it causes problems and limitations, not all of which are socially constructed. None of my relatives ever pretended that there was not something that I could do that they could not do and that this did not disadvantage them. It was simply “unfair,” our childhood cousins would sometimes complain, that my siblings and I could hear as if, by having an “extra sense” (Padden & Humphries, 1988), we were cheating at the game of life. In a sense we were cheating because we did actually have an advantage—and that is my very point.

If there were in some abstract or even real sense “a choice” about being deaf or hearing, the choice is surely not to be disadvantaged or disabled by deafness. The Bristol survey would seem to suggest that this conclusion is valid for a lot of deaf people also. The

claims of some deaf advocates and social theorists notwithstanding, there is nothing odd about those deaf members of my extended family, nor some of the many deaf people I know, who have said things like this to me.

Of course, much depends on how one asks about being deaf. It is no surprise that the questions “Wouldn’t you rather be hearing?” can appear nonsensical or next to impossible to answer (Humphries, 1993). It is simply often not possible to remove deafness from one’s sense of self, any more than one can easily remove one’s gender or race from one’s sense of self. One simply would not be the same person if one was not deaf (or hearing), male (or female), white (or black, or Asian), or heterosexual (or homosexual). Furthermore, it can be almost impossible to imagine oneself having been another person and wishing it had been so (perhaps because of some disadvantage one has experienced) without devaluing oneself or one’s significant others in the very act of doing so. So one tends not to do so in an ongoing, life-long fashion (though doing so is not an unusual feature of adolescence).

None of this should be taken to imply that deaf people who confide that they would prefer to have been hearing spend their lives in maudlin regret that they are deaf. It is simply a fact of life. Like everyone else, these deaf people just get on with their lives. Those lives can be as rich and full as any hearing person’s life—and they often are, especially if one comes from a deaf family. However, this is not the point—deaf people can still experience a sense of limitation, disadvantage, and disability because of their biology, which is additional to socially constructed stigma and disabling prejudice that deaf advocates and social theorists have documented.

All things being equal, we are grateful if we came into the world with the good use of our five senses, an ability to form social relationships and learn a language, normal intelligence, and with no major physical abnormalities that caused us distress or pain, inhibited independent mobility or the ability to fend for ourselves at an appropriate age, and with no known predisposition to succumb to or develop any major debilitating disease. We expect and hope that our children and all other people are similarly blessed. Moreover, if circumstances rob us of an ability we once enjoyed and took for granted and which virtually everyone else has, this is invariably experienced as undesirable, and certainly

tragic when that loss of ability makes us dependent on others for much of our everyday needs to a much greater extent than our peers. Whether it be an early intrinsic loss (e.g., genetic or congenital hearing loss) or a loss experienced through unexpected misadventure (e.g., adventitious hearing loss), we do whatever we can to avoid such events.

Coming to a more sophisticated and informed understanding as to how a disability or people with a disability are treated within a society or culture can vastly change attitudes and ameliorate the lives of people with a disability. Understanding that many aspects of disability are socially constructed, especially individual and collective attitudes towards a disability, reveals how these attitudes are themselves disabling and disempowering (Branson & Miller, 2002; Ladd, 2003; Lane et al., 1996), and it is important to articulate this in order to unshackle the lives of people who have a disability, deaf or otherwise, of unnecessary impediments.

Discovering the existence of deaf communities and signed languages is revelatory for people who know nothing of deaf people, and the knowledge can be transforming of their attitudes to deaf education and to public policy on deafness. However, at least with respect to deafness, some scholars imply that what we commonly understand to be disabilities are purely social constructs and the disadvantages experienced simply manifestations of relations of power (Branson & Miller, 2002; Finkelstein, 1991; Lane, 1995, 2005; Lane et al., 1996; Wilcox, 1987). The implication that there is no real and significant loss of function or ability at some level is naive, if not disingenuous. For most of the deaf people I have known, they regard their deafness as a disability as measured against the standard of what most other people are like, and in terms of the impact it can have on their lives, all other things being equal.

However, as we all know, all other things are rarely equal: an exclusively deficit model of deafness is completely facile. We know, for example, that if one's parents are deaf and one is a deaf child then the "disability" in one's early life is virtually nonexistent and early-life experiences are essentially normal. On the other hand, communication with people outside the immediate family remains problematic, and the presence of deafness creates limitations and difficulties in life opportunities, especially in the area of educa-

tion. Even pointing to the normality of the situation of a deaf child with deaf parents, we should note that this experience is quite unusual for deaf people because it is very rare for deaf people to have deaf parents or other deaf relatives (Mitchell & Karchmer, 2004). Of course, if everyone was deaf this disadvantage vis-à-vis other people would disappear completely. However, this is not the case in any community, has never been the case, and is unlikely ever to be the case. More reasonably, it is inevitable that the disadvantage of being deaf would virtually disappear if the majority of people within a deaf person's community, hearing or deaf, were signed language users (Branson, Miller, Marsaja, & Negara, 1996; Groce, 1986).

Unlike other disabilities, deafness creates a need for its own language—a signed language—that, in its turn, creates a linguistic community with a culture and a history. In many contexts, it is possible to ignore the disability dimension of deafness because it is simply not relevant. But deafness as a disability is not always irrelevant, and to reject this fact is to invite unsympathetic incredulity.

Lane (2005), in one of the clearest statements of this position, believes deaf people are "misunderstood as a disability group." He appears, however, to concede the disability dimension is actually real *at some level* by criticizing the understanding of deaf people "as both an ethnic group and a disability group at the same time" to be wrong because it is dangerous politically and strategically, not because it is actually false.

Denial of deafness as a disability, even if the stance is simply a political strategy, is quite unnecessary and distorts the meaning and intention of some of the scholars, activists, or social theorists who first drew our attention to the social and cultural dimension of deafness. In conclusion and with the appropriate qualifications in place, I see nothing controversial or pernicious in understanding deafness as both a disability and an "ethnicity," and thus insofar as deafness is a disability, it is to be avoided, if possible.

### Is a Deaf Identity Just Like Any Other Minority Identity?

Of course the similarities between deaf communities and cultural and linguistic minorities have been long

noted. This is uncontroversial and there is no need to repeat them here (see Lane, 2005, for a recent recapitulation). However, they are not identical because deaf communities have unique features of their own.

The belief that deafness is identical to an ethnicity (i.e., that signing deaf communities are no different from other cultural and linguistic groups) is perhaps a possible conclusion if deafness is not also recognized as a disability. However, deafness is a disability in a way in which being the speaker of a minority language, the believer of a different religious tradition, a member of a particular ethnicity, or a person of a different racial group or particular gender are not. Indeed, people generally—regardless of ethnicity, religion, or gender—regard deafness as a disability (Levy, 2002).

Although members of linguistic groups, ethnic groups, racial groups, and genders can experience disadvantages because of differences they have with the majority or the powerful, none of these characteristics are disabling in themselves. Deaf people are not identical to racial groups or genders simply because they too form a group with biological, genetically transmitted characteristics that can cause its members disadvantage.<sup>1</sup> Women or racial minorities may well be disadvantaged, but that disadvantage *is* purely the result of culture and the relations of power, contingently based on physical facts that have no inherent loss of expected function. The harm a deaf person experiences is, on the other hand, not *just* socially imposed on them by the majority.

Moreover, contrary to identities of race and gender, the disadvantage potentially experienced by linguistic and ethnic groups is to all intents and purposes culturally based. Indeed, ethnicity is not, at basis, biological, and it is unhelpful to imply that ethnicities essentially consist of groups of people who share some superficial physical (“racial”) characteristics as well as cultural traits (cf. Lane, 2005). One’s biology does not determine one’s ethnicity though historically both are often aligned.

Thus, the very fact that the deaf community would not exist without people who are deaf (despite the sizeable numbers of hearing native signers who are part of the deaf community) suggests that deaf communities are only *like* ethnic minorities. Deaf commu-

nities are better understood as linguistic and cultural minority communities with their own *sui generis* characteristics. If one does not understand how deafness can be a disability but also be like an ethnicity, does one understand deafness at all?

### Is Deafness Just Natural Genetic Variation?

It is a fact of biology that populations vary. They are never homogeneous. Indeed, this is the very engine of evolution, a process through which natural selection (including sexual selection, which is very relevant to humans) operates on variable populations. Variation from the norm can confer unexpected or unknown advantages—*vis-à-vis* functioning and surviving the natural environment, including the environment of other conspecifics—on an individual or group of individuals and, thus, difference or variation need not be disadvantageous (disabling). We should be aware of this.

On the human lifetime scale, however, evolution is a rather abstract consideration, and any significant disabling variation that is difficult to accommodate in the normal course of life is regarded by virtually every parent and culture as undesirable and not simply as an example of diversity and difference. Most deaf people have hearing parents, and most parents experience deafness in their child as a difficulty. Even hearing parents who recognize the importance of signed language experience difficulties, and, sadly, despite three decades of positive messages about signed languages and a proliferation of courses for the study of community signed languages, the majority of them fail to learn the relevant language proficiently. It is irrelevant that many parents “triumph over adversity” and find the parenting experience in difficult circumstances enriching, if not inspiring. There are some types of difference—we call them disabilities—that we would prefer that we, our children, or anyone did not have to experience. Deafness is one of them.

### Is It Ethical to Knowingly or Intentionally Have Children Who Are Deaf?

If one does not consider deafness to be a disability at all, it is possible that one would have no problems with having children who are deaf. On this point Lane

(2005) is absolutely right. Nothing I could say could therefore change one's likely affirmative answer to the above question. However, if one does regard deafness as disabling, as it appears most people do, this scenario does present the majority of us with an ethical dilemma.

Of relevance to resolving this dilemma is the degree of knowledge and certainty one may have about the likely hearing status of one's potential offspring and the power one may or may not have to do anything to influence that outcome. In the question posed above, the operative words are *knowingly or intentionally*. If there is little or no certainty or power in affecting outcomes of our actions, then there must be less responsibility and hence moral accountability that can be attributed to these actions. This applied in the past and still equally applies where individuals do not have access to knowledge and power over the hearing status of their children and thus have no effective choice in this matter. This is still almost everyone on the planet, but the situation is about to change dramatically.

There is no implication, therefore, that in the past deaf people should have been sterilized, forbidden to marry each other, or forced to have abortions because of the potential for having deaf children. I certainly do not think, for example, that deaf people, including my grandparents and parents, behaved in any way that was unethical. In the past, there was no certainty at all regarding the hearing status of one's children. This applied to both deaf and hearing parents-to-be. Indeed, it has long been a well-known fact that the vast majority of deaf people have hearing children (Fay, 1896; Murray, 2004).

When genetic science was nonexistent or barely nascent, there was nothing one could have done to avoid the possible, though unlikely, outcome of deaf children, apart from celibacy or contraception. In these circumstances, sterilizing deaf people, forbidding marriages, or performing forced abortions in order to avoid deaf births was, rightly I believe, seen as futile, unnecessary, and wrong. One accepted the increased likelihood of deaf births from deaf couples, though they were still relatively rare because, on balance, this led to the greater good and happiness of all. "[T]his is simply a price we must pay for the freedom of association, which is a right upon which our culture places a very high value." (Nance, 2004, p. 103).

Let us not however, rewrite history. Some communities, religious groups, or individuals did consider deaf children an undesirable possible outcome, and deaf people were urged not to marry and become parents (Murray, 2004). Indeed, in the Nazi era deaf people were banned from marriage, were forced to undergo sterilization or abortion, or were murdered (Schuchman, 2004). Of course, it would also be rewriting history not to acknowledge that some deaf and hearing individuals who had a history of deafness in their families freely chose not to procreate for this very reason.

As foreshadowed above, today the situation in the developed world is changing rapidly, and genetic screening and reproductive technologies are beginning to change what we are able to do. The power to make a choice regarding the hearing status of one's offspring is becoming a reality and thus more likely to be acted on, especially if doing so does not involve any other act that is itself unethical. This is influencing and changing the ethical landscape: where there is knowledge of and access to "choice technologies" not to act to avoid a disability like deafness, when this is possible, will in all likelihood be viewed negatively, as unethical.

By the same token, one must not be moralistic and seek certainty and simplicity by applying moral absolutes on to all people regardless of their circumstances. Thus, people who do not know about or have any meaningful, fair, or practical access to this type of emerging technology should not be condemned by rich, educated individuals in rich societies who do. Indeed, if any moral opprobrium is to be dispensed at all, it should be to those educated and powerful people in the rich world who through their action or inaction effectively prevent such a choice being available to their fellow citizens in their own or in other highly unequal societies (in terms of access to health care) or to citizens in other much poorer societies.

There is little need to state that every parent wishes the best for his or her offspring. It is actually quite difficult to imagine a would-be parent who wished to reproduce himself or herself with a known and avoidable disability that he or she may have (or might not even have but simply carry in their genes). This strikes me as a very odd type of parent, and until the well-publicized case of a deaf couple trying to have a deaf child through donor insemination, I suspect few



of us would have ever thought such a type of parent could exist. Indeed, perhaps no such parent actually exists because even these extremely rare deaf parents are able to make this decision ethically because they *do not see deafness as a disability*. In other words, there really is no dispute: we all actually agree that it is wrong to intentionally pass on a disability to one's offspring *if it is in one's power not to do so and do no other act which is itself unethical*. There is no other ethical position. One has to redefine deafness as "not a disability" in order to act ethically in this regard. This is indeed the position of Lane (2005).

### Is a Deaf Parent's Wanting to Have a Deaf Child Just Like Any Other Parent?

Deaf people are no different from any other parents in expecting their children to be biologically like themselves and to share in their heritage, culture, and life experiences. This is a valid and almost universal desire. Provided they are the biological parents of a child, deaf parents cannot avoid having a child who is physically like them, even if it is hearing. The child does not need to be deaf in order to fulfill this desire (after all, no child is completely like either of its parents). A deaf parent who insisted that physical similarity was only possible with a deaf child would be like (and as disturbing as) a male parent who insisted on, and could only relate to, a male child. (I take for granted the fact that being male or female is not a disability.)

Moreover, though deaf parents may be able to offer a deaf child a rich and varied linguistic and cultural life and milieu, we should remember that they cannot avoid giving this gift of language and culture to a hearing child. It is automatic, "it is their birthright" (Levy, 2002). A child does not have to be deaf to learn sign language as his or her first language or to enjoy the richness of deaf culture. In other words, there is no need to create a deaf child for one to share all the important aspects of culture and language with one's child, if one is deaf, save the actual experience of being deaf.

A deaf parent can raise a deaf child in the most normalizing environment imaginable. However, there is simply no need to create a child with deafness for this to happen. There would be many homeless or rejected deaf children in the developing world who

would benefit from adoption if privileged deaf people in the developed world really wanted to have a deaf child. I am full of admiration for the one deaf person I know who has actually taken this course of action. (Of course, the best option in both the developed and developing world is for deaf children, regardless of the hearing status of their parents or the possibilities of adoption, to be exposed from birth, or awareness of their deafness, to the relevant community signed language as their first language.)

It appears that the deaf community has entered a period of serious decline in some developed countries (Johnston, 2004), and the desire to have a deaf child is thus sometimes claimed to be part of a desire to help preserve this linguistic and cultural minority. The loss of some deaf communities and their signed languages would be an unambiguous cultural and linguistic tragedy. I feel enormous distress and sadness at contemplating this future, as anyone who knows or is part of a threatened language, culture, or way of life would. Despite this, I, for one, could not try to guarantee the continuation of a culture and a language that are ultimately based on a disability by advocating that one deliberately caused people with that disability to continue to be born. This could not be justified. It would be wrong to do so and, with a heavy heart because I am mindful of the consequences this is likely to have on deaf communities, I cannot do so.

### Do Deaf Parents Prefer to Have Deaf Children?

As is well known, many deaf people are not at all unhappy to have a deaf child. They know that they are ideally suited to give a deaf child the experience of a normal family life. Having a deaf child poses no problems for these parents. However, whether deaf people generally *prefer* a deaf child to a hearing child, or would act to ensure this income if they could, is, I believe, unknown for two reasons.

First, until very recently no one has ever had a real choice in determining the hearing status of his or her child, so the question is somewhat hypothetical. Second, there has been very little attitudinal research conducted in deaf or hearing communities, and scholars or advocates who claim to know the mind of the deaf community on these issues should be critically

evaluated. In other words, it is very hard to predict what people will do at the “moment of truth” if they were actually presented with a real choice.

With regard to a preference for deaf children, there are, of course, some deaf people who are on the record as saying they really do prefer to have deaf children and apparently would take measures to ensure this outcome—and some of them have received an enormous amount of publicity because of this very stance—but are they representative of deaf people generally? The little attitudinal research that has been conducted would suggest that they might not be. Middleton (2004) and Middleton, Hewison, and Mueller (1998) showed that 8% (11 out of 132) of culturally deaf people interviewed said they preferred to have a deaf child; none of the 56 hard-of-hearing and deafened people preferred to have a deaf child; and only 0.4% (1 out of 258) of hearing people (all of whom had a deaf parent or a deaf child) preferred to have a deaf child. Only 3 culturally deaf people (2%) said they would actually do something to ensure this outcome (e.g., abort a hearing fetus). The authors of the article, however, express doubt that any of these deaf respondents would actually act in this way if presented with such a choice. Anecdotally (and I readily concede it is nothing more than that), my own life experience and discussions with deaf people over many years suggest to me that a preference for deaf children within the community is not at all common. On the contrary, many deaf parents do not want their children to experience the limitations they experienced as a deaf person, and they do not see being deaf as in any way *preferable* to being hearing. That perspective notwithstanding, they may be no less advocates for the language, educational, and vocational rights of deaf people nor any less encouraging of the respect and understanding of the deaf community by the wider community.

### Can Deafness Have Positive Consequences?

Some genetic variation in the population may cause no apparent harm to the individual and can even confer an unexpected advantage in certain circumstances. It is for this reason it may persist in the population and even spread within an entire subpopulation in a certain environment. One example is sickle cell anemia that

confers on carriers a certain resistance to malarial infection. We are thus rightly cautioned about any attempt to remove from our gene pool apparently disabling characteristics that may, as yet, be connected to unknown advantages. Recently, for example, it has been shown that though people with Down syndrome have much shorter life expectancy because they suffer from a variety of ailments, they seem to be protected against certain forms of cancer. It is possible that future genetic research with people with Down syndrome may unlock important treatments or cures for cancer (Hasle, Clemmensen, & Mikkelsen, 2000). None of this would be possible if we had selected against Down syndrome and did not have this subpopulation to study. Could there therefore be some unknown advantage in being deaf? Regardless of the possible positive consequences of some forms of variation, however, it would be unethical to intentionally create an individual with a disability (or do nothing to avoid his or her conception or birth) in order for them to serve as some kind of “natural experiment” or “biological resource” for the rest of us. Whatever may be learnt, the immediate well-being and maximal health of people we bring into the world should be our primary concern.

### Is Deafness an Expression of Diversity and a Vehicle for Tolerance?

Deafness is a vehicle for us all to understand diversity and to experience tolerance of difference, as are all disabilities and indeed all sorts of conceivable differences between people, disabling or not. However, this point is not relevant in the debate about the ethics of genetic screening and choosing to avoid reproductive outcomes with deafness. Regardless of the positive consequences of diversity, once again it must remain unethical to knowingly and intentionally create an individual with a disability (or do nothing to avoid his or her conception or birth) so that he or she could serve as a kind of moral lesson to the rest of us, teaching us all the value of diversity and tolerance (cf. Menand, 2004).

### Is It Unethical to Select Against or Avoid Deafness?

It has been suggested that if deafness can be selected against, then why not gender or race (insofar as race



can be identified by any set of genes whatsoever)? Because selecting against race or gender is clearly unacceptable, surely the premise must be wrong and one should not be able to select against deafness either. It is thus equally unethical.

However, they are not equivalent, and avoiding deafness is not comparable to selecting on the basis of race or gender because deafness is a disability, race and gender are not. Deafness is a disability (albeit with its own special features such as a cultural and linguistic dimension) because there is a real loss of expected function and, thus, as with any unwanted disabling condition, it is considered right and proper for individuals, medical science, and the society as a whole to act to avoid it. The disadvantages an individual may experience due to a disability are not purely the result of the social construction of that disability. By selecting against deafness we may be able to avoid unnecessary intrinsic loss of abilities and functionality expected of all people and, as a consequence, also reduce or eliminate disadvantage in educational and employment opportunities or the artificial circumscription of the number and quality of unmediated social relationships they may enjoy compared to their peers.

All of our medical interventions are based on the premise that certain conditions are to be avoided (they cause pain, suffering, disability, etc.), and we do nothing to deliberately induce these conditions. It *is* ethical to act in this way. This is really just an extension of the moral and practical responsibility of doctors and other medically trained people to come to the assistance of any person in medical need.<sup>2</sup> The medical need in terms of universally recognized disability is the need of a would-be parent carrying a gene for a disabling condition (whether or not that gene is expressed in the would-be parent) not to pass on that gene or condition if it is medically possible to do so (and financially affordable for the individual or the society, and actually available and accessible).

#### Should Parents Have the Right to Select for Deafness if They Have a Right to Select Against Deafness?

It is questionable that parents have the right to reproduce themselves without regard for the well-being of

their offspring (i.e., it is not acceptable to intentionally pass on a disability). Indeed, the extension of the notion of human rights to biological reproduction may actually have an entirely different outcome than those very few people who have claimed a right to choose deafness may assume.

For instance, the coming decades may see the articulation of the notion of “human biological rights” that may have an impact on this question. Just as the 18th, 19th, and 20th centuries saw the emergence of a notion of each individual’s legal, political, social, and economic rights, the 21st century may see the emergence of this new type of right. Economic rights, such as a right to a basic minimum living wage, emerged as the political and economic circumstances of industrializing societies made it possible to realize such rights. Similarly, perhaps, human biological rights may emerge at a time when our scientific and medical knowledge creates the circumstances in which we can expect or even demand them. For example, we may be able to meaningfully assert that on being born we have an expectation (“right”) to have our five senses intact and functioning, if our creators (parents, scientists, and society as a whole) had it within their power to maximize, if not ensure, this outcome. That is, it would be a violation of our human biological rights for someone to have acted in such a way (or failed to act) as to cause us to be born with significantly impaired sensory capacities.

There is, thus, no complementarity in selecting for deafness and selecting against deafness. The former is not the mirror image of the latter. Just because it is ethical to select *against* deafness, this does not make it ethical to select *for* deafness because we do not have any right to disregard the consequences of our actions, even as parents.

#### Does a Child Have a Right to an “Open Future” and a Society a Claim to No Unnecessary Burden?

Indeed, I would ask the reader to consider the possible consequences of *not* behaving in this way. Would it be acceptable for one not to avail oneself of cheap, available, accurate and effective genetic science to avoid deafness in one’s offspring? After all, does not each of us have a right to expect an “open future” (Davis,

1997) as much as is possible? (By open future it is meant that one has “life endowment” that has not been intentionally circumscribed and limited in some way, making it unlike and unequal to that of most of one’s peers.) How is someone who has grown up with deafness going to feel when he or she learns that his or her deafness had actually been “avoidable”?<sup>3</sup>

Before any of us casually celebrates deafness as merely a variation on the human condition of little consequence to the lives of our potential future children, we should consider the following hypothetical and unhappy scenario and ask ourselves how it would feel as a parent if we had to deal with our child’s questions and demands for explanations in such a situation, or, indeed, how we might feel if we were the child in question.

In several decades from now, a young deaf adult could well discover that one of the following situations applied to his or her parents around or at the time he or she was conceived:

- The parents had reason to believe there was a possibility that some or all of their offspring would be born deaf but did not avail themselves of safe, reliable, uninvasive, accessible and affordable genetic screening and reproductive technology to avoid this outcome. (Abortion may or may not have been an ethical option for them.)
- The parents did avail themselves of such techniques but actually took no steps to avoid this outcome when they were told that a future potential child (yet to be conceived or conceived and in utero or in vitro) would be deaf. (Abortion may or may not have been an ethical option for them.)
- The parents actually used such techniques to ensure that their child would be deaf. (Abortion may or may not have been an ethical option for them.)

The child or young adult wants to know why their parents behaved in this way. Though one cannot pre-judge how any given individual “chosen to be deaf” would react, it is hard to believe that all such young adults would be universally pleased or indifferent, let alone thankful, to learn from his or her parents that “we wanted you to be deaf,” “we just didn’t mind either way,” or “we just didn’t care.” The children may deeply resent their parent’s behavior especially

if they have grown up in a world in which deafness was rapidly becoming extremely rare, the number of signed language users was shrinking dramatically, the deaf community itself was dissipating, and they were isolated because of their deafness. Just how sanguine will that person be about this situation especially if gene therapy had been available at the time of their conception (i.e., they really could have been the “same” person, but simply not deaf)?

In our litigious societies such a child (or, as is much more likely, the legal representatives of health insurance companies or governments) may seek legal redress (sanction and compensation) against whom-ever they feel responsible (parents and/or doctors) for the unnecessary suffering, distress, limitation of life choices, and loss of potential earnings (or, again as is much more likely, the increased costs of education and health care for that individual on the society) caused by their disability.

It is difficult to see the law evolving in any other way, individuals feeling any different about any disadvantage they experience, or communities and societies welcoming the extra unnecessary cost of health and education.

### **Is There a Use of Genetic Screening and/or Reproductive Technologies to Avoid Deafness That Does Not Involve Other Unethical Practices?**

Genetic screening and reproductive technologies can now be used to determine the genetic characteristics, with regard to certain limited identifiable traits, that a person will inherit. Abilities and techniques in this area are improving in accuracy and sensitivity extremely rapidly. Though little attitudinal research has been done it would seem a sizeable majority of people would avail themselves of this technology to, at least, screen for deafness. For example, some studies have suggested that as many as 87% (Brugner et al., 2000) or 64% (Martinez, Linden, Schimmenti, & Palmer, 2003) to as few as 49% of hearing people<sup>4</sup> and 21% of deaf people (Middleton, 2004) would consider prenatal genetic testing for deafness.

Genetic science and reproductive technologies can be used to (a) create (in utero or in vitro) an embryo

that does *not* carry a gene “for” (or more likely a suite of genes associated with) deafness and (b) detect the presence of such a gene (or genes) in an embryo (in utero or in vitro) before determining whether to abort (if in utero) or not to implant (if in vitro).

For many people from various cultures, societies, and religious traditions the use of these techniques in any of these ways in order to avoid the birth of children with disabilities is medically and ethically justifiable and acceptable. In other words, the creation and destruction of embryos, including the practice of abortion, is regarded as ethically acceptable when the well-being and health of the mother-to-be or child-to-be is or will be seriously compromised if this course of action was not taken.

For some individuals and in some cultures, societies, or religious traditions, however, abortion cannot be accepted under any circumstances. Can this technology be used in a way acceptable to these people? Looking at the gamut of what genetic and reproductive science has already to offer, it would seem so. Techniques of sufficient sophistication are or will be available very soon that will make it possible for at-risk couples to screen and select eggs and sperm from which only an embryo without a particular disability could be created. For example, at the time of writing these words, it has just been announced by scientists at the Monash Institute of Reproduction and Development (Monash University, Melbourne, Australia) that they have developed a reliable DNA test to detect Down syndrome in embryos before they are implanted in a womb during in vitro fertilization treatments. This DNA fingerprinting test can also be combined with existing tests for inherited disorders involving defects in single genes, such as cystic fibrosis or deafness (Connexin 26).

In other words, an embryo without an undesired gene could be created only with the express intention of being carried to term (if in utero) or implanted and carried to term (if initially in vitro). Thus, although a sizeable minority of people cannot accept abortion as ethical, one can present a possible scenario for avoiding deafness in newborns that involves genetic screening and reproductive technology, which would be ethical even by this much more stringent criteria.

## Will Selecting Against Deafness Devalue People Who Are Deaf?

Advances in genetic screening used in tandem with reproductive technology may cause changes in the way deaf people are regarded. One can understand why some deaf people may be wary of the consequences of increased power over the incidence of deafness in newborns or in the population generally. There is some concern that it will lead to the devaluing of deaf people (Middleton, 2004). This is indeed possible, and great care must be taken to minimize the possible unintended negative consequences for deaf people in our community.

On the negative side, one must recognize that acting to avoid deafness may indeed inadvertently lead to the devaluing of deaf people. If significant and increasing numbers of at-risk parents opt to screen against deafness, one cannot rule out the possibility that the small numbers of children born deaf could become thought of as “intentional” deaf people (people who are deaf by design rather than accident). The parents of these children could well experience negative social attitudes.

Down syndrome is a possible case in point. Until relatively recently, would-be parents had no prior knowledge of the presence of Down syndrome before birth. In recent decades the use of various tests has meant that parents could know this before birth but sometimes only relatively late in a pregnancy and with a risk of spontaneous miscarriage or a false-positive result. Because many parents found an abortion unacceptable by the time the diagnosis was confirmed or feared loss of the fetus spontaneously or unnecessarily, a certain number of children were born with Down syndrome despite there being tests for it for parents who would have been willing to have an abortion. Thus, without anyone “intending” to have a child with Down syndrome, children with Down syndrome continued to be born.

In the past year, a new test has made it possible to know definitively in the first couple of days or weeks of pregnancy if the fetus has Down syndrome, with no risk to the fetus from the test itself and with a very small chance of a false positive. It has been reported that an extremely high proportion of parents using this

test are now choosing an early abortion. It is apparently having a dramatic impact on numbers of children being born with Down syndrome in countries where it is available and accessible.

Moreover, preimplantation genetic diagnosis for Down syndrome is now available and can be used by parents who are “at risk” (i.e., older women). Consequently, it is likely that Down syndrome may become very rare in developed countries. At some point in time, the few children born with Down syndrome in these societies might be identified as intentional Down syndrome children in the sense that, one way or another, the outcome could have been avoided. Community attitudes towards at-risk parents who decide not to test or use preimplantation genetic diagnosis may become negative.

Finally, parents aside, could these types of developments lead to people (and future children) with Down syndrome being devalued or less accepted or, more to the point, is this likely to happen to deaf people who are already in our families, communities, or societies as well as to future deaf children and adults? Experience seems to suggest otherwise.

On the positive side, it appears that there is no necessary connection between wishing to treat or prevent a condition, disability, or illness and the devaluation of individuals or groups with that condition, disability, or illness.

For example, the whole of medical science and practice is based on this type of action without any associated “devaluation” of the very people doctors seek to assist. If anything, the opposite happens. Thus, acting to avoid deafness need not lead to a situation in which deaf people are devalued. Admitting or conceding that a newborn individual has an undesirable condition does not imply any particular negative response (above and beyond the “negative” response of calling the condition undesirable). Indeed, we know from experience that disabled individuals can stir compassion and inspire dedication and unselfishness in many individuals. As a society we take an active interest in the care and welfare of people with disabilities.

Consider also the case of people, say, with severe car accident injuries. As a society, we do many things (pass legislation against speeding, reckless driving, etc.) in an endeavor to reduce the number of injuries

and deaths caused by car accidents because we believe that death, brain damage, paraplegia and quadriplegia are all undesirable. We even punish, severely, people who act in a way on the road to cause these outcomes. Nonetheless, this does not diminish in any way our humane response as a society to individuals who suffer the undesirable consequence of car accidents. We go out of our way to value their lives and make their circumstances better—even for those whom some may suspect “have brought it upon themselves.”

On balance, there may well be a need for proactive social policies regarding disabilities to ensure that society as a whole will continue to value its deaf members despite the probable increased use of genetic screening and reproductive technology and in the decrease in the numbers of deaf people, especially those born deaf or who become deaf in early childhood. However, one thing remains unchanged: on the principle of “do no harm” it would remain unethical to intentionally cause a person with a disability to be born in order to make already existing people with a similar disability continue to feel just as valued. One could not encourage (let alone force) would-be parents to have a child with deafness because of fears that reducing numbers of such children meant that such individuals were being less accepted.

Finally, for those few deaf people for whom the description “disabled” is itself an act of devaluation, I can offer no comfort.

### Is the Deaf Community Concerned About This Technology?

Media reports that the deaf community as a whole is gravely concerned about and opposed to the advent of this technology remain to be substantiated. The little attitudinal research that has been conducted shows that only a minority of the community (33% of deaf and 23% hearing) is concerned with respect to this application of the technology (Middleton, 2004). This is important because many of us know from our own experience—through contact with family, friends, and colleagues—that many deaf people tell us something quite different from reported community attitudes. As in most things, attitudes vary. I have seen some deaf people express hope that the technology could be used

to ensure that their own future children, grandchildren, or great grandchildren were not deaf.

### Will Screening Against Deafness Become Compulsory?

It would seem that parents would want to avail themselves of the technology so that they can make positive, appropriate, and ethical decisions regarding the health of their offspring. Supportive peer-group and cultural attitudes may mean that the vast majority of at-risk individuals will behave in this way. I therefore wonder if there will ever be a call for making testing or screening mandatory. However, having said this, I cannot avoid the issue. Personally, I would be opposed to compulsion under law.

I do, however, make the following observations. There are arguments both for and against compulsory health measures. For example, we do have compulsory immunization and vaccination programs, justified on the basis of the greater good and the health of the community as a whole. They have been with us for a long time. Indeed, we have the mandatory notification of many diseases (such as HIV/AIDS and many other sexually transmitted diseases), and there is explicit legislation in place in many countries that criminalizes willful or reckless infection.<sup>5</sup> Of course, the simple fact of the matter is that deafness is not a “contagion” that has the potential to seriously affect entire populations within years or a generation. (However, diseases that can cause forms of deafness, such as rubella, are contagions, and we do take public health measures, such as vaccination programs, against them.) It is doubtful that genetically based deafness itself will ever be an important enough medical or health issue to elicit legal sanction in this regard. Indeed, is it highly unlikely that there will ever be any significant numbers of intentional deaf children.

One main concern in developed societies is not so much intervention by governments but perhaps the demands of private health insurance companies. They are likely to require at-risk couples undergo genetic screening tests for a much larger range of disabilities than is already the case (e.g., in the United States, women over a certain age are often required to screen for Down syndrome). This must be done either

to qualify for health insurance or to assess the risk and hence adjust the insurance premium. Smokers are another case in point: they must declare themselves and pay an added insurance premium. Failure to test or honestly declare health-related behaviors usually means an insurance company would refuse to offer health coverage or coverage related to that condition.

It now seems likely that screening will be extended to genetically linked forms of deafness. Given that non-discriminatory government-run health care systems are increasingly under attack around the world in favor of private health care provision and insurance, it is difficult to see how individuals could refuse to comply with such requests or that such requests would be ruled invalid by the courts, without specific legislation being enacted. I do not know if the community and its legislators would want to do this.

There is also concern that refusal to screen, and take appropriate action, will also disqualify parents from cost-free or subsidized special educational provision for their child. There may be pressure in future years for screening, especially for couples that are deemed to be at risk. Otherwise the community may well refuse to cover the cost of special educational services for intentional deaf children, seeing the extra burden being entirely the parents’ responsibility rather than “an accident” or “God’s will.” It is important to note that the one group it has been suggested *might* want to have a deaf child—deaf parents—would probably be the least able to afford to carry the cost of special education themselves.

### Is Deafness Only the Thin Edge of the Wedge?

One of the gravest fears in this entire area is the fear that what may appear reasonable, modest, and ethically justifiable acts open up a Pandora’s box of contradictions and unintended extensions such as “designer babies” (Sandel, 2004), the “Gattaca” scenario (Krentz, 2004), or even Nazi eugenics (Schuchman, 2004). We may begin to lose our moral bearings, as we are tempted to entertain other acts as reasonable because they may simply appear to be only one small step removed from that which we already accept. By increments we unknowingly move down a slippery slope to the indefensible, if not evil.



It is revealing that much of the debate about genetic screening and reproductive technologies has not actually been about interventions to avoid or treat disabilities or diseases. If anything, implicitly or explicitly, this is accepted as a good (Sandel, 2004). Rather, the debate has been about genetic science and reproductive technologies to enhance or select for particular desirable characteristics (insofar as this can be done) or to test for their presence. In other words, it is the “thick end of the wedge,” as it were, that bothers us, as it should. In jurisdictions where preimplantation genetic diagnosis is permitted, for example, both the law and government authority guidelines explicitly limit the use of the technology to test for genetic abnormalities or diseases and then only to avoid its transmission (Infertility Treatment Authority (Victoria, Australia), 2004; Victorian State Government (Australia), 1995). There is certainly no casual approach being taken to this problem by many governments, and its complexities are well appreciated.

In a sense every act deemed ethical is a type of wedge. With it we lever open a window of possibilities and situations that we have not anticipated fully, nor could we have. This is what I mean by the observation that the debate about genetic screening and reproductive technologies is not going to go away soon, nor will it be ended in one individual or collective act of resolve. Circumstances and possibilities change, and each dilemma (i.e., definition of disability) will have to be looked at on its own merits, especially if they present us with choices we have never seriously had to entertain before.

Of course, all is not moral relativism and mere contingency. Each of us has his or her own overarching moral framework, mostly shared or constructed within larger collective philosophical and religious traditions, and these frameworks give sense, order, direction, and a certain predictability to our deliberations. However, insofar as it is the “thick edge of the wedge” that really concerns us in this debate—few commentators appear to doubt the morality of reducing the incidence of disease and disability through genetic science and reproductive technology—then, yes, this is the thin edge of the wedge but in a good sense, not a bad one. The debate on the thick end of the wedge will, hopefully, be neverending.

## Conclusion

I continue to give all my support to my deaf colleagues, relatives, and friends in the deaf community for language rights, interpreter services, access to quality sign-based bilingual education, and improved job opportunities. I also continue to work to ensure the proper documentation, description, and teaching of Auslan (and other signed languages). Finally, I naturally continue to maintain that deafness (where there is use of sign language) has a linguistic and cultural dimension, not just a disability dimension (as commonly understood in the community), and, by so doing, I hope to encourage respect and understanding of the deaf community from the wider community.

Unfortunately, however, I sense an emerging confusion about deafness in the wider community because of the inability of most people to accept that deafness is not a disability *at all* or that the deaf community must be protected *at all costs*. They are being told that deafness as a disability is a negative social construction or that the protection of the deaf community is grounds for condemning people for not wanting to have deaf babies and for condoning others for intentionally having deaf babies. This may be causing some ambivalence in the community about deaf attitudes or, at least, the attitudes of deaf activists and scholars as reported in the media (Dennis, 2004).

Apart from war and peace itself, genetics and interventions based on genetics are going to be the major political, social, and ethical questions of our time. As human beings we have never had this much power over our biological destiny. The ethics of selecting against disabilities, itself difficult enough, is relatively simple compared to future more difficult questions. It will probably take many years, if not generations, for us put into place a democratic and informed mechanism whereby issues of medical and biotechnology can be examined and a social consensus arrived at. We may even need new institutions to deal with this process. In all likelihood, the process of deciding what is possible and acceptable to interfere with (remove from our genes or at least prevent from being fully expressed) and what is impossible, difficult, or unethical to change in our genetic makeup would appear to be potentially without end. It is clear, however, that the time for



some plain talking (and much more social research) about deafness, at least, is overdue. It may not be the black-and-white case that some deaf advocates, social theorists, or bioethicists believe it to be.

## Notes

1. I deliberately do not take up the issue of homosexuality in this context partly because of space limitations and partly because I have dealt with this elsewhere (Johnston, 1994).

2. Of course, I hope the reader will take it as given that medical intervention is not ethical if by so doing one seriously harms an individual or greatly increases, if not actually creates, distress. For example, I do not consider it ethical to deny a deaf child a real and accessible first (signed) language at cognitively, emotionally, and socially appropriate and essential times in their early development either as a part of a so-called habilitation program associated with a cochlear implant or as a matter of "principle" (contrary to all evidence) that it is essential for the development of the best possible oral/aural skills.

3. I qualify *avoidable* because unless there was actually a possible, real, and effective method of genetic correction (e.g., gene therapy) for a particular identified disabling condition at the time of conception (the science is still, I believe, in its infancy today), it would not really have been avoidable at all. That is, rather than being the same person without the disability, the person in question would simply never have existed (never having been conceived, never having been implanted if conceived in vitro, or actually having been aborted when first identified soon after conception).

4. It should be remembered that in the study by Middleton (2004) these hearing people had either a deaf parent or a deaf child. Overall, one might therefore expect their attitudes towards deaf people to be much more positive than that of hearing people with no experience, and perhaps fear, of deafness. This may partly explain the lower interest in genetic testing in this group.

5. On the questions of HIV/AIDS and homosexuality and their relevance to the discussion of deafness, genetics, and legal sanction, the reader will find by consulting Johnston (1994) that, as with deafness, I am hardly an outsider busying myself, inappropriately, with the lives of others.

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