STEVEN D. EMERY, ANNA MIDDLETON,
AND GRAHAM H. TURNER

Whose Deaf Genes Are They Anyway?

The Deaf Community's Challenge to Legislation on Embryo Selection

Scientific and technological advances in genetics have been proceeding at an astonishing rate. The Human Genome project, completed in 2003 after thirteen years, identified the full genetic code for human beings (see special supplement of *Nature* [June 1, 2006] on the "Human Genome Collection"). The basic objective of the project was to learn more about our genetic makeup in order to assist with diagnosing and treating or even curing human diseases.

By 1994 four genes involved with nonsyndromal deafness had been discovered; by 2007 this number had increased to forty-five, and the location of more than one hundred others had been pinpointed (Martini, Stephens, and Read 2007, ix). As these figures were published, another gene (known as TGBF1) responsible for causing a common form of hearing loss, otosclerosis, was discovered (*Times* [June 18, 2007]). As this present article was being drafted, further news emerged that highlighted developments in stem cell research indicating that hair cells can be repaired and, ultimately, hearing restored (*BBC News,* "Stem Cell 'Deafness Cure' Closer," April 1, 2009). Discoveries are

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likely to continue at a fast pace, given ongoing research and development in the field.

In the literature on the implications of genetics for Deaf people, their families, and their communities, a spotlight falls upon fears that genetic technology could lead to a significant reduction in the size of the Deaf population (Middleton, Hewison, and Mueller 1998; Stern et al. 2002). In particular, such a shift could be due to parents "selecting against" deafness by choosing to keep embryos with the genes for hearing or to the use of gene therapy to treat or cure deaf adults. Such fears can be exacerbated by those researchers who consider the ultimate goal of genetic research as being the prevention or treatment of deafness and the universal establishment of "normal" hearing (see, for example, Martini, Stephens, and Read 2007). This discourse is encouraged by regular media reports, which often refer to discoveries in genetics as having the potential to "cure" deafness (more recent examples appear in the *Telegraph* [August 27, 2008], "Cure for Deafness Now within Reach," and the *New Scientist* [February 2, 2005], "Gene Therapy Is First Deafness 'Cure'").

The practicalities of the impact of genetic technology on Deaf people have already been discussed in this journal (Arnos 2002) and also elsewhere (Middleton 2006, 2009; Scully 2008).

What Genetic Technologies Are Currently Available?

Around the world it is now possible to perform a prenatal genetic test on a fetus at about eleven weeks of pregnancy to determine whether it carries the genes for deafness or hearing. On the basis of the test results, action—including, in some cases, abortion—can then be taken. In previous research, both Deaf and hearing parents have indicated that they would consider having an abortion if they knew, via a prenatal genetic test, that their child was likely to be deaf (Middleton 2005). Indeed, some countries (e.g., Italy) offer prenatal genetic screening for deafness to whole populations, not just individuals, with the option to end the pregnancy if the fetus is found to be "affected" with deafness (Coviello et al. 2004). Several studies indicate that some Deaf adults state a preference for having deaf children (Jordan 1991; Dolnick 1993; Middleton, Hewison, and Mueller 1998, 2001; Stern et al.

2002). Furthermore, one study (Middleton, Hewison, and Mueller 2001) has shown in that a small minority of Deaf adults say that they might consider ending a pregnancy if it were confirmed that their baby was likely to be hearing. (This latter issue is controversial, and it should be noted that the study asked participants to consider what they *might do* in a hypothetical situation, not what they have actually done.) Moreover, the vast majority of Deaf parents have indicated that they do not mind having either deaf or hearing children: Most are also very concerned that it is even possible to select at all (Middleton 2005).

If having an abortion on the basis of hearing status is not an option taken (but the idea of avoiding having a deaf child is considered attractive), then parents have access to other genetic technologies. Preimplantation genetic diagnosis (PGD) enables an *embryo,* which is only a few days old (as opposed to a *fetus,* which is several weeks old), to be tested for the genes for deafness. Here, a woman undergoes in-vitro fertilization (IVF), in which her eggs are removed and fertilized in a laboratory, and the resulting embryos are tested for the deafness genes. If the embryos contain the genes that the parents want, then these embryos are implanted in the mother: Any embryos that contain other genes are then discarded. This creates an opportunity for the selection of a baby with specific genetic characteristics (e.g., hearing) without the need for parents to undergo prenatal genetic testing and the emotional and physical difficulties that may arise as a consequence. Nonetheless, the emotional and physical impact of having IVF and PGD should also not be underestimated; the success rate of these procedures is also very low. In general, PGD is used by couples who have strong family histories of serious, life-threatening genetic conditions that the parents wish to avoid at all costs. However, it is now also possible to use PGD to test for adult-onset, treatable conditions such as inherited breast cancer (Quinn 2009).

Preimplantation genetic diagnosis for deafness is technically possible and is indeed available in various countries around the world. This means that an embryo that is carrying a deaf gene can, once identified, be chosen for implantation or discarded. It is not a procedure that is widely used. In fact, it is likely that only a handful of couples worldwide have utilized this technology. This practice, which was not possible ten years ago, indicates how far the science has advanced. As with

the use of prenatal testing for deafness, certain couples may be interested in using PGD to select for deaf embryos and against hearing ones. There is mixed opinion on this around the world. In Victoria, Australia, the Infertility Treatment Authority (ITA), which licenses the use of PGD there, has allowed the use of PGD to select against deafness but not against hearing (ITA 2003): Critics have described this as discriminatory (Middleton 2002). In the United States, conversely, couples may use PGD to select for either deafness or hearing. In fact, one American survey found that, of 190 clinics that provide PGD, 3 percent of users had intentionally sought PGD to test for the "presence of a disability" (Baruch, Kaufman, and Hudson 2008). The researchers speculate that Deaf couples are likely to be among this 3 percent (personal communication).

The Human Fertilization and Embryology Act 2008

The proposed legislation that sparked the recent British debate was first introduced in 2007. The Human Fertilization and Embryology (HFE) Bill was written to update the original 1990 HFE Act of the same name. (Prior to being passed and becoming UK law, an act is called a bill.) As introduced, the new HFE Bill of 2008 was a complex piece of legislation specifically drawn up to accommodate technological advances in science since 1990, such as stem cell therapy, assisted reproduction services, and the ability to mix human and animal embryos. The HFE Bill was passed in November 2008 and is now termed the HFE Act 2008. Among other things, the act ensures that the increased discovery of genes does not lead to the development of "designer babies." Since PGD has been used to screen out several traits that cause illness and disease, there were growing fears that such technology could be used to ensure the selection of embryos likely to lead to babies with particular characteristics (e.g., brown eyes, long legs, high IQ). In other words, whereas scientific development has generally been helping couples to have a baby who is born *without* a particular genetic defect (such as those associated with cystic fibrosis or sickle cell anemia), some medical professionals might wish to offer a "designer baby" service, which would proactively *seek out* and give preference to specific features. These fears have increased following

the birth of "savior siblings," children whose birth has been specifically planned for their ability to produce cells that can be used to treat a sick sibling (Horsey 2005; Miller 2008). The HFE Bill also attempted to reflect social changes by recognizing same-sex couples as legal guardians of children conceived through assisted reproduction.

Opposition to the HFE Bill

In late 2007 a UK blog called "Grumpy Old Deafies" alerted its readers (www.grumpyoldeafies.com, November 22, 2007) to comments being made in the UK's House of Lords about a particular clause of the HFE Bill. (The House of Lords is the upper house of Parliament, which critically assesses bills but is ultimately less powerful than the democratically elected House of Commons.) The clause, which became known as Clause 14/4/9 (and is referred to as such hereafter), reads as follows:

> Persons or embryos that are known to have a gene, chromosome or mitochondrion abnormality involving a significant risk that a person with the abnormality will have or develop—
>
> (a) a serious physical or mental disability,
> (b) a serious illness, or
> (c) any other serious medical condition,
>
> *must not be preferred to those that are not known to have such an abnormality.*

In other words, the clause attempts to ensure that under no circumstances can an embryo that is liable to develop into a seriously ill or disabled grown person be selected in preference to an unaffected counterpart.

Three particular factors led to an international campaign by Deaf and hearing people against the clause. First, a prominent member of the House of Lords, Baroness Ruth Deech, made a speech in the House that alerted bloggers on "Grumpy Old Deafies" and others in the international Deaf community to the fact that this clause was partly designed with deaf people in mind. Baroness Deech was particularly important since she had chaired the Human Fertilization and Embry-

ology Authority (HFEA) in the UK. This organization is responsible for granting licenses to clinics in the UK to carry out procedures such as PGD. In her comments, Baroness Deech said, "In the scientific field, the Bill confirms the wider use of pre-implantation genetic diagnosis. That is good. I hope that your Lordships will be pleased that the deliberate choice of an embryo that is, for example, likely to be deaf will be prevented by Clause 14" (HL Deb November 19, 2007, 696, col. 673).

Second, bills put before the houses of Parliament usually have explanatory notes that accompany them to explain the wording of a particular bill in more detail. In the case of the HFE Bill, explanatory note number 110 states the following:

> Clause 14 . . . amend[s] the 1990 Act to make it a condition of a treatment license that embryos that are known to have an abnormality . . . are not to be preferred to embryos not known to have such an abnormality. The same restriction is also applied to the selection of persons as gamete or embryo donors. Outside the UK, the positive selection of deaf donors in order deliberately to result in a deaf child has been reported. This provision would prevent selection for a similar purpose.

Leaving aside issues such as the veracity of some of the reports alluded to here and, more important, the reasons that one might deliberately try to bring about the birth of a deaf baby, the explanatory note and the comments by Baroness Deech could hardly fail to increase the chances of a clinician's labeling a deaf embryo "abnormal" or a deaf donor as a potential carrier of an "abnormal" gene and hence as "unsuitable."

The third reason for the campaign against the clause was the fact that the Human Genetics Commission, which advises the UK government on developments in human genetics, in conjunction with the UK's Department of Health, failed to make concerted efforts to consult with Deaf people during the period of the bill's preparation. This failure to seek the views of Deaf citizens meant that Deaf people—who might predictably object to the singling out of deafness as a "serious illness," a "physical disability," or an "abnormal" condition—were not readily able to have their views taken into consideration. A social or cultural perspective of Deaf people, sign language, and Deaf culture

was therefore missing from the debate. The point of view that a deaf child is far from "unhealthy" but merely requires access to sign language was not part of the input. Instead, the Human Genetics Commission consultation document stated that "[no] treatment services should be used specifically to create a deaf child—or, indeed, a child with any other inherited disorder" (paragraph 5.35).

In summary, several issues were raised. Firstly, deaf embryos and donors were being considered "abnormal": This, in itself, was quite sufficient to cause offense to adult Deaf citizens. Second, parents were to be denied the opportunity of testing the status of their embryos *for information purposes only:* Once a test had been taken, specific actions were then to be made mandatory since the new law meant that, having chosen to take a test, they *must* thereafter choose a hearing embryo (where available). Perhaps the furthest-reaching immediate consequence was the depiction of Deaf people—in law, by government, and after the hard-won social and legislative progress to which people had dedicated the better part of their lives in the late twentieth century—as people whose condition would now be considered so "serious" that they were "better off not being born."

As a result, the feeling mounted that a collective, public response must be made. A "Stop Eugenics" website (http://www.stopeugenics.org) and campaign organization were set up to oppose Clause 14/4/9. The site became an online space for those who were opposed to the clause to express their objections, initially in the form of creative video clips and posters highlighting the implications of the clause. Information was disseminated in BSL, as well as English, and as the media took up the issue the website became a focal point for activists. An e-group forum was set up, and many forms of media campaigning took place, including the following:

- radio (e.g., BBC Radio 4, BBC World Service, BBC Radio 5 Live)
- television (e.g., BBC Breakfast, BBC News, ABC News, CNN News)
- articles in newspapers (e.g., the *Guardian,* the *Herald,* the *Times,* the *Peninsula* [Qatar], the *Sun)*
- blogs (e.g., Grumpy Old Deafies, Tiger Deafie, Deaf DC Blog, www.bioethics.com, Mike Gulliver's Blog, BioEdge)

- online discussion forums (e.g., Games Radar, Aspies for Freedom)
- public events (e.g., a public debate in Cardiff, Wales; a march in London that ended up outside Downing Street, the prime minister's residence)
- other actions (e.g., online petitions)

Just one example can perhaps give a slightly more vivid sense of how significant the issue became in the wider public consciousness. *The Moral Maze* is a flagship national BBC Radio 4 program that has been broadcast for some years. The program offers what it calls "combative, provocative, and engaging live debate examining the moral issues behind one of the week's news stories" (http://www.bbc.co.uk/programmes/b006qk11). Four celebrity panelists—regularly including a prominent former member of Parliament and Conservative Party leadership candidate, Michael Portillo—quiz a series of invited "witnesses" on a topical moral question. When discussion of Clause 14/4/9 was at its height, Steven Emery acted as one of these witnesses as the clause became the mazy moral issue of the day. Initially skeptical about the campaign, Portillo was observed elsewhere in the media in the following days referring to the topic as "a genuine moral dilemma"—clearly he, for one, had had his eyes somewhat opened by the arguments he had heard.

Preimplantation Genetic Diagnosis, Prenatal Diagnosis, Abortion, and Eugenics

Clause 14/4/9 dusted off many issues that had been widely covered (see Barnes and Levitt 1997) in the mid-1990s in the UK in the wake of the Deaf Futures Seminar: Deaf People, Deaf Genes, and Deaf Ethics, convened by Graham Turner. At that time, many of these issues were hypothetical questions that were nonetheless based on real scientific possibilities. Since that time, it has been widely recognized that genetics potentially poses a much greater risk to Deaf people—and to sign language (Turner 2003, 2006)—than the development and spread of cochlear implants. It has even been referred to as a "final solution" in "eradicating" Deaf people (Jones and Bunton 2004; Ladd 2003). The "Stop Eugenics" campaign name and some of its literature

suggested that the clause had eugenicist implications. It is worth taking a closer look at the science behind the HFEB clause to see why people believed that this was a step toward eugenics in the UK.

The media widely reported that those campaigning to oppose Clause 14/4/9 were doing so because it would prevent Deaf couples from preferring a deaf embryo or donor should they seek IVF (Templeton 2007; Cockcroft 2008). This was partly true since, prior to the legislation, it would not have been illegal to test an embryo for a deaf gene and have this embryo implanted into the womb. This would have been possible through private consultation and with the agreement of clinicians, but the extreme rarity of this situation appears to have been overlooked by journalists on the lookout for a sensationalist type of story (see above). The explanatory notes refer to "the selection of deaf donors" "outside of the UK," widely taken to refer to the case of Sharon Duchesneau and Candy McCullough in the United States (Spriggs 2002). This couple chose a sperm donor who, they believed, would increase the chances of their baby's being born deaf (Teather 2002) (i.e., the child was not "created" via genetic technology).

Thus, the media discourse fails to distinguish between the *desire* for a deaf baby and the *creation* of one. There *are* Deaf couples who wish for a deaf baby (see Middleton, Hewison, and Mueller 1998, who report that 15 percent of Deaf research participants would prefer a deaf baby, although our latest research puts the figure at 6 percent), but there is no strong indication that Deaf people on the whole would be interested in using preimplantation genetic diagnosis with the specific aim of choosing a deaf baby. It is far more likely that legislation will lead to the prevention of deaf births. In China, for example, women *must* undergo prenatal testing for "deformities" and abort the fetus if they are discovered (King, in United Kingdom's Disabled People's Council 2000). This does not prevent deafness or disability altogether, of course, since many people acquire these after birth.

What the UK media focus missed, argued the "Stop Eugenics" campaigners, was that the clause actually mandated the selection (where a choice existed) of a *hearing* embryo, which raised the question as to whether this was a step toward the use of science to promote state-sponsored eugenics against Deaf people. The term *eugenics,* however, has come a long way from its first definition by Francis Galton,

who intended it to mean improving or repairing "racial quality" (Gillman 2001). Prominent in the early twentieth century, it is often associated with practices such as sterilization or abortion of those deemed "unhealthy" or "genetically disadvantaged." More recently, the disabled people's movement has, in general, warned against what it sees as the "new eugenics." In the late 1990s, for example, David King (1998, 7) wrote these words: "The danger we will need to guard against is the development of a kind of eugenic common sense, that it is irresponsible to refuse to undergo tests, and that every child has the 'right' to a healthy genetic endowment. . . . We will need to be vigilant for eugenics disguised as public health measures."

The legislation in the UK applies only if a couple decides to have PGD *and to test* for a deaf gene. They cannot be *forced* to take such a test. The concern is that, if such technology becomes widely used, future generations might start to *expect* couples to undergo such tests for a wide range of what others consider abnormal genes. We are, therefore, approaching new and perhaps somewhat unintended consequences as the technology develops and legislation is created. Much is possible unless there are checks and balances in place to ensure that small-scale changes in the law do not become the impetus for more far-reaching legislation.

The Campaign's Impact: Toward a Conclusion

The campaign quickly had an international impact and received input from the World Federation of the Deaf and from staff at Gallaudet University, as well as across Europe and Australia. There were fears that the UK was setting a precedent for other governments around the world, highlighted by the fact that the Dutch government appeared to have been influenced by the legislation. Activists in the UK were contacted by the media from the United States, Canada, Germany, and Brazil, for example. Such was the strength of feeling about the clause.

Ultimately, this campaigning did have some effect. After a meeting between representatives of the "Stop Eugenics" campaign, the British Deaf Association, and the Department of Health (following the media coverage and the department's realization of the strength of

opinion against the clause), the key explanatory note was changed. While the furor caused by the campaigners brought the issue of genetics and Deaf people into the public domain, the statement still leaves open to interpretation the exact definition of a "serious medical condition." The note is now number 114 of the HFEB 2008 Act[1]:

> Section 14(4) contains a provision that relates to the provisions on embryo testing (see note on section 11). New sections 13(8) to (11) amend the 1990 Act to make it a condition of a treatment license that embryos that are known to have an abnormality (including a gender-related abnormality) are not to be preferred to embryos not known to have such an abnormality. The same restriction is also applied to the selection of persons as gamete or embryo donors. This would prevent assisted reproduction technology being used to select an embryo with a view to increasing the chance of giving birth to a child that had or would develop a serious medical condition or to select a donor to increase the chance of a child having a serious medical condition.

The public debate indicated a complex and volatile "interface" between Deaf people and genetics. It would be a mistake to position these into simplistic, opposing camps, however, because there were exceptions. One member of Parliament, for example, eventually tried to have the clause eliminated but was unable to bring about a debate on the subject in the House of Commons.[2] Some journalists and scholars were sympathetic to the campaign against the clause (Lawson 2008; Gavaghan 2008). Genetics counselors were also concerned about the clause's implication for reproductive liberty (Blankmeyer-Burke, Belk, and Middleton 2008; Middleton and Belk 2008).

In his introduction to this issue of *Sign Language Studies,* Thoutenhoofd discusses the complex relationships that occur at the interface between science and democracy. The principles of democracy require Deaf people and organizations to cooperate and communicate in the sphere of genetics. The campaign to challenge the proposed UK legislation demonstrated that Deaf people are still eager to become involved and debate issues of relevance to them. Critically, the media penetration mentioned earlier was achieved in large part because it was driven by Deaf input. This, we claim, is a new feature in the ecology of Deaf-hearing dialogue, which, arguably, arises in large part because of the democratizing power of the video-enabled Internet,

which encourages people from diverse communities all over the world to feel that (a) they *can* articulate their views in ways that people will understand (something that has not always been true for BSL users) and (b) when they do, people really *will* pay attention to them.

The key question now is this: Can ongoing public dialogue be established in such a way as to incorporate fairly those who provide services (the scientists), those who are the recipients of those services (Deaf persons), and those who are responsible for national service policy (governmental and other public authorities)? Again, we certainly can say that using at least the full range of forums listed earlier *has* allowed a lot of stakeholders to enter the picture. To reinforce this, we might note that, in addition to Deaf people, on whom we have focused our attention here, many members of the *general* public, with no apparent personal stake in the issue, were moved to involve themselves in bulletin-board discussions (e.g., on the BBC's disability pages, *Ouch!)* on the Deaf genetics topic.

Engagement in such dialogue is crucial if we are to avoid or mitigate the effects of genetic science becoming what Thoutenhoofd terms "politics conducted by other means" (this issue, p. 151). From a Deaf perspective, the sciences have never needed to adapt more quickly—before technology advances in such a way that it becomes accepted wisdom within science to work toward the eradication of difference in society. It could hardly be more urgent that Deaf perspectives become routinely represented in scientific and medical circles: How that is to happen is a big question that all of those who care about this matter must help each other to answer.

Such a strategy for action and change will probably ultimately involve radical decisions to ensure that its influence is felt within social policy at government level. It might be necessary to be widely spread across a variety of health institutions (of which genetic counseling is just one service). Deaf people's roles, however, are probably not, on the whole, as salaried professionals in this context (or if they are, tokenism should be avoided). Nevertheless, Deaf adults and also hearing parents can bring crucial knowledge to these institutions via their everyday communicative channels. Deaf studies has a role to play here by encouraging science to become organized around public participation, whereby Deaf adults' knowledge of parenting, for example, can

be informative to privileged science and in the process influence and affect scientific developments.

In summary, then, scientific developments in genetics have led to the introduction of laws in the UK to regulate research and development in the field of fertilization and embryology. Although contrasting perspectives were identified, the government characterized deaf people as carrying an "abnormal" gene, implying that deaf babies are born with a "serious illness" or are "physically disabled." Deaf people challenged this view and succeeded in raising public awareness of the moral complexity of the issues and securing adjustments to the legislative framing of them. The original problem with the bill, however, has not gone away entirely with its ratification, and the status of Deaf people in British society is not unaffected by this development. Fundamentally, this experience reinforces the fact that public perceptions of deafness and Deaf people remain fragile despite the gains of recent decades.

Notes

1. Details cited in this paragraph are taken from personal correspondence with individuals knowledgeable about British law. One of those individuals is from the Department of Health and assisted with the drafting of the HFE Bill.

2. Philip Davies, MP, proposed an amendment to scrap the clause; the original website with this proposal was accessed on September 8, 2008, but was defunct as of April 8, 2009. http://www.publications.parliament.uk/pa/cm200708/cmbills/120/ame nd/pbc1200807 a.3009–3010.html.

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