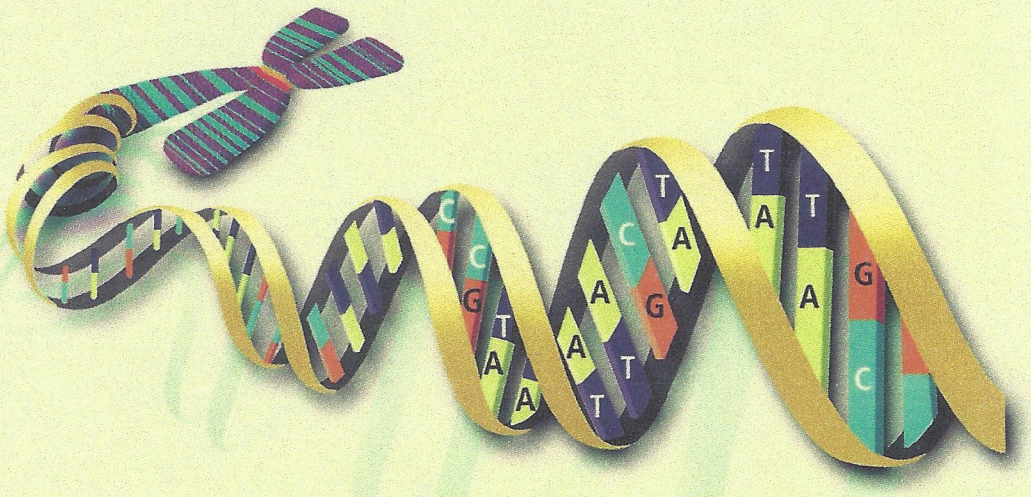
Genetics, Disability, and Deafness



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The photographs on pages 95 and 101 appear courtesy of the Gallaudet University Archives, Washington, D.C. The photograph on page 97 appears courtesy of the Gentile family.

CONTENTS

INTRODUCTION

Disability theorists have argued since the late-twentieth century that disability is a social construct and that cultural and political decisions, rather than biological characteristics, restrict their full and complete participation in society. Historian and activist Paul Longmore, for example, has written that "for the overwhelming majority [of disabled persons] prejudice is a far greater problem than any impairment; discrimination is a bigger obstacle than disability."[1] Deaf people also have tried to shift the focus of public discussion from their personal physical attributes to society's response to them. They have argued that deafness is not fundamentally different from ethnicity and should be viewed from the same perspective. The use of accessible language, either a signed language or a spoken language in written form, they continue, renders deafness an interesting human variation, one that should be cherished, respected, even preserved.[2] In these views, the "problems" encountered by people who are deaf or disabled are variable, socially constructed, and not inherent in their biological being.

The attitude of the general, nondisabled public is different. In the popular imagination, disability "promises an unmistakable and noncontingent correspondence between biology and the self," as one author has noted.[3] The even more radical view that biology is destiny is gaining adherents in the United States, fueled in part by the claims of evolutionary psychologists, who view individual realization and social interaction within a framework of supposed evolutionary selection of biologically determined behavioral traits.[4] Louis Menand notes in the

...Arnos, L. Murrelle, K. O. Welch, W. E. Nance, and A. Pandya. 2002. Attitudes of deaf and hard of hearing subjects towards genetic testing and prenatal diagnosis of hearing loss. *Journal of Medical Genetics* 39:449–53.

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DEAF AND HEARING ADULTS' ATTITUDES TOWARD GENETIC TESTING FOR DEAFNESS

Anna Middleton

Genetic factors play a major role in the development of both congenital and late-onset deafness (Cohen and Gorlin 1995). More than 120 different genetic loci involved with deafness have been identified over the past ten years (Van Camp and Smith 2004), and one particular gene, *GJB2* or connexin 26, is thought to play a part in the most common form of genetic deafness—nonsyndromal recessive deafness. This is deafness in isolation (not part of a syndrome), and the person who is deaf usually has two parents who are both hearing but carriers of an altered gene, such as connexin 26.

Testing for *alterations* in such a gene can be done via a blood sample. A *diagnostic* genetic test can inform a deaf person if his or her deafness is likely to be due to known genetic factors. A *carrier* genetic test can inform a hearing person if he or she has a deafness-causing gene. If both partners are hearing but are carriers for the same altered gene, they have a one in four chance of having deaf children. A *prenatal* genetic test is a test in pregnancy that can inform a pregnant couple whether their fetus has the gene alterations that could cause it to be deaf

(but would not indicate to what level). There are many genetics laboratories that now offer genetic testing for changes in various deafness genes, particularly connexin 26. This chapter considers research that ascertains how deaf people and their families feel about this testing.

DEAFNESS—MEDICAL PROBLEM OR CULTURAL DIFFERENCE?

Deafness can be viewed from different perspectives. People who are culturally Deaf (written with an uppercase "D") may not predominantly perceive their deafness as a problem that needs to be "treated" with a hearing aid or cochlear implant. It is the medical model that would consider deafness in this way. The cultural or sociological model views deafness as a condition to be preserved and celebrated, offering a strong identity, rich language, and a distinct cultural community (Padden 1980). Many Deaf people who embrace this perspective do not want to be treated for their deafness and reject medical services that may offer this. For them personally, their deafness is not a disability; it is societal attitudes that are disabling.

PRENATAL GENETIC TESTING FOR DEAFNESS

Many clinical and research professionals involved with deaf families believe that the incorporation of genetic testing for deafness should be part of routine practice within clinical genetics services (Reardon 1998). If carrier and diagnostic genetic testing become more widely available, then it is almost implicit that prenatal genetic testing could also be on offer. For example, if a deaf child has a diagnostic genetic test that confirms his or her deafness is due to altered connexin 26 genes, and the parents are confirmed as carriers for this genetic alteration, then they know that they have a one in four chance of having more deaf children. Parents may wish to have a prenatal genetic test during a subsequent pregnancy, and if the fetus is found to have two altered connexin 26 genes (and thus is likely to be deaf), they may choose to end the pregnancy. For parents who have had a particularly difficult time with their deaf child(ren) (e.g., in obtaining education or support in teaching their child to communicate), this may well be an option they choose for future pregnancies (Middleton 2004). For culturally Deaf people and also many parents of deaf children, and also deaf, hard of hearing, and deafened adults, this eventuality could be seen very negatively. For them, deafness may not be seen as a condition "serious" enough to warrant an abortion.

An additional dynamic is that some Deaf parents prefer to have deaf children and do not want the numbers of deaf children born to be reduced, threatening the future of their culture (Middleton et al. 1998). Hearing people with no knowledge of Deaf culture may find this perspective difficult to understand.

The following paper details a large research project that documented attitudes and beliefs about genetics and prenatal genetic testing for deafness. The hypothesis was that deaf and hearing people would have different attitudes toward such testing.

The terminology includes using "deaf" to refer to all individuals affected by hearing loss, including the culturally Deaf, and the term "Deaf" to refer to culturally Deaf individuals only.

METHODS

Participants

The study involved 644 deaf individuals, 143 hard of hearing and deafened individuals, and 527 hearing individuals with either a deaf parent or deaf child. The participants determined their own hearing status classifications. Those who termed themselves "deaf" tended to have severe or profound hearing loss; the "hard of hearing" tended to have a mild or moderate hearing loss. "Deafened" usually meant they had lost their hearing later on in life. Sociodemographic data relating to these participants is given in table 1. Culturally Deaf participants were those who considered themselves deaf, hard of hearing, or deafened; said they used British Sign Language (BSL) as their preferred language; and associated more with the Deaf community rather than Hearing World. Therefore, only those participants who met all these criteria collectively were classified as culturally Deaf. Numbers are given in table 2.

Ascertainment

Participants were collected from a number of different sources in the United Kingdom between June 1998 and June 1999. These included various hospital departments such as Clinical Genetics, ENT, and Audiology as well as social services for deaf people, schools, colleges, and

TABLE 1. SOCIODEMOGRAPHIC INFORMATION FOR THE SAMPLE

Sociodemographic Characteristic	Total Sample Size = 1314	%
Age range		
13–19	36	3
20–29	152	12
30–39	441	35
40–49	390	30
50–59	179	14
60–69	54	4
70–93	32	2
Female	833	63
Had Children (deaf or hearing)	958	73
Married or Living with Partner	930	71
Owns own Home	922	70
Had a Religious Affinity	662	50

charities. A letter was sent to each health or education professional involved with the different potential participants, asking them to pass on a questionnaire to their clients. Questionnaires were also handed out at deaf clubs and to delegates attending conferences for deaf people. Participants were given the option of completing the questionnaire via a sign language interpreter if they preferred not to use a written

TABLE 2. NUMBER OF CULTURALLY AND NONCULTURALLY DEAF PARTICIPANTS

All participants with a hearing loss	664	%
—Culturally Deaf	212	32
—Nonculturally deaf	452	68

format. The questionnaire was also posted directly to participants as part of their subscription to three different magazines for deaf people. Recipients were asked to return the completed questionnaire if they wished to take part in the study. St. James's University Hospital Ethics Committee (Leeds, U.K.) granted ethical approval for the research.

Questionnaire

Deaf sign language users provided input to ensure that the questionnaire design was Deaf-sensitive and easily translated into BSL. For example, in the questionnaire, the term *abortion* rather than *termination of pregnancy* was used, since the former translated more fluently into BSL. For Deaf readers, this term is also used in the written text here.

This chapter discusses a small selection of the questionnaire's twenty-one questions, which covered such issues as preference for having deaf or hearing children, interest in utilizing a prenatal genetic test for deafness, reasons for having such testing for deafness, and interest in abortion for deafness and "hearingness" (i.e., ending the pregnancy if the fetus is found NOT to have the deafness-causing genes, since the parents prefer to have deaf children).

RESULTS

Questionnaires were made available to 6,674 potential participants, and 1,314 were returned (average response rate: 20%). The following sections give details of responses to specific questions.

Feelings about New Discoveries in Genetics

Participants were given a list of positive, neutral, and negative words and asked to check off those that described their feelings about new discoveries in genetics. The results showed very different attitudes between groups (figure 1). Deaf participants were more likely to select negative words ($\chi^2 = 42.2$, $df = 6$, $P < 0.001$). The most popular word was *concerned.* Hearing participants were more likely to select positive words ($\chi^2 = 156.7$, $df = 8$, $P < 0.001$). The most popular word was *hopeful.* Hard of hearing and deafened participants were more likely to check a mixture of words. The most popular was *cautious.* This latter group's attitudes reflected the whole spectrum of views—some had the same as

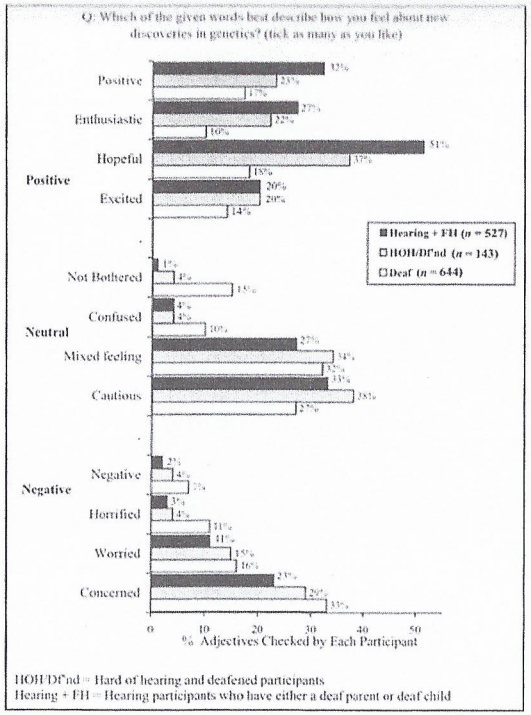

Figure 1. Percentage of participants checking different adjectives to describe their feelings about new discoveries in genetics

the deaf group, some the same as the hearing group, and many in between.

Participants were given the opportunity to comment on their feelings about new discoveries in genetics. The following are a selection of these.

Some participants felt that new discoveries in genetics would be positive:

> We must go forward in genetics to help us understand causes of deafness and other disabilities caused through genes.
>
> *A nonculturally deaf participant*

> I think it is a good idea—to stop the genes passing on into the next generation.
>
> *A nonculturally deaf participant*

Some had negative comments about new discoveries in genetics:

> Angry at people trying to mess with nature and interfering with deaf people—leave us alone!
>
> *A culturally Deaf participant*

> "My hands is little nerve [I feel nervous]. To think it is worst soon [I feel this is the worst situation].
>
> *A culturally Deaf participant, who used BSL as their first language, translated his or her feelings from BSL into written English*

And some comments were mixed:

> Interested but do not feel involved.
>
> *A nonculturally deaf participant*

> Enthusiastic about benefits it can bring—early diagnosis, treatment to improved levels/quality of hearing, BUT concerned it will be used to increase abortion.
>
> *A hearing parent of deaf children*

Interest in Using Prenatal Genetic Diagnosis for Deafness

Deaf participants were less interested in prenatal diagnosis for deafness than hearing participants ($\chi^2 = 113.1$, $df = 4$, $P < 0.0001$; see figure 2). Out of the deaf participants, those who were culturally Deaf were the least likely to be interested in prenatal diagnosis for deafness ($\chi^2 = 21.1$, $df = 2$, $P < 0.0001$; see figure 3).

Those participants who said that they would be interested in prenatal diagnosis for deafness (figure 2) were also asked if they would prefer to have deaf or hearing children (or did not mind). Therefore the data from figure 2 is presented again to show which participants would have a prenatal genetic test and whether they would prefer to have deaf or hearing children. The results of this are presented in figure 4, and they show that while 69% of hearing and 61% of hard of hearing and deafened participants might use prenatal genetic diagnosis for deafness to have hearing children, deaf participants were not so emphatic. Of those who wanted prenatal genetic diagnosis for deafness, 56% did not mind

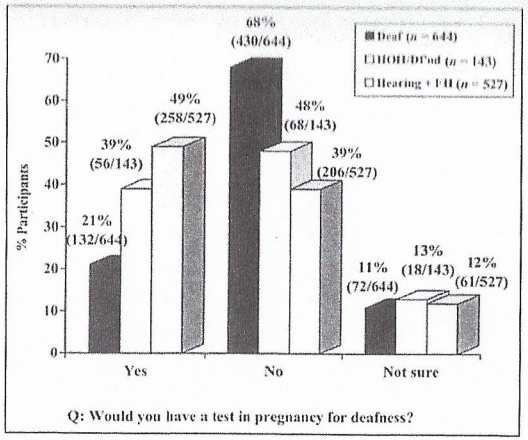

Figure 2. Percentage of participants who were interested in a prenatal genetic test for deafness

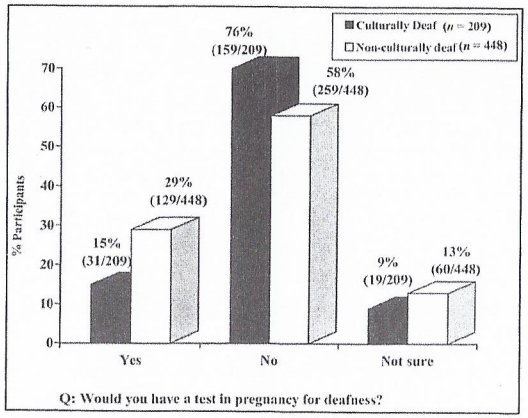

Figure 3. Percentage of culturally Deaf and nonculturally deaf participants who were interested in a prenatal genetic test for deafness

whether their future children were deaf or hearing. For the deaf participants who did mind, 36% said they would rather have hearing children, and 8% said they would rather have deaf children ($\chi^2 = 41.3$, $df = 2$, $P < 0.0001$). Out of the deaf participants who would have a prenatal genetic test and who preferred to have deaf children, the majority (nine out of eleven, i.e., 82%) were culturally Deaf.

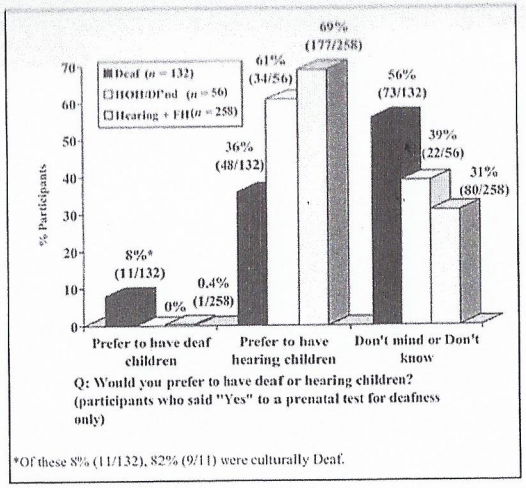

Figure 4. Percentage of participants who wanted prenatal genetic testing and preferred to have a child of a specific hearing status

Reasons for Having Prenatal Genetic Diagnosis for Deafness

Participants were asked to give their reasons for wanting to have prenatal genetic diagnosis. Figure 5 shows that the majority of all groups would only use such testing for preparation—so they could prepare mentally or so that they could prepare for the language needs of the child. The majority would not choose to have an abortion if the fetus was found to have a hearing status the parents did not want. However, a small number of participants (6% deaf, 11% hard of hearing and deafened, 16% hearing) said they would be prepared to consider an abortion if the fetus was deaf; 2% of the deaf participants also said they would consider having an abortion if the fetus was found to be hearing (since they preferred to have deaf children). Of these 2% (three individuals), two were culturally Deaf, and one did not identify with the Deaf community.

Participants were asked to give their comments on abortion for the "wrong" hearing status (be that deaf or hearing depending on what the parents prefer).

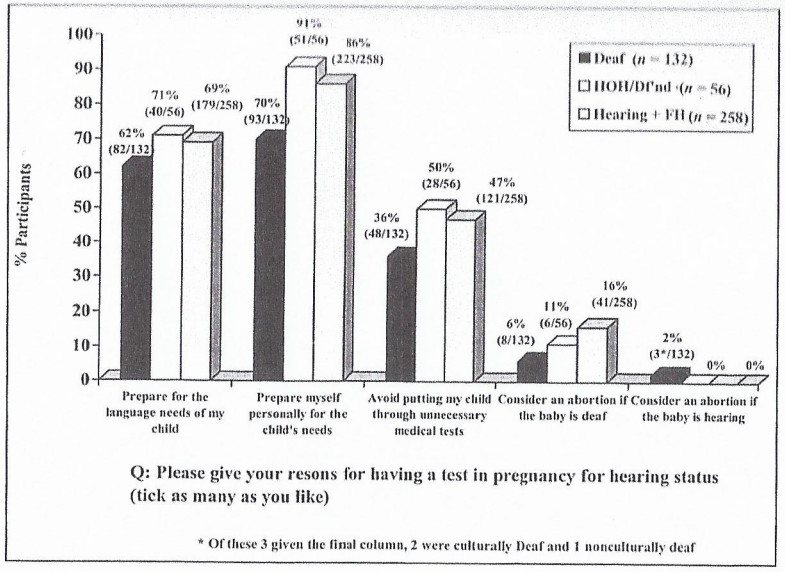

Figure 5. Reasons participants gave for having prenatal genetic testing for hearing status

One participant who would have an abortion for deafness commented:

> I would not wish deafness on my worst enemy. I certainly would not on my own child if it could be avoided.
>
> *A nonculturally deaf participant*

Another participant who would have an abortion for a hearing fetus stated:

> [I would prefer to have deaf children since] I worry that a hearing child would not learn speech and be taken away from me by social services.
>
> *A nonculturally deaf participant*

Participants who would not have an abortion for the "wrong" hearing status made several comments:

> I will be disappointed if I'll have deaf babies, but I'll have to accept it. (Deaf culture will hate me if they read that!)
>
> *A culturally Deaf participant*

> I think it's disgraceful to even consider an abortion of a deaf baby. My hearing friends are horrified.
>
> *A nonculturally deaf participant*

> Attitudes to deafness change once a baby is born. You might agree with having an abortion, but once you have a deaf child, you realize what a positive experience it really is.
>
> *A hearing participant*

> Abortion is a personal issue which differs for every individual, However, I strongly believe that more time and effort should be spent on attempting to integrate deaf people into society instead of being treated as a minority.
>
> *A nonculturally deaf participant*

DISCUSSION

This study documented the attitudes of deaf, hard of hearing, deafened, and hearing participants towards issues surrounding genetics and prenatal genetic testing for deafness.

Hearing participants who had knowledge and experience of deafness through their family history in either their parents or children were more likely (49%) than other groups to feel "hopeful" about new discoveries in genetics and also be interested in having a prenatal genetic test for deafness (compared with 39% hard of hearing and deafened and 21% deaf participants who said they were interested in prenatal genetic testing for deafness). Those hearing, hard of hearing, and deafened participants who were interested in prenatal genetic testing were more likely to prefer to have hearing children. Therefore one could assume that they may choose to end the pregnancy of a deaf fetus. Alternatively, they may accept the baby if it is deaf but might initially be extremely disappointed. They may use the information gained from a prenatal genetic test to prepare themselves for their baby and allow time to come to terms with their situation. Such participants

may have this attitude because they view deafness more from a negative perspective.

Deaf children tend to have more behavioral problems than other children (Meadow 1976), and hearing parents of deaf children can often find it difficult to raise a deaf child (Schum 1991). It is understandable, therefore, that some people with personal experience of deafness may perceive it as a difficult condition with which to cope.

The results from the present study can be compared with findings from other studies that have documented the views of hearing people toward this issue. Brunger et al. (2000) studied the attitudes of 96 hearing parents of deaf children ascertained via a hospital setting. They found that 96% had a positive attitude towards genetic testing, and 87% of these were interested in having prenatal genetic testing for deafness for preparation reasons (none indicated they would have an abortion for deafness).

Another study by Martinez et al. (2003) documented the views of 133 hearing students from a U.S. university that had significant numbers of deaf and hard of hearing students (i.e., these hearing students were therefore familiar with deafness). They found that 64% of hearing students said that they would be interested in having prenatal genetic diagnosis for deafness, with no comment on whether they would have an abortion for deafness. These two papers report a much higher interest in prenatal genetic testing for deafness among hearing people than the present study. Brunger et al. (2000) also reported that there was great naiveté and misunderstanding about genetics and inheritance patterns. It is possible therefore that, although an immediate response was that having a prenatal genetic test for deafness was a preferable option, accurate counseling and information about what the test could offer could reduce the actual numbers wanting the test. Since the study participants for Martinez et al. (2003) were students with no family history of deafness, it could also be argued that the issue of having deaf children and having to contemplate a prenatal genetic test for deafness is not even relevant, and thus responses to this issue may not reflect a true situation. A future study looking at pregnant couples where prenatal genetic testing for deafness is a realistic proposition would offer a useful comparison of results.

Out of all the participants in the present study, deaf participants were the least interested (21%) in having a prenatal genetic test for deafness, and of those deaf participants who were interested, the majority did not identify with Deaf culture. This result is very similar to that found by Stern et al. (2002), who used the same study questionnaire. Here the researchers documented the views of deaf (n = 135), hard of hearing, deafened (n = 166), and hearing individuals (n = 37) ascertained from support groups for deaf people, a genetics clinic, and Gallaudet University. This research showed that approximately 23% of deaf participants were interested in prenatal genetic diagnoses for deafness. Such a low interest in prenatal genetic diagnosis for deafness is likely due to deaf people generally not perceiving a problem with having deaf children themselves, and therefore not being interested in knowing prenatally if their child is likely to be deaf. Deaf parents of deaf children are less likely to have the same problems raising their children as hearing parents (Schum 1991). This may be due to shared language and understanding of what being *deaf* means.

Culturally Deaf participants were the least interested in prenatal genetic testing for deafness and were also the most likely to say they felt "concerned" about new discoveries in genetics. These findings fit in with previous research and show that there may also be less interest in a technology that could potentially reduce the numbers of deaf people born because of the direct effect on the viability of the Deaf community (Middleton et al. 1998).

Current prenatal genetic tests are done via chorionic villus sampling or amniocentesis at approximately eleven to sixteen weeks into the pregnancy, where a needle takes cells from the placenta or amniotic fluid, respectively, to be used for the genetic testing. Both are invasive procedures and confer a risk of miscarriage from the procedure itself. Therefore, it would be useful to know if there is the same interest in prenatal genetic testing when this information is given. Would prospective parents still be interested in testing and accept the risk of miscarriage just to know whether their baby is deaf or hearing before it is born?

Deaf Parents Preferring To Have Deaf Children

Out of the deaf participants who said they would have prenatal genetic testing for deafness, 8% said that they would prefer to have deaf children. This may mean that they would consider using prenatal genetic testing with selective abortion of a hearing fetus. When specifically asked

about this, 2% said that they would consider this course of action. It is not known, however, if faced with a live pregnancy, whether many deaf people would proceed with this. It is also questionable whether geneticists would support the testing and whether obstetricians would perform the abortion. However, three individuals (2%) felt strongly enough on this subject to suggest they would go ahead with such an action.

The issue of deaf parents preferring to have deaf children is not a new phenomenon; it has been well documented in the past. Passing on deafness to the next generation would keep the Deaf culture alive and would mean that the Deaf community would continue to thrive (Jordan 1991; Dolnick 1993; Middleton et al. 1998). Dolnick (1993) comments on this in "Deafness as Culture."

> So strong is the feeling of cultural solidarity that many deaf parents cheer on discovering that their baby is deaf.

Those deaf participants without ties to Deaf culture who nevertheless preferred to have deaf children may have this view because the thought of having hearing children fills them with fear—leading to difficult questions: "How will I cope?" "How will I teach the child to speak?" "What school will they go to?" Schein (1989) suggests that the psychological reaction of a deaf parent to having a child of unexpected hearing status (either deaf or hearing) is very similar to a hearing parent having a deaf child with potential feelings of disbelief, fear, and grief. If deaf parents already had other deaf children, then it is possible that another deaf child would fit into the family unit more successfully, as opposed to a hearing child who may feel isolated. One hearing participant in the present study indicated that she was from a deaf family with several generations of deafness and that she would actually prefer to have deaf children even though she was personally hearing (Middleton 1999). As a hearing person among many generations of deafness, this participant found it hard to cope with being different from the rest of the family.

Abortion for Hearing Status

The research has shown that although there may be interest in having prenatal genetic testing for deafness, the majority of participants would not want to have an abortion for hearing status, be that deaf or hearing. This finding is also supported in other studies done on this subject (Stern et al. 2002; Brunger et al. 2000).

A minority of participants were interested in abortion for hearing status—16% of the hearing participants said they would have an abortion for deafness, and 2% of the deaf participants (three individuals) said they would consider an abortion for a hearing fetus. The figures are very small, but nevertheless still present. Out of the three deaf participants who said they could have an abortion for a hearing fetus, two of them were culturally Deaf. This finding fits in with the Deaf culture stereotype—that deafness is such a positive experience that people may go to extensive lengths to ensure it is passed on. However, when faced with a live, wanted pregnancy, it is debatable whether deaf couples would choose this option. The decision people think they might make may be very different from the decision they actually make when faced with a real situation.

Therefore, it seems that hearing status is not a "condition" that most people feel is "serious" enough to warrant ending a pregnancy. This will be reassuring news for deaf and hearing people who are particularly concerned that the introduction of more genetic testing for deafness will lead to a significant increase in abortion for deafness.

Preimplantation Genetic Diagnosis for Deafness

One alternative to coping with abortion for hearing status could be the use of preimplantation genetic diagnosis when in vitro fertilization is used to create several embryos. These are then tested to see if they have the altered genes for deafness or not, and those that the parents want are selected and transferred back to the mother. There is no need for abortion and the trauma that this may bring since, in theory, the unaffected embryos have already been implanted. However, the current process of IVF itself can be lengthy and the success rate low, so the emotional burden of this should not be underestimated.

Preimplantation genetic diagnosis has already been accepted for hearing parents who would prefer to select deafness out of their future pregnancies. An Australian couple won the right to use preimplantation genetic diagnosis to ensure that their next baby was not deaf; they were both carriers for alterations in the connexin 26 gene (Kelly 2002;

Australasian Bioethics Information 2002). The couple went ahead with this procedure, but to date, it is thought that this was unsuccessful (Noble 2003).

Bioethicists have declared that offering preimplantation genetic diagnosis to enable hearing parents to avoid having deaf children is discriminatory and that deafness is not a valid reason for such selection (Kelly 2002). The Infertility Treatment Authority (ITA) in Melbourne who sanctioned the use of this technology have said it can be available to enable hearing couples to have hearing children, but the same technology would not be available to a deaf couple wanting to have deaf children (Infertility Treatment Authority 2003). This appears to discriminate against potential Deaf couples who may prefer to have deaf children.

Choosing to Have Deaf Children

Deaf couples may want to use genetic technologies to enable them to have deaf children. In 2002, a deaf lesbian couple from the United States chose to have artificial insemination from a male deaf friend with the hope that this would increase their chances of having a deaf child (McLellan 2002). Although not actively using genetic intervention, they hoped that genetic inheritance would be favorable for them, as they wanted to increase the chances of passing deafness on. This case caused international debate about the ethics of deliberately creating what some people felt was a "disabled" child (Levy 2002; Spriggs 2002; McLellan 2002; Fletcher 2002; Anstey 2002; Savulescu 2002). The following are some comments from these articles:

> Couples who select disabled rather than non-disabled offspring should be allowed to make those choices, even though they may be having a child with worse life prospects. (Savulescu 2002)
>
> Couples should not be allowed to select neither for or against deafness. (Anstey 2002)
>
> Deaf people are behaving like hearing people. They feel good about themselves and want to have babies like them. Why should they be morally blamed? (Fletcher 2002)
>
> To intentionally give a child a disability . . . is incredibly selfish. (Ken Connor, president of the Family Research Council, in Spriggs 2002)
>
> Cultures are simply the kind of things to which we are born, and therefore to which the children of deaf parents, hearing or deaf, normally belong. Thus these parents are making a mistake in choosing deafness for their children. Given their own experience of isolation as children, however, it is a mistake which is understandable, and our reaction to them ought to be compassion, not condemnation. (Levy 2002)

There is currently no worldwide consensus of opinion on whether this prenatal testing for deafness with selective abortion for the "wrong" hearing status should be routinely available or not.

Opinions of Genetics Professionals

The American Medical Association (1994) recognises that genetic technology poses dilemmas, in that it is unclear to what extent parents should be able to externally control the genetic makeup of their children. Best practice within today's genetic counseling services is to offer nondirective information about genetics and help clients make fully informed decisions that are right for them. However, if geneticists and genetic counselors are to be truly nondirective, it should be possible for parents to receive prenatal or preimplantation genetic diagnosis for deafness, whether the parents are deaf or hearing, and whether they wish to select either deaf or hearing children. There is currently no policy that determines how far this nondirective approach would be taken with regard to this issue. There seems to be a general view that this would be self-regulating, meaning that deaf or hearing parents would, on the whole, not be interested in using this technology; those that are would be considered on a case-by-case basis.

It is debatable whether geneticists would feel able to offer such testing. In a large international study of genetics professionals, attitudes towards offering prenatal genetic diagnosis to a deaf couple wanting to have deaf children varied across the world (Wertz and Fletcher 1999). The percentage of genetics professionals who said they would perform prenatal genetic diagnosis for a deaf couple wanting to have deaf children ranged from 0% in Norway to 43% in Cuba (9% United Kingdom, 18% Canada, and 35% United States). Those who said they would offer this tended to use the "autonomy" argument—that if this is what

the parents chose, and they were able to make a fully informed autonomous decision, then it would be acceptable to offer the technology to them.

Opinions of the British Deaf Association

The British Deaf Association (BDA) is "the UK's largest national organization run by Deaf people for Deaf people" (BDA website). The BDA has written a policy on genetics (updated in May 2003) that does not comment on prenatal genetic diagnosis for deafness with the intention of having deaf children (i.e., selective abortion for a hearing fetus). However, it does stress concern over the use of prenatal genetic testing with the selective termination of "deaf" pregnancies. In addition, they *demand* that

> all genetic counsellors should receive Deaf awareness training to ensure a clear understanding of the Deaf community and Deaf culture . . . [and that] . . . parents are not formally or informally pressured to take prenatal tests or to undergo termination where it is discovered that the foetus is deaf. (BDA 2003)

Therefore, the BDA advocates choice and informed decision making. They believe that this is not currently in place in the United Kingdom, and in order to rectify this, they want geneticists and genetic counselors to all potential parents of deaf children to present the Deaf culture perspective. With this scenario, hearing parents would receive information about Deaf culture and the community to which deaf people can belong prior to choosing to have prenatal genetic diagnosis and selective abortion for deafness.

CONCLUSIONS

Genetic testing for deafness is a very sensitive issue. Many within the genetics profession assumed that there would be a seamless integration of molecular genetic research into clinical practice and that genetic testing for deafness would be a positive issue for all concerned. There has been surprise and disbelief that not everyone could view this positively. Deaf people may feel devalued by the potential use of genetics (Middleton et al. 1998) and may feel threatened that genetics will in some way interfere with their culture. Since 90% of deaf children are born to hearing parents, the future of the Deaf community is in the hands of the hearing parent. This fact may not sit comfortably with many culturally Deaf people.

In looking to the future, it is clear that deaf people and the organisations that represent them should be involved in any policy decision making about genetics. There is always a greater need for more communication between deaf organisations and the medical profession. As more studies are done to look at how genetics services should be offered to deaf people and their families, a better clinical service will emerge. With regards to improving services for deaf people within the field of clinical genetics, there really is a collective accountability for this:

> while genetic counsellors have the responsibility to learn about the deaf community, . . . they cannot do this alone. There is a shared responsibility to educate each other. Deaf people need to be informed about genetics in order to be advocates for themselves. Geneticists need to be informed about deafness in order to perform their jobs in an ethical way. (Jordan 1991)

It is therefore vital that more research is done in this field and more public debate is initiated so that appropriate and effective services can be developed within the many agencies involved with deaf and hearing individuals and their families. The arguments for and against prenatal genetic diagnosis for deafness evolve with time. As it becomes possible to test for more non-life-threatening conditions, the boundaries of ethical practice will be pushed. Maybe it is time for us as a society to assess how we want to regulate this.

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Genetics, Disability, and Deafness

John Vickrey Van Cleve, Editor

Drawn from the Genetics, Disability and Deafness Conference at Gallaudet University in 2003, this trenchant volume brings together 13 essays from science and the humanities, history and the present, to show the many ways that disability, deafness, and the new genetics can interact and what their interaction means for society.

Pulitzer Prize-winning author Louis Menand begins this wide-ranging volume with an essay that extols diversity and warns of the dangers of modifying the human genome. Nora Groce reviews the ways that societies have defined disability and creates an interpretive framework for discussing the relationship between culture and disability.

In essays devoted to historical perspectives, Brian H. Greenwald comments upon the real "toll" taken by A. G. Bell's insistence upon oralism, while Joseph J. Murray recounts the nineteenth-century debate over whether deaf-deaf marriages should be encouraged. John S. Schuchman's chilling account of deafness and eugenics in the Nazi era adds wrenching reinforcement to the impetus to include disabled people in genetics debates.

Mark Willis offers an intensely personal reflection on the complexities of genetic alteration, addressing both his heart condition and his blindness in surprisingly different ways. Anna Middleton extends Willis's concepts in her discussion of couples currently considering the use of genetic knowledge and technology to select for or against a gene that causes deafness.

In the part on the science of genetics, Orit Dagan, Karen B. Avraham, Kathleen S. Arnos, Arti Pandya clarify the choices presented by genetic engineering and geneticist Walter E. Nance emphasizes the importance of science in offering individuals knowledge from which they can fashion their own decisions. In the concluding section, Christopher Krentz raises moral questions about the ever-continuing search for human perfection, and Michael Bérubé argues that disability should be considered democratically to ensure full participation of disabled people in all decisions that might affect them.

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