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Deaf Community and Genetics

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People who are culturally Deaf have a positive attitude toward being deaf. Typically, they do not wish to be treated or cured of their deafness and may feel threatened that genetic technology could reduce the numbers of deaf people being born.

What is the Deaf Community?

Medical versus cultural model of deafness

Deafness can be viewed from different perspectives. The 'medical model' describes deafness as a medical pathology that requires an intervention or treatment, whereas the 'cultural or sociological model' views deafness as an alternative phenomenon defined by social and group characteristics (Christiansen, 1991).

Culturally Deaf (written with an uppercase 'D') people do not see deafness as a disability; they often have a very positive Deaf identity, feeling they are part of a distinct cultural community sharing common values and history (Padden, 1980).

Sign language

People who are culturally Deaf tend to use a sign language as their first language. Sign languages are often unique languages in their own right, in many instances they are not direct translations from spoken language. Sign languages differ around the world, for example British Sign Language (BSL) is different from American Sign Language (ASL).

Although exact figures are not known, it is thought that in the UK there are at least 70 000 people who use BSL as their first language (British Deaf Association, 2001), this is a major indicator of Deaf cultural identity.

The term deaf (lowercase d) is used in this article to refer to people with any level of hearing loss and who utilize any model of deafness. The term Deaf refers to all deaf people who utilize the cultural model of deafness only.

Deafness and disability

People who utilize the cultural model of deafness often view society as the driving force in making deaf people

disabled; for example, some deaf people cannot use the telephone without special modifications to allow them to do so: these difficulties do not arise because the person is deaf but because society has determined that telephones are mainly accessible to hearing people, thus enforcing discrimination against deaf people.

Not all people with a hearing loss subscribe to the cultural model of deafness. In fact there are many people who feel that their deafness is a real problem and do not have a positive Deaf identity. Such people may prefer to be part of the Hearing World and may also rely heavily on medical technology to give them some level of hearing.

Attitudes Toward Genetic Technology

On the whole, mainstream society views the advancement of genetic science positively if this can result in treatments or cures for serious medical conditions. Many people feel that deafness is a disability and therefore genetic research into deafness is welcomed. The assumption is made that life would be unfulfilling if one was deaf as opposed to hearing. However, culturally Deaf people, in the main, would disagree with this. They often feel that being deaf is not a problem and wish for neither treatment nor cure for themselves. It has been observed that culturally Deaf people have felt threatened by the development and introduction of the cochlear implant or 'bionic ear'. Any technology that aims to restore hearing to a deaf person is usually resisted vigorously by culturally Deaf individuals.

Intermediate article

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Genetic Counseling and Deafness

Culturally Deaf people can sometimes feel distrustful of genetics professionals, because there is the assumption that the purpose of genetic counseling is to cure deafness or stop it being passed on in a family. Many couples will not seek genetic counseling because they fear that they will be advised not to have children (Israel, 1995). Contrary to this expectation this advice would not be given within today's genetic counseling services. Nowadays the focus of genetic counseling for deafness is concerned with offering information (about the deafness in the family, how it is inherited and the chances of passing it on to children etc.) and support to any person who is deaf or has a family history of deafness. This information is given in a nondirective manner, that is, patients are not given advice nor told what they should or should not do. In this context, deaf parents would never be told that they must not have children just because there is a chance they might also be deaf. (See Nondirectiveness.)

Genetic Testing for Deafness

Recently there have been many advances in research into the molecular genetics of deafness. A number of genes causing deafness have been discovered, the result of this is that diagnostic and carrier genetic testing for genes causing deafness are available and can be offered as part of routine clinical practice within genetic counseling services. In theory, prenatal testing for these genes is also possible, therefore a pregnant mother could find out whether the baby she is carrying has the genes for deafness. Thus, there is an option for such a woman to be offered a termination of pregnancy if she decides that she does not want to have a deaf child. Different people will have different attitudes to this. Some feel that deafness is not a serious enough condition to warrant the use of prenatal testing with selective termination of pregnancy. Others feel strongly that they should have a right to use this technology. There are also people who do not agree with prenatal testing or termination of pregnancy for any reason.

Prenatal testing for deafness

It has been reported that prenatal testing for deafness provokes much fear among culturally Deaf people. In studies documenting the attitudes of many different people affected by deafness, culturally Deaf participants said they felt the use of genetic testing would do more harm than good and would devalue Deaf people

(Middleton *et al.*, 1998). Most culturally Deaf people surveyed said they had negative views about new discoveries in genetics and most said they would not use prenatal testing for deafness (Middleton *et al.*, 2001). There is a real fear that genetic technology could genuinely reduce the numbers of deaf children being born, thus having a direct effect on the viability of the Deaf community. This fear of genetic research is deep-rooted in Deaf culture; one possible source of this fear is attributed to history – in the past some D/deaf people have been mistreated in the name of eugenics (Bahan, 1989).

Impact of prenatal testing on the Deaf community

Deafness can arise as a result of different factors, genetics is only one of these. It is likely that there will always be environmental causes of deafness and so there will always be deaf people in society. At present there are no effective treatments or cures for deafness that can restore hearing completely. However, it is possible that at some point in the future these will exist. The only realistic way that genetic technology could have an effect on the numbers of deaf children being born at the moment would be if all pregnant women used prenatal testing for deafness with selective termination of pregnancy for deaf fetuses.

Research undertaken in the UK has shown that although most hearing parents of deaf children would prefer to have hearing children, most of them are not interested in having a test in pregnancy for deafness (Middleton *et al.*, 2001). Of those that would have such a test, only a very small number have reported that they would consider having a termination of pregnancy for deafness. Therefore, it is unlikely that in society today the Deaf community could be reduced as a consequence of the use of prenatal diagnosis and selective termination of pregnancy.

Ninety per cent of deaf children are born to hearing parents. This statistic creates a sense of unease within the Deaf community, because the result of genetic inheritance means that the future of Deaf people is in the hands of the hearing parent. It is thought that it is this fact that lies at the heart of the fear among the culturally Deaf.

Preference for having deaf children

It has been observed that some deaf people have said that they would prefer to have deaf children. Such people may come from Deaf families or have more than one deaf child already. Another deaf child would fit in with their family unit and would continue the Deaf cultural heritage. A small number of culturally

Deaf people have reported that they would consider using genetic technology to allow them to have deaf children, that is, they may consider having a prenatal test with termination of pregnancy for a hearing fetus (Middleton *et al.*, 2001). There are many varying perspectives on this issue and it is a sensitive subject that often stimulates lively debate.

Attitudes of professionals

There are some difficult ethical issues for geneticists and genetic counselors today. Should prenatal testing for deafness be available as part of routine clinical practice and is deafness a serious enough condition to warrant a termination of pregnancy? If termination of pregnancy for deafness is deemed acceptable, then termination of pregnancy for 'hearingness' should be considered, that is, for when deaf parents prefer to have deaf children. Some people are resistant to this possibility, because it questions our ideas of what is normal. However, to many Deaf people being deaf is the norm and hearing abnormal.

Genetics professionals may find themselves in untenable positions if they subscribe to the model of nondirective genetic counseling. If a Deaf person requests prenatal testing for deafness with the intention of having a termination of pregnancy if the fetus has not inherited deafness, then the geneticist would allow the Deaf person to do this if they subscribed to being truly nondirective and respecting patient autonomy. However, if genetics professionals are uncomfortable offering prenatal testing for indications such as deafness, the wrong sex or a treatable physical defect, then they may come under criticism for denying individuals access to services or options that they may feel they have a right to use. This should be open to wider debate and requires serious consideration of many issues. As yet, within the international genetics community, there is no consensus of opinion.

See also

Deafness: Hereditary

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Web Links

- Hereditary Hearing Loss home page
<http://www.uia.ac.be/dnalab/hhh/main.html>