

Deaf Community and Genetics

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Based in part on the previous version of this eLS article 'Deaf Community and Genetics' (2006) by Anna Middleton.

Advanced article

Article Contents

- What is the Deaf Community?
- Deafness as Disability
- Deaf Communication Awareness
- Genetic Counselling and Deafness
- Genetic Testing for Deafness
- Human Fertilisation and Embryology Bill in the UK
- Acknowledgements

Online posting date: 15th January 2013

The Deaf community consists of a group of like minded people sharing a common sign language and culture. This community has a positive attitude toward being deaf. Typically, deafness is considered a strong part of linguistic and cultural identity and Deaf individuals do not wish to have treatments or a cure. Deaf people have concerns that a hearing society, with little knowledge or experience of their rich culture and language, would encourage the use of pre-implantation genetic diagnosis and prenatal genetic testing for deafness with the ultimate aim of having hearing children. They feel strongly that deafness is a source of human variation that does not warrant the use of genetic technology in this way. Deaf (written with an uppercase 'D') refers to people who belong to the Deaf community. Deaf people use sign language (e.g. British Sign Language, American Sign Language, Auslan, etc.) as their first or preferred language. They also have a positive identity attached to being Deaf. People who consider themselves deaf (written with a lowercase 'd') or hard of hearing tend to use speech as their preferred form of communication, and may experience being deaf as a medical disability that needs to be treated. These groups often have very differing attitudes towards the use of genetic technology.

What is the Deaf Community?

Medical versus cultural model of deafness

Deaf culture can be viewed from different perspectives. The 'medical model' describes being deaf by the term 'deafness'

eLS subject area: Bioethics & Philosophy

How to cite:

Middleton, Anna; Emery, Steve; Palmer, Christina; and Boudreault, Patrick (January 2013) Deaf Community and Genetics. In: eLS. John Wiley & Sons, Ltd: Chichester.
DOI: 10.1002/9780470015902.a0005875.pub2

and treats it as a medical pathology that requires an intervention or treatment, whereas the 'cultural or sociological model' refrains from using the term 'deafness' and views Deaf persons as members of a community defined by social and group characteristics (Christiansen, 1991; Ladd, 2003; Padden and Humphries, 2005).

Deaf people do not see being deaf 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; Ladd, 2003). Individuals who are Deaf tend to use a sign language as their first or preferred language, and feel part of Deaf culture. Signed languages are unique languages in their own right; they are not direct translations from spoken language. Signed languages differ around the world, for example, British Sign Language (BSL) is different from American Sign Language (ASL). Although exact figures are not known as yet (although the 2011 Census in the UK will offer some insight into this), it is thought that in the UK there are somewhere between 50 000 and 70 000 people who use BSL as their first language (British Deaf Association, 2001; Department of Work and Pensions, 2002). It is estimated that 0.38–0.41% of the US population is deaf or hard of hearing. When considering individuals who use ASL as either their primary or secondary language, ASL is one of the most frequently used languages in the US after English and Spanish (Mitchell *et al.*, 2006). Use of a signed language is a major indicator of Deaf cultural identity.

Cultural identity is a complex phenomenon. Many Deaf people are bilingual because they use a signed language and a written language (Grosjean, 2008). Culture and language are strongly correlated and the mastery of two languages would lead to bicultural identity, that is, an affinity with both the Deaf and Hearing Worlds. These individuals may also be described as Bi-Bi (bilingual and bicultural).

It is interesting to note that sometimes the same terms used to describe deaf and hard of hearing people have different meanings around the world. For example, in the UK, people who call themselves 'hard of hearing' tend to be those who started hearing and then became 'hearing impaired' over time ('hearing impairment' is a medical term that doesn't tend to be used by Deaf people themselves as it has a negative connotation to it – being 'impaired' or defective). In

the US, 'hard of hearing' is a term used to describe someone who has a congenital hearing loss but who wouldn't consider themselves deaf (e.g. 'profoundly deaf') or Deaf; this terminology is also sometimes used in the UK too. Hard of hearing people may wear a hearing aid and often use speech, lip reading and the written form to communicate. Generally, those who subscribe to the medical model perceive their being deaf as a disability, as a loss and feel part of Hearing culture rather than Deaf culture.

'Deafened' people tend to be those who started out hearing but then developed a profound hearing loss, which may or may not have occurred suddenly via an accident or a tumour. Deafened people often feel very disabled by this loss and will utilise lipreading and the written form to communicate. They may gain little use from a hearing aid but a cochlear implant may be beneficial in some cases.

The term 'deaf (with a lower case 'd') is often used to define the audiologic feature of not hearing. It may also be used by some people to mean a 'profound' deafness. In addition, people who deem themselves as having a hearing loss (or possibly a profound deafness), and may identify themselves as deaf, hard of hearing or deafened, usually prefer to communicate using speech, the written word, lip reading, hearing aids, technology and other forms of communication. Some deaf people may also be proficient in sign language.

Deafness as Disability

People who utilise the social model often view society as the driving force in making Deaf people disabled regardless of their language and culture; for example, difficulties do not arise because the person is Deaf but because society has determined that sound-driven telecommunication technologies are mainly accessible to hearing people, thus enforcing communication barriers and discrimination toward Deaf people.

Not all people with a hearing loss subscribe to the cultural model. In fact there are many people who feel that being deaf is a real problem and as such 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.

Deaf Communication Awareness

'Deaf communication awareness' is aimed at increasing and reinforcing effective communication between hearing and deaf people. Such 'deaf communication awareness' is often lacking and depending on the geographic location, there may be courses and training that hearing people can take, for example, through their employment, so that they can better communicate and work with D/deaf customers, employees, people in society. Such awareness training teaches people that a D/deaf person will often rely heavily on facial expressions and clear lip patterns to follow a conversation, it is thus unhelpful to shout to get a message

across, this is both ineffectual and also culturally insensitive. Also, shouting exaggerates lip patterns and makes lip reading more difficult. Written notes may be helpful for a hard of hearing person but may be less helpful for a sign language user whose first language is sign language rather than written or spoken language. The best tactic is to ask the D/deaf person how best to communicate with them rather than making assumptions about this.

Genetic Counselling and Deafness

Intuitively, many would agree that mainstream society views the advancement of genetic science positively if this can result in treatments or cures for serious medical conditions, for example, cancers and heart disease. Many health professionals who classify deafness as disability (Stephens and Danermark, 2005) make it easy to justify that genetic research into deaf genes, or deafness, should be welcomed. However, 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.

There is evidence to suggest that members of the Deaf community can sometimes feel sceptical of genetics professionals, because there is the assumption that the purpose of genetic counselling is to cure deafness or stop it being passed on in a family (Middleton *et al.*, 2010). Many couples will not seek genetic counselling because they are apprehensive that they will be advised not to have children (Israel, 1995; Middleton *et al.*, 2010). Contrary to this expectation today's genetic counselling services are not directed to give this information. Nowadays the focus of genetic counselling for deafness is concerned with offering information (about the deafness in the family, how it is inherited, the chances of passing it on to children, the risk and benefits of genetic testing, etc.) and support to any person who is D/deaf or has a family history of carrying a deaf gene (Baldwin *et al.*, 2012). In many countries, this information is given in a nondirective manner, that is, patients are not to be given advice nor told what they should or should not do. In this context, deaf parents should never be told that they must not have children just because there is a chance they might also be deaf. When given accurate and linguistically culturally sensitive information about what genetic counselling involves (and perhaps more importantly, what it does not involve), Deaf people are interested in finding out more about the causes of their deafness or are interested in attending genetic counselling for conditions completely unrelated to their deafness (Middleton *et al.*, 2010; Boudreault *et al.*, 2010). **See also:** Deafness: Hereditary; Genetic Counseling: Nondirectiveness

Genetic Testing for Deafness

Over the past 20 years there have been rapid advances in research into the molecular genetics of deafness. Hundreds of

genes causing deafness have been discovered (Van Camp and Smith, 2011), and 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. Ideally this would be within genetic counselling services with appropriate cultural sensitivity training to serve deaf and hard of hearing individuals. Diagnostic genetic testing is used to provide an explanation to a deaf/hard of hearing child or adult why they are deaf. Diagnostic genetic testing can also be used to learn about the genetic makeup of future children. Prenatal genetic testing is possible, therefore a pregnant woman and her partner could find out whether the baby has genetic variants for deafness or none. Thus, there is an option for parents to make a decision about termination of pregnancy if they decide that they do not want to raise a deaf (or hearing) child. Preimplantation genetic diagnosis for deafness is technically possible, with the option to select, for example, embryos with genetic variants for hearing (or deafness) for implantation into the uterus. There are very strong views about these technologies with some arguing that selecting for hearing is eugenic (Emery *et al.*, 2010) and others arguing that selecting for deafness is dysgenic (Nunes, 2006). Different people will have different attitudes to this. Some feel that deafness is a non-medical condition (Robertson, 2003) or that deafness/hearing represents variation in a human trait and in either case that it does not warrant the use of prenatal testing with selective termination of pregnancy (Mand *et al.*, 2009). Others feel strongly that they should have a right to use this technology for their individual preferences. 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 controversy in the Deaf community. When asked for their views, Deaf participants said they felt the use of genetic testing would do more harm than good, that is, have a negative effect on the Deaf community, and would devalue Deaf people (Middleton *et al.*, 1998; Martinez *et al.*, 2003; Stern *et al.*, 2002). Most Deaf people surveyed were not positive about new discoveries in genetics and most said they would not use prenatal testing for deafness (Middleton *et al.*, 2001). There is a real concern that genetic technology could genuinely reduce the numbers of deaf children being born, thus having a direct effect on the sustainability of the Deaf community. One possible source of this unease of genetic research is attributed to history – in the past D/deaf people have been mistreated in the name of eugenics (Bahan, 1989; Schuchman, 2004).

Impact of prenatal testing on the Deaf community

Being deaf can arise as a result of different factors, genetics is only one of these. It is likely that there will always be environmental causes, newly arising genetic causes, and people who do not use genetic technology for diagnostic

purposes, and so there will always be D/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 (Wang *et al.*, 2007; Pfister and Lalwani, 2007; Euteneuer and Ryan, 2007).

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 or all couples used preimplantation genetic diagnosis for deafness with selective termination of pregnancy for deaf fetuses or selective implantation of hearing fetuses, respectively.

Research undertaken in the UK, US and Israel has shown that although most hearing parents of deaf children would prefer to have hearing children, the percentage who indicated an interest in having a test in pregnancy for deafness can vary from very small to nearly half of the sample (e.g. Brunger *et al.*, 2000; Middleton *et al.*, 2001; Dagan *et al.*, 2002). Interest in prenatal diagnosis can be higher among parents who have a child with a known genetic type of deafness, for example, Connexin 26 deafness, compared to parents who have a child with an unexplained deafness (Palmer *et al.*, 2009). More importantly of those who would have such a test, typically only a very small number (e.g. 14/188, or 7% in Middleton *et al.*, 2001) reported that they would consider having a termination of pregnancy for deafness, though the percentage can be higher in some studies (e.g. Dagan *et al.*, 2002). The more commonly reported reason for prenatal genetic testing is to reduce parental uncertainty and to prepare for the needs of a deaf/hard of hearing child (Burton *et al.*, 2006; Dagan *et al.*, 2002). There is also evidence from the US that genetic counsellors are less comfortable offering genetic testing in situations involving prenatal testing for hearing status compared with situations involving paediatric genetic testing (Enns *et al.*, 2010), suggesting that genetic counsellors may see deafness as a condition where prenatal diagnosis is not necessary because it is not a life-threatening trait. Therefore, research demonstrates it is unlikely that in society today the Deaf community could be significantly reduced as a consequence of the use of prenatal diagnosis and selective termination of fetuses with deaf genes.

Ninety per cent of deaf children are born to hearing parents (Ladd, 2003). This statistic means that if genetic testing is left to the choice of the individual, the future of the Deaf community could be in the hands of the individual hearing parent together with the, most likely, hearing professional with no or very little knowledge of the Deaf community perspective. It is thought that this fact is at the heart of Deaf community fears; and is why they are keen for more consultation about genetic research.

Preference for having deaf children

It has been observed that some Deaf individuals have said that they would prefer to have deaf children (Hoffmeister, 1985; Dolnick, 1993; Middleton *et al.*, 1998; Martinez *et al.*,

2003; Stern *et al.*, 2002). Such individuals 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 linguistic and cultural heritage. Because a small number of 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; Stern *et al.*, 2002), there has been a lively debate about the ethics of this (Levy, 2002; Murphy, 2009). There are many varying perspectives on this issue, and it is the choice to have, what some might perceive, a 'disabled' child that challenges people to think about 'what is normal'. For many Deaf people, being Deaf is entirely.

Human Fertilisation and Embryology Bill in the UK

In 2008, the Human Fertilisation and Embryology Bill was being revised by Parliament in the United Kingdom. Clause 14 referred to the technology of preimplantation genetic diagnosis (PGD) and in the explanatory notes to the Bill, deafness was cited as an example of a 'serious condition' which the clause would prevent preimplantation genetic diagnosis being used to select for. This caused absolute outrage amongst, not only the British and World Deaf community but also amongst many hearing people worldwide. The point being that the UK government wished to make it law that if a couple were having PGD for deafness and they had a selection of embryos, some which had the genes for deafness and some which had the genes for hearing, then there would become a legal decision to only implant the embryos with the genes for hearing. There would also be legal restrictions on the use of D/deaf egg/sperm donors who are known to carry a deaf gene. The outcome would be that an inequality would be created in law between the status of the 'deaf' versus the 'hearing' donor or embryo (Emery *et al.*, 2010). Representatives from the British Deaf community together with representatives from the genetic counselling community challenged the Department of Health to change the wording of this Bill (Emery *et al.*, 2008). They were successful in that any reference to 'deafness' was removed from the explanatory notes and thus deafness would no longer be referred to as a 'serious' condition, specifically singled out as a condition that could be selected against but not selected for. However, irrespective of the explanatory notes, the Bill was passed and is now an Act of law. This means that, when faced with a selection of embryos, some with a 'serious' condition and others without the same condition, the couple would have to only implant the embryos without the condition. The interpretation of the word 'serious' is very subjective and open to clinical biases (Robertson, 2003), thus it is still feasible that an IVF clinic would feel very uncomfortable allowing a Deaf couple to select to implant

embryos with the genes for deafness for fear of potential investigation by the Human Embryology Authority (this body is being reformed at the moment and thus the name may change). In addition to this an IVF clinic would not be able to offer donor eggs or sperm from a person with a 'serious' disability. Again, due to the subjective nature of the term 'serious', it is possible that a D/deaf donor would be declined the opportunity to donate gametes for IVF, including possibly to close family or friends.

Although this discussion is specific to the UK, it underscores the concerns of the worldwide Deaf communities that genetic technologies can be used against their communities when coupled with the medical perspective on what it means to be deaf.

Attitudes of professionals

There are some difficult ethical issues for geneticists and genetic counsellors to contend with when thinking about the application of genetic technology to individual families with strongly held views. 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 so, would it be considered a form of linguistic and cultural genocide of a minority group (Nance, 2003) and thus in keeping with previously banished eugenic practices of the past? If termination of pregnancy for deafness is deemed acceptable, then termination of pregnancy for 'hearingness' also should be considered, that is, for when deaf parents prefer to have deaf children. Some people are resistant to this possibility, because it questions their ideas of what is normal. However, to many Deaf people, being deaf is a very normal form of being (Ladd, 2003); a hearing person, with no knowledge nor experience of the Deaf community is simply an outsider.

Genetics professionals may find themselves in untenable positions if they subscribe to the model of nondirective genetic counselling. 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 (Note: this also relies on the attending obstetrician satisfying themselves that the situation could be justified under the Abortion Act). However, the genetics professional may feel uncomfortable offering prenatal testing at all for indications such as deafness, or a treatable physical defect. And yet, if they acted on this unease and refused access to services then they may come under criticism for being directive and paternalistic. This should be open to wider debate and requires serious consideration of many issues; in addition to this the views of the obstetric profession are pivotal as without their cooperation an actual termination of pregnancy would not even be possible. As yet, within the international genetics and obstetric community, there is no consensus of opinion. In addition to this issue, we need to look after the human rights of

linguistic and cultural minority groups to reconsider the definition of being different and part of the human diversity.

Acknowledgements

Dr Anna Middleton works for the DDD study (www.ddduk.org, www.genomethics.org) which is funded by an award from the Health Innovation Challenge Fund and the Wellcome Trust Sanger Institute. Dr Anna Middleton and Dr Christina Palmer would like to acknowledge the support of the Brocher Foundation, Geneva, Switzerland (www.brocher.ch) who awarded both professionals a visiting researcher scholarship. Dr Steven Emery would like to acknowledge the support of the Leverhulme Trust. Dr Christina Palmer and Dr Patrick Boudreault would like to acknowledge the support of the National Human Genome Research Institute (Ethical, Legal and Social Issues Branch) (R01 HG003871) and the National Cancer Institute (R25 CA154290). Finally, all four authors thank the D/deaf community because this manuscript would not have been possible without their willingness to express their views.

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Web Links

- Deafhood and genetics: <http://www.deafhoodgenetics.com/>
- Hereditary Hearing Loss home page: <http://hereditaryhearingloss.org/>
- Overview of various BSL publications: <http://www.bsuptake.org.uk/category/dr-steve-emery/>
- University of Manchester, information about genetic counselling in BSL: <http://sites.mhs.manchester.ac.uk/what-is-genetic-counselling>