

MEDICAL ADVANCEMENTS IN GENETICS AND INTERVENTIONS TO PREVENT OR REDUCE HEARING LOSS

National Deaf Children's Society position statement

Last updated: 26th September 2024

1. Summary

- 1.1 Medical advances in our understanding of genetics and the role different genes play in deafness are happening at a rapid pace.
- 1.2 At the same time, research is giving us a greater understanding of how deafness could be lessened or even eliminated for some children, leading to the development of clinical trials for gene therapy that aim to reduce hearing loss for some deaf children.
- 1.3 We recognise the rights of families with deaf children and potential parents from families who have a history of deafness to take advantage of the various medical interventions or genetic technologies and to use the results of any medical/genetic tests in a way that suits the individual family.
- 1.4 It is important that families receive balanced and clear information about deafness, medical interventions and genetic technologies to enable them to make an informed choice. This includes all information relating to both benefits and risks. It is also important that professionals act with care and sensitivity in how they engage with families on this issue and in the language they use to refer to deafness and medical interventions.
- 1.5 We will continue to campaign for a world in which families' different choices can be realised in a way that works for them. We will also continue to campaign for a world in which childhood deafness is not stigmatised and deaf children are viewed as individuals who have all the opportunities that are available to hearing people to develop and maximise their skills and abilities.
- 1.6 We support all families to make choices that work well for their family on medical interventions and deafness¹. It is for families and deaf children/young people to own their experiences of deafness, and no family or deaf child/young person should be made to feel anything less than positive about the choices they make around deafness.

2. Our position

- 2.1 This position statement is underpinned by our vision and values:

¹ There may be occasions in which there are ethical considerations involving potential risk or harm, where a family's preferences may be at odds with the child's rights and assessed needs. The welfare of the child remains paramount but in the vast majority of cases we believe parents are best placed to make that judgement based on all the information available.

- a. Deaf children can do anything other children can do, given the right support from the start.
- b. Effective language and communication skills lie at the heart of deaf children and young people's social, emotional and intellectual development.
- c. Families are the most important influence on deaf children and young people, and need clear, balanced information to make informed choices.
- d. Deaf children should be involved in decisions which affect them as early as possible.
- e. Deaf children should be valued by society and have the same opportunities as any other child.

2.2 We believe families are best placed to make decisions about medical interventions. This includes deaf children and young people themselves being involved and supported in any decision-making. Families should be provided with clear and balanced information to enable them to make informed choices. We support all families to make choices that work best for them on medical interventions and deafness. It is for families to own their experiences of deafness, and no family or deaf child should be made to feel anything less than positive about the choices they make around deafness.

We expect children and young people to be fully involved in decision-making about interventions as appropriate for their age and mental capacity. This means information being age-appropriate to support children and young people to make their own informed choices. We expect 'Gillick competence' principles to apply with regards to children providing consent for their own treatment².

2.3 We believe deafness should not be regarded as an illness or a life-threatening or life limiting condition. The social model of disability asserts that deafness in itself is not a disability, but the way society responds to it does disable people. For this reason, we believe that it is important that professionals act with care and sensitivity in how they engage with families and in the language that they use.

2.4 Our policy on inclusion states that we believe that inclusive practice arises from a philosophy which views diversity of strengths, abilities and needs as natural and desirable, bringing to any community the opportunity to respond in ways which lead to learning and growth for the whole community, and giving each and every member a valued role.

2.5 We welcome all medical discoveries that give us a better understanding of deafness, empower individuals by giving them choices and enhance the potential of deaf children and young people and their families to lead lives which are as rich and varied as possible.

2.6 We also welcome any research into medical interventions that may prevent hearing loss happening or reduce existing hearing loss, allowing parents a way to mitigate the impact on their deaf child's social and educational development. We recognise that if any form of intervention does become available in the future the resulting improvement in access to sound could possibly be more permanent than that afforded by cochlear implants or hearing aids.

² 'Gillick competence' refers to a legal precedence where young people, under 16, with capacity, can make decisions about their healthcare. Its name originates from a 1985 court ruling.

- 2.7 We believe that the prospect of future medical developments in deafness should not detract from the support that deaf children presently need. We will continue to campaign for health, education and social care services to provide the support that deaf children need to achieve their potential.

Genetic counselling and testing

- 2.8 There are many factors that may result in deafness and only about half of the causes of deafness can be attributed to genetic factors. Until recently only a few genes known to cause deafness were routinely tested for, meaning that even if genetic testing was carried out the responsible gene may not have been identified. Through NHS genomic services, families who have a child with severe to profound bilateral deafness may be offered 'whole genome sequencing' (WGS). This is more likely to be able to locate a 'responsible gene' meaning that more families will get information about the cause of their child's deafness. We welcome the rapid advances in our understanding of the genetics of deafness, but stress that the wider implications of all genetic testing are extremely complex, families must be given clear information about the potential implications of such testing, and the data collected must be treated with the utmost sensitivity and care.
- 2.9 Genetic testing and counselling services should be offered to deaf children and young people and their parents where it is wanted and considered to be appropriate in providing knowledge of benefit to either the child or the family.
- 2.10 Before and after testing it is vital that families have access to clear and accessible information on what is being tested and what the results mean for them. Families should also be signposted to balanced and impartial information such as our website pages on genetics: www.ndcs.org.uk/information-and-support/childhood-deafness/causes-of-deafness/genetics/ Families should be made aware of the limitations of genetic testing and that when results come through they may not provide full clarity as to the cause of a child or young person's deafness.
- 2.11 It is important that services for families are fully accessible to deaf parents and young people who have sign language as their first language.
- 2.12 We support the development of research and services that:
- a. enables the early identification of disabilities or health conditions that may, at some point in childhood, co-exist with deafness so that appropriate monitoring, intervention plans and services can be put in place
 - b. identifies the vulnerability of a child to medication that, if administered, will create hearing loss or exacerbate the degree of hearing loss.

Genetic screening

- 2.13 We do not support whole-population genomic screening of adults for genetic conditions, with the consequent risk of moving towards a society in which deafness is no longer accepted or tolerated.

Prenatal genetic testing

- 2.14 We acknowledge that some parents, whether deaf or hearing, choose to undergo prenatal genetic testing to prepare for the child's future, while others may consider a termination of the pregnancy. It is important that parents are aware of any risks involved in such testing and receive good quality, balanced information about deafness. It is not our role to express an opinion about the way in which an individual chooses to use the information, but fundamental messages that we will continue to promote include:
- a. deaf children and people can make a positive contribution to society and do have happy and rewarding lives
 - b. if appropriate support is provided to the family and child and positive attitudes are fostered, there is no reason why deaf children should not achieve at the same level as hearing children.

In vitro fertilisation and pre-implantation genetic diagnosis

- 2.15 Pre-implantation genetic diagnosis (PGD) is available for couples who have a chance of passing on specific genes including several which cause deafness. IVF techniques are used to produce embryos, but with the additional step a few cells are removed from each embryo and tested to see whether or not that embryo has inherited a particular gene or not. This allows selection of which embryos will be placed in the uterus. The law prevents families from using PGD to select embryos with an 'abnormality' that will develop into a 'serious physical or mental disability'.
- 2.16 We acknowledge that some families with a history of deafness may wish to use this type of technology in planning their family. Some may wish to reduce the risk of passing on particular genes. A small number of families, particularly from within the Deaf community, may seek to increase the chances of bringing another deaf child into their family if they were undergoing IVF.
- 2.17 It is not our role to express an opinion on the way society decides to make use of preimplantation genetic diagnosis. As per pre-natal genetic testing, we believe it is important parents are aware of any risks involved and receive good quality balanced information about deafness if families are considering undergoing screening.

Stem cell and gene therapies

- 2.18 There are significant research developments into how stem cell and gene therapies can be used to prevent or reduce hearing loss. We recognise that many families will seek opportunities to increase their child's hearing to mitigate the impact on their social and educational development. Where clinically appropriate, we will support families to secure access to any such interventions.
- 2.19 It is not our role to express an opinion about the way in which stem cells are used or in how these therapies are developed.
- 2.20 It is important that families and deaf children/young people are given clear and balanced information about any benefits and risks involved in any intervention, particularly if they

are undergoing any clinical trials. Information should be tailored to the needs of the child, recognising that medical interventions available may depend on the type of deafness that children have and/or on any interventions they have already received (such as cochlear implantation). If families or deaf young people seek a medical intervention abroad, they should ensure they have comprehensive information on standards for clinical trials and interventions in that country.

- 2.21 It is important that services anticipate the needs of deaf children and young people following any interventions. Deaf children and young people may still experience delays in their language and communication. In addition, some deaf young people and their families may need counselling and emotional support to help them come to terms with the impact of the medical intervention.