

Dear Sir / Madam

## **Draft Response to Human Fertilisation and Embryology Bill**

The identification of genes associated with deafness and other technology now makes it possible to screen for the presence of those genes. The proposed uses of this technology raise several questions about the moral permissibility of genetic screening. Given the potential effect of genetic screening on deaf people and potential deaf people, we wish to issue a public statement.

We would like to address the proposed change to the Human Fertilisation and Embryology Bill in Clause 14, section 4, number 9 (Lines 23-30, Page 10), which states:

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.

We oppose the language and intent of the above proposed text for the following reasons:

1. It restricts the reproductive liberty for a citizens who possess specific characteristics, including deaf people
2. It prevents the birth of certain kinds of people, including, but not limited to deaf people

The issues raised in Clause 14, Section 4, Number 9 can be classified into two broad ethical concerns that affect the basic human rights of many citizens:

Who is not permitted to reproduce?

Who is prevented from coming into existence?

### **Who is not permitted to reproduce?**

Under the language of the proposed bill, deaf people are defined as having a serious physical disability, and thus fall under “persons...that are known to have a gene, chromosome or mitochondrion abnormality involving a significant risk that the person will have a serious physical...disability...must not be preferred to those who are not known to have such an abnormality”.

The language of this clause implies at least two potential classes of actions violating the fundamental human right of deaf persons to reproduce, for example, Article’s 12 and 14 of the Convention of the Human Rights 1998 Act. This is particularly relevant to deaf parents. The Act protects the rights of deaf parents not to be discriminated against. For example, a deaf couple should not be told they couldn’t have children because

they might pass deafness on. They must also not be told to end a pregnancy if there is a chance their baby might be deaf. Deaf couples also obviously have a right to fertility treatment.

- 1. Deaf people whose genes are associated with deafness will be prohibited from becoming gamete donors.** Imagine an infertile couple wishing to bear a child that is biologically related to both of them; the male is fertile, but the female does not possess any viable eggs. The female's only living female relative offers to donate gamete(s) and her offer is rejected because of her genetic deafness, making it impossible for this couple to have a child genetically related to both of them. The couple is denied the opportunity to bear a biologically related child because of the female relative's genetic deafness.

A related issue is that the language of this bill effectively prevents all people who hold carrier status for any genetically identifiable serious physical or mental disability, illness, or other serious medical condition would be prohibited from becoming gamete donors. There are currently more than 1300 conditions for which genetic tests are clinically available, several hundred genetic screening tests used in research and even more in various stages of development – the language of this clause makes it highly likely that a significant number of citizens will not be permitted to donate gametes.

- 2. Deaf people seeking fertility treatment will be denied access to these services if they possess genetic conditions that result only in the formation of embryos associated with deafness.** Consider the infertile deaf couple desiring to have a child. Before fertility testing commences, genetic testing is conducted on the couple, and results indicate that all of their offspring will be deaf. The infertile couple's request for fertility services is denied for the reason that embryos associated with genetic deafness are not preferred. Thus, the couple is denied the opportunity to have *any* children based on the stated preference against "abnormality". In another possible scenario, a deaf couple has one deaf child, conceived through IVF several years ago, who is currently in need of a bone marrow transplant due to illness unrelated to her deafness. The child is quite ill, and her best chances of survival will come from marrow donated by a well matched donor, such as a sibling. The parents hope to save their existing child's life by conceiving another child through IVF, using PGD to select embryo with the best bone marrow match for their existing child. Since the parents can only have deaf children, and the law prohibits access to fertility services on the basis of genetic deafness, the couple is not only denied fertility services, but denied the opportunity to pursue the strategy offering the best chance of survival for their remaining child.

### **Who is prevented from existing?**

Parents who select an embryo on the basis of a physical characteristic, such as sex selection for family balancing or perfect musical pitch are commonly viewed as having gone down the morally suspect route of designing babies. Yet genetic selection to prevent disability can be viewed as a morally commendable choice, especially if the embryo(s) not selected would have resulted in the birth of a child dealing with intractable pain and suffering.

Motivations for prohibiting genetic selection should be carefully evaluated for eugenic bias preferring certain physical characteristics. It is assumed that one motivation for prohibiting genetic selection of certain genotypes is to reduce harm and/or suffering. Another motivation for genetic selection may be to reduce the economic costs related to creating an inclusive society that values all kinds of people. Both of these reasons are flawed. In almost all cases, the "benefit" of existence outweighs the "harm" of disability. Establishing social expectations that discourage the birth of citizens with a diversity of physical characteristics can result in negative social attitudes towards those born with these physical characteristics and their parents– this is well documented against families with young children born with Down Syndrome. Widespread prenatal (nongenetic) testing strongly correlates to the plummeting birth rate of children with Down Syndrome over the past decade, despite the increased birthrate for older mothers, who have a higher chance of having a child with Down Syndrome.

1. **Impact of genetic screening and selection against deafness and the negative effect on the remaining population of deaf people.** By codifying into law a preference for selecting embryos that are genetically associated with hearing, potential deaf people who would have otherwise been born will not have an opportunity to exist. Over time this is likely to bring about a less diverse society, including the potential for the decline or demise of BSL. Smaller numbers of deaf people overall may result in less communication access and fewer services offered to this population.
2. **Impact of restricting genetic selection for deafness.** If genetic selection is to be permitted, it should be applied fairly and available to all citizens. Currently the arguments proposed against permitting deaf people to select embryos with genes associated with deafness fall into two categories: the 'right to an open future' argument and the 'conditions of exit' argument. Both of these arguments fail to persuade.

In the 'right to an open future' argument, selecting embryos associated with deafness purportedly violates the parental duty to provide a child with the greatest number of opportunities possible. It is typically (and wrongly) assumed that a deaf child has been forever prevented from experiencing a variety of opportunities, including the chance to obtain a high quality education, the ability to drive a car, the opportunity to pursue a variety of careers, the experience of hearing and these missed opportunities severely limit the child's life experience. These are false assumptions: deaf people can drive, receive excellent educations, work in a wide variety of careers, and have an open future with a wide range of possible life experiences. One scholar likens this difference to having to choose between two buffet tables – one with 20 items and one with 23 items, rather than being a vegetarian at a buffet table laden with meat.

The 'conditions of exit' argument is similarly flawed. Here, it is assumed that deaf people who are members of a sign language community are isolated from mainstream society and cannot leave this community, even if they wished to do so. Aside from the numerous oral deaf people who operate as counterfactuals to this argument, this argument posits a degree of isolation from mainstream society that is not reflected in the reality of signing deaf people's lives. Deaf people who sign spend a considerable amount of time interacting with hearing people, including purchasing groceries, attending mainstream public events, and communicate with their hearing family members and friends. It may even be the case that, in general, signing deaf people are more able to adapt to different environments because of their natural abilities as visual people.

For the reasons outlined above we request that Clause 14, number 4, section 9 be omitted from the proposed Human Fertilisation and Embryology Bill.

Yours sincerely



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Chair of BDA