

## **Briefing on the Human Fertilisation and Embryology Bill**

### **Introduction**

The Human Fertilisation and Embryology Bill was introduced into the House of Lords in November 2007.

The main area of contention for some members of the Deaf community is that the Bill prohibits the selection of a deaf embryo in IVF treatment when a hearing embryo is available.

While the Bill clearly states that its contents do not affect the rights of deaf parents when conceiving naturally, there is some concern amongst the Deaf community that the Bill could lead to forced abortions if pre-natal testing has identified deafness.

This briefing sets out RNID's position on genetics and pre-implantation genetic diagnosis (PGD).

### **Background**

Genetics research could lead to new therapies for hearing loss for those who want it, but it also raises ethical questions, particularly with respect to reproductive decisions. There are political issues raised by members of the Deaf community who believe that deaf parents should be able to choose not to have hearing children and that deafness is not a disability.

The nature of genetics research opens up many new routes to therapies for, and prevention of, hearing loss. RNID supports and funds genetics research where the outcome will lead to the benefit of deaf or hard of hearing people, or those with tinnitus.

Much of the public concern about genetic research is about the potential uses of genetic testing.

The most difficult ethical issues arise when considering genetic testing in reproductive medicine. Currently this exists as pre-natal diagnosis and pre-implantation genetic diagnosis. The latter is employed only during *in vitro* fertilisation (IVF). While RNID supports pre-implantation genetic diagnosis (PGD) we are firmly against compulsory genetic testing.

### **Informed choice and Pre-Implantation Genetic Diagnosis (PGD)**

RNID believes that informed choice is critical in all areas of healthcare and medicine. However we do recognise that PGD is causing, in some circumstances, conflict between the medical community and disabled rights activists.

While ultimately RNID believes in the individual's right to choose, we do support selection of hearing embryos for implantation after PGD.

It is important to recognise that clinicians are likely to be reluctant to initiate pregnancies that will lead to the birth of a disabled child, particularly if unaffected embryos are available, through PGD/IVF. This is where the conflict can arise with disabled rights activists. Some members of the Deaf community may wish to implant deaf embryos in preference to hearing embryos.

Which embryos are chosen for implantation should remain a decision for individuals and their clinicians. However, RNID would not actively encourage deliberate implantation of deaf embryos when hearing embryos that are healthy are available. Where only deaf embryos are available we support the individual's right to choose implantation.

RNID would of course unconditionally support any child born deaf and his or her family.

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