

## Choosing the Future

### ***The Church of England's response to the Human Genetics Commission's consultation: Choosing the Future***

We welcome the opportunity to respond to the Human Genetics Commission's consultation.

*1. Various forms of prenatal screening have now become a routine part of medical practice in the UK today. An increasing number of genetic conditions may be included in screening programmes in the future. How do you feel about these developments?*

Prenatal screening programmes, especially those leading to late abortions, are acceptable only for very serious conditions. We understand 'serious' conditions to be either life-threatening or involving a quality of life that most people would consider to be unbearable. There may be debate about which conditions fall under this category, but we believe some clearly do not, such as a cleft palate.

*2. Do you have confidence in the provision of prenatal screening and diagnostic services?*

We cannot, on the basis of current evidence, answer this positively. Rigorous empirical research is needed to discover whether counselling is in fact adequate and fully accessible. Anecdotal evidence suggests it may not be.

Counselling should be equally accessible to all and of a consistent standard. It should help parents to understand properly the possible consequences of prenatal screening and, in the light of these, to make morally responsible choices, rather than telling them what those choices should be. Parents need to be clear about their own perceptions and any influences to which they may be prey, including general societal ones, for example the attitude of people in general to abortion. In coming to decisions parents need to be helped to see the consequences to their future offspring, themselves, and to society in general. For example, it is important to help parents to see that prenatal screening may have unforeseen consequences for their child's future prospects of employment and insurance. Screening for a genetic condition for which there is as yet no treatment, let alone cure, should be approached very cautiously.

*3. Does abortion following prenatal diagnosis of genetic disorders reflect a wider negative assessment of the value of the lives of persons with disabilities and/or genetic disorders?*

The person is valuable and should be distinguished from the disabling condition that he or she may have. Only those genetic abnormalities which are very seriously disabling can justify late abortion. There is a danger that all 'minority variations' will come to be regarded as undesirable. This would be wrong.

*4. Should PGD be governed by the same principles as PND? Should parents have the right to require (not request, we presume) PND or PGD for particular genetic conditions?*

We would be concerned to see PGD used for anything other than serious genetic disorders, because of the increased commodification of babies. Trivial conditions and non-therapeutic

genetic enhancement would not be appropriate reasons for seeking PGD. We also continue to be concerned about purely 'social' justifications of PGD (for example, for family balancing).

5. *To what extent should people be able to choose the characteristics of donors?*

The current UK policy of not permitting choice of donor, other than attempting to find one that is as similar as possible to the recipient, is acceptable to us.

6. *What developments in this field give you hope/concern? How might these be addressed?*

We would wish to affirm the use of PGD for therapy and not for genetic enhancement.

We are concerned with the possibly excessive burden of choice that early genetic screening may give people. It could medicalise normal and harmless genetic differences so that people feel themselves to be abnormal and seek treatment to become normal, ie genetically 'perfect' (rather as people are now seeking surgery to make their bodies 'perfect'). Another worrying consequence of early screening could be an increasing tendency for mutilating or otherwise damaging prophylactic measures to be taken because of fears of developing inherited conditions in the future.

7. *Are there any issues about the framework and organisation of services in the light of potential developments in genetics?*

Genetics needs to develop for the purpose of therapy, not enhancement. Research and treatment should be organised to encourage this.

8. *Are there any additional concerns you would like to raise?*

We have great sympathy for the reported cases of 'saviour siblings', but we remain concerned that the acceptability of 'saviour siblings' tips us on to a slippery slope, where individuals are increasingly seen only as a means to an end and not as an end in themselves. Having said that, some of us also believe that there might be strong compassionate grounds for 'saviour siblings', provided that it is clear that: (a) there is no other therapeutic option available; (b) the medical treatment on the 'saviour sibling' really does involve no more than minimal discomfort; (c) the 'saviour sibling' is wanted, loved and cherished as a baby in his or her own right.

There may be significant legal developments in the field of genetics that need to be anticipated, for example if rights to genetic information are established.

Signed

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