

British Humanist Association response to HGC consultation *Choosing the Future - genetics and reproductive decision making*

About the British Humanist Association (BHA)

The BHA is the principal organisation representing the interests of the large and growing population of ethically concerned but non-religious people living in the UK. It exists to support and represent people who seek to live good and responsible lives without religious or superstitious beliefs. It is committed to human rights and democracy, and has a long history of active engagement in work for an open and inclusive society. The BHA's policies are informed by its members, including philosophers, scientists and other eminent authorities in many fields, and by other specialists and experts who share humanist values and concerns.

Humanist principles and bio-ethics

Humanists defend as important ethical principles the right of each individual to live by her / his own personal values, and the freedom to make decisions about her / his own life so long as this does not result in harm to others. Reproductive choice should generally be a matter of personal choice, and attempts to curtail personal autonomy and liberty require weighty justifications, such as probable harm to others or to society in general. We recognise that many of the difficult ethical issues raised by genetics and reproductive decision making hinge on the evaluation of potential harms and benefits to individuals, to the children they might have in the future, and to society as a whole. In general, humanists will welcome developments which would reduce suffering (of families and unborn children), but would adopt a more cautious attitude to those intended to enhance unborn children. Humanists would consider these sometimes conflicting concepts and desires and often unpredictable consequences, using reason, experience and shared human values, as far as possible.

There are, however, some values that are not shared by everyone. Humanists do not share the attitudes to "interfering with nature" or "playing God" or the definitions of "personhood" held by some religious believers. We respect the rights of those holding religious beliefs on the sanctity of life and the rightful limits of medical intervention not to participate in some of the processes covered by the work of the HGC. However, we do not believe that the beliefs of the religious, when they are based on supernatural arguments, should be imposed on other people.¹

¹ It is worth pointing out here that at least 15.5% of the population is non-religious according to the 2001 census, making this the second largest "belief" group in the UK. Other surveys on religious belief in Britain have found 30 - 40% of adults declaring themselves atheists or agnostics, and 65% of young people are not religious, according to *Young People in Britain: The Attitudes and Experiences of 12-19 Year Olds*, a 2004 research report for the DfES.

(See <http://www.dfes.gov.uk/research/data/uploadfiles/RR564.pdf>)

A recent Home Office research report (see <http://www.homeoffice.gov.uk/rds/pdfs04/hors274.pdf>) found that though most white Britons call themselves Christian, faith plays a minor part in their lives and identities, well below family, work, age, interests, education, nationality, gender and income and class.

Neither do we believe that scientists and the medical profession should be left to decide these matters for themselves. What science and medicine *can* do is not necessarily a good guide to what *ought* to be done, and scientists and doctors are no better qualified than religious leaders to make moral decisions on behalf of society. Panels making these kinds of ethical decision should always contain a range of experts, including secular humanists with a good understanding of bioethical issues.

The consultation questions

The BHA focuses here on those questions dealing with ethical or social issues where humanist ideas are relevant. We leave questions about clinical practice to those with relevant experience.

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?

Humanists generally support choice in the matter of abortion, recognising it as often the lesser of several evils. Thus they would have few objections to the *offer* of screening and the terminations that might follow, believing that this offers better life prospects for the babies that are chosen as a result of screening. Offers of screening should always be accompanied by counselling on the implications of any findings.

3. It has been claimed that prenatal screening and diagnosis presupposes that most women and couples will opt for termination if a genetic disorder is identified, some feel this reflects a wider negative assessment in society of the value of the lives of disabled people and/or people with genetic disorders. Do you agree or disagree with this view? And why?

The availability of pre-natal screening and diagnosis does not presuppose that most women and couples will opt for termination. Screening may reveal genetic disorders that are often taken as grounds for termination, but this does not of itself push people in the direction of termination; for example, women who know they are carrying a Down's syndrome child do not always terminate.

We do not accept the argument that an individual parent choosing to terminate a pregnancy because a genetic disorder has been identified is thereby devaluing the lives of disabled people in general or denying them rights to life and to the full support of society. They are making a decision based on their own capacity to cope in that situation, not a judgment of the value of other people's lives.

We feel that the disability lobby is in danger of overstating its case and restricting the freedom of others on spurious grounds. It is reasonable to acknowledge that disability has disadvantages; it implies a condition in which people lack an ability that most other people have and find useful. Blindness is the lack of a useful ability. To take steps to save one's sight or to think it would be awful to lose one's sight is reasonable, because of the many things sight is useful for. But to think it would be awful to lose one's sight does not imply that thinking that blind people are not worthy

of respect or of assistance when required, or that they are not talented or trustworthy. It is only to imply that their lives are harder in some ways and that they cannot have some experiences that the sighted have and value. Similarly in the case of deafness: in the case (cited in 5.15) where a deaf couple wanted to select for deafness in their child, they were opting for a harder life in some respects for that child, and so the onus would be on them to give reasons for their choice weighty enough to counterbalance the problems arising from deafness.

“Designer babies” raise other issues. The few cases that have been permitted so far, where permission has been given for screening and selection for a “saviour sibling”, seem to us to be reasonable, on grounds of compassion for extremely ill siblings, and because there was no evidence that the new baby would not be loved for itself. Additionally these cases are so rare that they are unlikely to provoke mass demand or have wider social repercussions. Parents should, of course, be fully informed about the probable success rate of the process, from screening to therapy.

However, the “designer babies” of the popular imagination are a different matter. If they were possible, and given the complexities of inheritance and the nature / nurture balance this seems highly improbable, they would be the prenatal counterparts of hot-housed children, where parents have a predetermined design or image of how their child should turn out and a desire to manage every detail of the child’s development. In such cases, the future happiness of the child should take precedence over a parental wish to control.

Wider social concerns arise too. If such babies were considered luxuries, and, for instance, unavailable on the NHS, inequalities between rich and poor would be increased, both in the choices available to them and in their life chances. If the choice were freely available, there could be unintended consequences such as a serious imbalance of the sexes, perhaps particularly in some ethnic groups.

4. There are a number of genetic disorders for which embryos and fetuses can be tested. Should the use of PGD to test and select an embryo be governed by the same principles as the use of prenatal genetic testing (PND)? And to what extent should people have the right to request the testing of an embryo or fetus for particular genetic conditions?

Families with a history of genetic disorders should certainly have the right to request tests. If certain genetic disorders disappeared as a result of screening we would consider that a positive outcome, just as the eradication of small pox was. Again, accurate information and counselling are essential.

5. Whilst treatment using donor sperm, eggs and embryos is regulated in the UK, there exist companies outside the regulatory framework who can match potential donors with recipients. To what extent should people be able to choose the characteristics of a donor in the hope that they will conceive a child who inherits these characteristics?

It is natural to want a child who will fit into the family, and the child will probably be happier if it is reasonably matched to its family. Choices that make that more likely should generally be enabled. The selection of characteristics different from those of

the family would require weighty reasons to counterbalance the disadvantages: parents with a disability might have good reasons for choosing to have a child different from themselves, but it is more difficult to imagine what weighty reasons a couple may have for choosing to try and conceive a child with different racial characteristics, for example.

6. What, if any, are the potential future developments in this field that give you hope and/or concern? How might your hopes or concerns be addressed most effectively?

7. Genetics is a rapidly changing field, particularly in relation to reproduction. Are there any issues you would like to raise about the framework and organisation of services in light of potential developments over the next decade?

8. Are there any additional issues or concerns you would like to bring to the attention of the Human Genetics Commission that have not been addressed in this document?

The elimination of some inherited diseases is something to hope for. No one who has known a young person who died of cystic fibrosis would regret the passing of that disease. Concentrating resources on developments that would achieve this and alleviate suffering, and improved public education about inherited conditions and about so-called “designer babies”, would help to bring that about.

Our concerns might include inequality of access to some of these developments. There is also a potential problem in increased access to some developments for social reasons, to the detriment of children; ideally the needs of future children as well as those of parents would always be taken into in order to avoid that.

It is difficult for us to forecast with any accuracy future developments or their potential for good or harm. The questions they raise will always benefit from informed discussion. Humanists would want to participate in that discussion but with more evidence and information than we presently have.

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