

**REVIEW OF THE HUMAN FERTILISATION & EMBRYOLOGY ACT:
A PUBLIC CONSULTATION.
DEPARTMENT OF HEALTH 2005**

This pro forma repeats all of the questions and proposals in the above titled consultation document. The boxes below will expand as you type. When completed it should be e-mailed to review-hfe-act@dh.gsi.gov.uk

The closing date for responses is Friday 25 November.

Personal details	
Title:	Professor
Names:	Sandy Thomas
Organisation: (if relevant)	Nuffield Council on Bioethics
Address:	28 Bedford Square London
Postcode:	WC1B 3JS
E-mail address:	bioethics@nuffieldbioethics.org

Questions and proposals for consultation

The use and storage of gametes and embryos

18. The Government believes that on balance, the HFE Act's existing requirements for written consent remain proportionate and appropriate, and provide a valuable protection of the wishes of patients and donors. Do you agree? (Paragraph 4.10).

In the Discussion Paper, *Stem cell therapy: the ethical issues* (2000),¹ the Council recommended that embryo donors should be asked explicitly whether or not they consent to embryonic stem cell research and subsequent use of the cell line. We welcome, therefore, stipulations in the HFEA's Sixth Code of Practice (2003) that "where consent is sought for the use of embryos in stem cell research, donors must be given 'thorough and appropriate information, including that any stem cell lines may continue indefinitely and may be used in different research projects'".

¹ *Stem cell therapy: the ethical issues* is available to download at:
<http://www.nuffieldbioethics.org/go/screen/ourwork/stemcells/introduction>

Reproductive choices: screening and selection

31. The Government invites views on whether legislation should set out the general criteria under which embryo screening and selection can be undertaken. If so, what should those general criteria be? (Paragraph 5.19).

The Council has considered general criteria for embryo screening in its Report *Genetics and human behaviour: the ethical context* (2002).² The Report discusses the use of pre-implantation genetic diagnosis (PGD) for both clinical and non-clinical reasons. It recommends that PGD, which is currently restricted to serious diseases and disorders, should not be extended to include behavioural traits in the normal range such as intelligence, sexual orientation and personality traits. The Report does not, however, take a view on how the restrictions it advocated might be implemented.

Law and clinical practice support the use of genetic information to provide informed choice for prospective parents. But professional and public opposition has been voiced, for a variety of reasons, to the use of non-clinical attributes such as behavioural traits in testing and selection. There seems to be a consensus in clinical genetics and in public opinion against use of PGD in order to select babies on the basis of non-clinical characteristics.

In the Report, we evaluate the arguments for and against selection on non-clinical grounds, including the right to procreative autonomy, the 'expressivist' argument, matters of equality and natural humility. These are outlined in more detail at Annex A. In summary, the main argument in favour of the permissibility of selection is that this is a legitimate exercise of individual liberty. On the other hand, the 'conservative' opponent of prenatal selection would argue that the kind of interference involved in prenatal selection undermines the proper relationship between parents and their children. Given that we are dealing here with only speculative possibilities, and since the likely small effects of individual genes may make accurate predictions of future behaviour very difficult, it is hard to evaluate the disagreement between conservatives and liberals. In particular, it may be that the contrast between the liberal's affirmation of a right to procreative autonomy and the conservative's defence of natural humility is too simple. It might turn out that there are possibilities for modest applications of PGD in relation to behavioural traits which would not seriously undermine the present relationship between parents and their children. **While not entirely persuaded by this conservative line of argument, we do accept that, at present, the case for permitting prenatal selection based on the identification of genetic predispositions for enhanced abilities remains to be made. We recommend, therefore, that the technique of preimplantation genetic diagnosis, which is currently restricted to serious diseases and disorders, should not be extended to include behavioural traits in the normal range such as intelligence, sexual orientation and personality traits.**

² *Genetics and human behaviour: the ethical context* is available at: www.nuffieldbioethics.org/go/ourwork/behaviouralgenetics/introduction. See Chapters 13.57-13.78.

Research

62. The Government invites views on whether the current list of legitimate purposes for licensed research involving embryos remains appropriate. (Paragraph 9.38).

In the Discussion Paper *Stem cell therapy: the ethical issues* (2000)³, the Council recommended that research involving human embryos be permitted for the purpose of developing therapies from the derived embryonic stem cells and that Schedule 2 of the HFE Act be amended accordingly.

In 2001 the Government extended the list of purposes for which research could be licensed by the HFEA to include:

- (a) increasing knowledge about the development of embryos;
- (b) increasing knowledge about serious disease, or
- (c) enabling any such knowledge to be applied in developing treatments for serious disease.⁴

The development of therapies, therefore, is now allowed under purpose (c). We welcome this development and the Council has made no further recommendations on the topic.

THANK YOU

³ *Stem cell therapy: the ethical issues* is available to download at:
<http://www.nuffieldbioethics.org/go/screen/ourwork/stemcells/introduction>

⁴ The Human Fertilisation and Embryology (Research Purposes) Regulations 2001. Crown Copyright. Available at: <http://www.opsi.gov.uk/si/si2001/20010188.htm>

ANNEX A

Extract from the Nuffield Council on Bioethics Report, *Genetics and human behaviour: the ethical context* (2002)

Selection on non-clinical grounds: ethical arguments

13.61 The forms of selection outlined above are currently only practised on clinical grounds in the UK. However, the start of a trend towards selection on other grounds can be identified. The recent decision by the HFEA to allow the selection of embryos free from genetic conditions that can also act as donors to existing siblings is an important move in this direction.⁵ Another relevant example is sex selection. In the UK, PND and PGD can be used for sex selection if it is necessary for clinical reasons, for example to avoid the birth of a child with an X-linked genetic disease. However, there is a policy of not offering sex selection on nonclinical grounds using PGD or PND. In the US, the Ethics Committee of the American Society of Reproductive Medicine concluded that PGD should not be initiated for purposes of sex selection, and that PGD for sex selection during IVF treatment should not be encouraged.⁶ A complex set of concerns underlies such policies, involving the ethics of terminating healthy pregnancies, the need to accept offspring for themselves and not their particular characteristics, tendencies in some societies to favour male rather than female offspring, and the limited availability of genetic services.

13.62 Recently, some commentators in the US have called for this policy to be reassessed and for the possibility of sex selection of gametes to be reconsidered in certain circumstances.⁷ In the UK, the Government has requested that the HFEA examines the advances in techniques of gamete selection on the basis of sex, something which is already possible and unregulated in the private sector. The HFEA intends to launch a public consultation on sex selection in late 2002.

13.63 There are numerous companies in the US that offer infertile couples the opportunity to purchase donor sperm or eggs. Donors with a few common genetic or infectious diseases are excluded, although some genetic risk remains nevertheless. Some information about various characteristics of donors is made available to prospective parents, including eye, hair and skin colour, so that parents can aim to have children who bear some physical resemblance to them. In the UK, couples requiring donated sperm are able to make use of similar information to provide a means of matching the characteristics of the donor to that of the husband. However, it has been suggested that private fertility clinics in the UK may allow couples to 'select sperm donors who bear little resemblance to

⁵ Recently, this was extended to allow the parents of a child with a serious blood disease to select an embryo that did not have the same condition and which had been tissue-typed to ensure that it could be a matched donor of bone marrow cells to its sibling. The HFEA announced on 13 December 2001 that PGD and embryo selection would be allowed in order to ensure the birth of a child without a genetic disorder who would be a matched donor for a sibling. The way in which this decision was reached was criticised by the House of Commons Select Committee on Science and Technology. (House of Commons Science and Technology Committee. (18 July 2002). *Developments in Human Genetics and Embryology*. Fourth Report of Session 2001–02. London: HMSO). The HFEA subsequently rejected an apparently similar request from a family whose child suffered from a rare condition called Diamond Blackfan anaemia. Their application was turned down on the grounds that the embryos were at no increased risk of having the condition: the use of PGD and tissue typing would be purely for the benefit of the existing child, and was not necessary to ensure the health of the implanted embryo. This ruling contradicted the advice of the HFEA's own Ethics Committee which took the view that there was no moral distinction between the two types of case (Ethics Committee of the HFEA. (November 2001). *Ethical Issues in the Creation and Selection of Preimplantation Embryos to Produce Tissue Donors*).

⁶ Ethics Committee of the American Society of Reproductive Medicine. (1999). Sex selection and preimplantation genetic diagnosis. *Fertility and Sterility* 72, 595–8.

⁷ Robertson, J. A. (2001) Preconception gender selection, *Am. J. Bioethics* 1, 2–9.

themselves', in particular, donors who have 'desirable' characteristics.⁸ The *5th Code of Practice* of the HFEA does not explicitly state that parents may not select 'desirable' traits when choosing a gamete donor.⁹ It only states, in section 3.18, that 'centres should take into account each prospective parent's preferences in relation to the general physical characteristics of the person providing gametes for donation.' Preventing the selection of gametes based on non-clinical features, whether physical characteristics or behavioural traits such as intelligence or personality would therefore require new guidance.

13.64 In the US, most companies also provide information about the educational qualifications of donors and even their grades on school and college examinations. Some individuals who regard themselves as 'high achievers' have subsequently sold or given away their sperm on the internet. The most famous sperm bank of this kind was the Repository for Germinal Choice, which operated from 1980 to 1999. It collected sperm from people of high intelligence, including a number of winners of the Nobel Prize and the Field medal, a prestigious award in mathematics. Men of high intelligence who had family histories of serious genetic disease or disorders such as schizophrenia were excluded. Women purchasing the sperm were excluded if they were unmarried, unhealthy, over the age of 40 or had criminal records. Another group that received considerable publicity is Ron's Angels, which offers donor eggs and sperm from attractive men and women. The company's website asks, 'If you could increase the chance of reproducing beautiful children and thus giving them an advantage in society, would you?'¹⁰

13.65 Law and clinical practice support the use of genetic information to provide informed choice for prospective parents. But professional and public opposition has been voiced, for a variety of reasons, to the use of non-clinical attributes such as the traits considered in this Report in testing and selection. There seems to be a consensus in clinical genetics and in public opinion against use of PGD or PND in order to select babies on the basis of non-clinical characteristics (Box 13.3 contains examples of responses to the Working Party's public consultation that address this issue). **In the case of PND, we share this view. Setting aside the contested issue of the ethics of abortion on social grounds, which is outside the scope of this Report, we take the view that the use of selective termination following PND to abort a fetus merely on the basis of information about behavioural traits in the normal range is morally unacceptable.**

13.66 But the issues raised by the use of PGD are different. Whereas selective termination following PND is applied to a fetus that has already implanted and is developing in the womb, PGD is used to select which embryos to implant. Thus, PGD does not precede the termination of a potential human life, but precedes instead the choice as to which embryo, among those created by IVF, is to be given a chance of developing into a human being. And in this context, it is not so clear that it is morally unacceptable to make this choice on the basis of genetic information about the traits that are the focus of this Report. Whereas PND would be used to end a life, PGD is, in effect, used to choose which life to start. Hence, the moral prohibitions which apply in the case of PND, do not apply in the same way in the use of PGD. Nonetheless, the potential use of PGD to select embryos that are more or less likely to exhibit particular behavioural traits is widely thought unacceptable. In the final part of this chapter, we attempt to evaluate this position.

⁸ Calvert, J. & O'Reilly, J. (2002). Babies-to-order raise 'eugenic' fears. *The Sunday Times*. 21 July.

⁹ Human Fertilisation and Embryology Authority. (2001). *Code of Practice*. 5th Edition.

¹⁰ Ron's Angels. Egg Auction. 2000. <http://www.ronsangels.com/auction.html> (16 Jul 2002). The website states that the company has generated an income of \$3.2 million in sales since 1999.

For selection

(i) The right to procreative autonomy

13.67 The main argument in favour of the permissibility of selection is that this is a legitimate exercise of individual liberty. There is, quite generally, a strong presumption in favour of the exercise of individual liberty wherever its exercise does not conflict, directly or indirectly, with the legitimate interests of others. This presumption is especially powerful when the activity in question lies within what is normally the sphere of private life, as the conception of children clearly does. For, on the one hand, within this sphere it is hard to see how others are harmed by what is done; and, on the other hand, intimate matters of this kind matter greatly to those directly concerned, so that it is all the more important and difficult to justify any interference in them. Hence, the liberal position is sometimes described in terms of the existence of a 'right to procreative autonomy', which would include a right to employ safe and reliable methods for the selection of children with a genetic predisposition for enhanced abilities within the normal range.¹¹

Against selection

(i) The 'expressivist' argument

13.68 One argument opposes selection for traits in the normal range because of the signals it might send about the value of different types of people and different forms of life. Many advocates of disability rights use this 'expressivist' objection to oppose selection on clinical grounds, arguing that termination of pregnancies affected by disability signals that disability is unacceptable or that disabled people are inferior.¹² In the case of behavioural genetics, if parents used selection to avoid the birth of babies carrying alleles associated with homosexuality, for example, this might reflect and reinforce prejudices such as homophobia. Selection for higher intelligence or sporting prowess might be thought to similarly devalue others who did not possess these traits, or whose parents could not afford to invest in selection techniques. However, this argument does not seem particularly strong in the case of non-disease traits. By definition, most of the traits in question are possessed in some degree by everyone and many of them, such as higher intelligence, are already valued widely in society and aimed at through educational programmes and other social policies. So it is hard to see why permitting selection on the basis of genetic predispositions in favour of enhanced abilities within the normal range, if it were possible, should be thought to 'express' a specially worrying evaluation of these abilities which is not already manifest in social practices.

(ii) Equality

13.69 We have noted previously (paragraphs 13.44 – 13.48) that the introduction of interventions based on genetic tests which aim to enhance abilities within the normal range poses a threat to the equality of opportunity. Does the same anxiety apply here? Since prenatal selection is the issue, it is not clear that it does: for a child who is conceived and born without any method of selection is not someone who has been deprived of an opportunity for enhancement that has been made available to a child whose conception has made use of methods of selection such as PGD. In this context, the method involved is one that selects for different people, rather than enhancing the abilities of a given person. Nonetheless, egalitarian anxieties do have a genuine basis: a society divided between those possessing enhanced abilities as a result of prenatal selection and those conceived naturally with the ordinary range of abilities might well develop consequential divisions which make life more difficult for ordinary people. But much depends here on the

¹¹ Dworkin, R. (1993). *Life's Dominion*. London: Harper Collins.

¹² This concern can be seen as arising from the eugenic programmes we discussed in Chapter 2, in which people without desirable traits were devalued and abused.

rest of the assumed social and political context. If we assume a democratic context whose political institutions and culture are organised in such a way that the public as a whole, and in particular those who are less talented, benefit from the exceptional abilities of a few, especially talented individuals, then there seems no good reason for thinking that things will get worse, in ways that are unfair, if such people are created. By contrast, if the society is one in which a talented elite enjoy their good fortune without any commensurate benefits for the rest of society, then there is no reason why the latter should welcome the creation of a larger and correspondingly more powerful elite.

13.70 The conclusion to be drawn, therefore, is that the introduction of PGD as a method of prenatal selection does provide grounds for egalitarian anxieties; but also that if one assumes a background social and political system in which anti-elitist egalitarian values are already well entrenched, it should be possible to accommodate prenatal selection without any great resulting unfairness. Hence, the judgement in any particular case as to whether there is a significant egalitarian objection to prenatal selection depends on whether egalitarian values are already well established in the social and political context in question.

(iii) Natural humility

13.71 The intuitive objection to prenatal selection is that it is 'interfering with nature'. By itself this is no argument, since all medical interventions involve some such interference. But the 'conservative' opponent of prenatal selection will argue that the kind of interference involved in prenatal selection undermines the proper relationship between parents and their children. For by inviting parents to exercise their preferences in making a selection it introduces an element of control over the result of conception which makes the experience of parenthood very different from the present situation in which, in the majority of cases, parents are happy just to take their children as they find them. One might compare the present situation to that of eating at the kind of family restaurant which used to be common, where there is no menu and one simply takes what is given; and then compare the envisaged use of prenatal selection to eating at a restaurant where there is a menu from which one can make a selection (and send back a dish if it was not what one ordered). Just to make this comparison, of course, is not to provide an argument; and the challenge for conservative opponents of prenatal selection is to convert this kind of intuitive reaction against prenatal selection into arguments that are robust enough to defeat the liberal proponents of a 'right to procreative autonomy' (see paragraph 13.67 above).

13.72 One attempt to do so has been made by Deena Davis, who deploys Joel Feinberg's argument that children have a right to an open future.¹³ This concept was developed by Feinberg in relation to existing children, to explain that they had rights which they were not capable of exercising but which should be 'held in trust' for them until they were fully autonomous individuals. Until that point, anything that reduced the child's available options and eliminated opportunities for it to make its own choices could be said to infringe its right to an open future. If this argument is transferred to prenatal selection, it might suggest that choosing traits – from sex to enhanced abilities – narrows the options for that child. The obvious difficulty with this argument, however, is that it mischaracterizes the parental choice: for it is a choice between different possible children and not one concerning different abilities which one and the same child might have possessed. So it is not true in a straightforward sense that prenatal selection 'narrows the options' for a child.

¹³ Davis, D. S. (2001). *Genetic Dilemmas*. New York: Routledge.

13.73 Nonetheless, it can be argued that what is wrong with prenatal selection is that it restricts a child's freedom by the pressure it places upon a child to fulfil the hopes and wishes of the parents which guided their decision to select that child for implantation rather than the other embryos that were available. People who want a male child so strongly that they resort to prenatal selection techniques may well seek to bring up their son to conform to a stereotyped gender role. It can be objected that one should distinguish the selection of an embryo from what parents do to the resulting child once he or she exists. There is no reason to assume that parents, having selected a child, would necessarily place pressure on the child or treat him or her in an undesirable way. However, if people care so strongly about a trait that they are willing to select for it, it is perhaps to be expected that they will rear the child in a stereotypical way or place pressure on the child and be upset if he or she does not fulfil the aspirations for which they have selected.

13.74 The conservative opponent of prenatal selection holds that this kind of parental pressure is a symptom of the changed relationship between parents and children which prenatal selection will motivate. At present, parents accept their children as they find them in an attitude of 'natural humility' to the unchosen, or chance results of procreation. This attitude is an important feature of parental love, the love that parents owe to their children as individuals in their own right; for this is a love that does not have to be earned and is not dependent on a child having characteristics that the parents hoped for. When we fall in love as adults we exercise some degree of choice in selecting our partner, the person we love. But parental love for children does not include a similar element of choice and it would be very destructive of it if it were to do so.

13.75 Natural humility is entirely compatible with the familiar parental aspiration, which is indeed another element of parental love, that one should do what one can to enable one's children to make the best of themselves by overcoming natural weaknesses and developing natural abilities by means of education, encouragement and so on. Involvements of this kind, however, are not attempts to ensure a specific future for a child. Not only are such attempts likely to fail, thereby leading to resentment or a sense of failure or both; more importantly, they manifest a failure by parents to understand that parental love requires the respect which gives children the opportunity to frame their lives for themselves in accordance with their own abilities and aspirations.

13.76 For the conservative, parental love which includes this element of natural humility is, therefore, incompatible with the will to control. It is not compatible with attempts to interfere in the life of a child except where the interference is in the child's own interest. Equally, it is not compatible with the practice of prenatal selection which seeks to identify, as a basis for choice, genetic predispositions for enhanced abilities or special traits. For this is an attempt to determine the kind of child one will have, which is precisely not the unconditional, loving acceptance of whatever child one turns out to have.

13.77 For the conservative, therefore, the advocates of prenatal selection in the name of the right to procreative autonomy fail to take account of the value inherent in our present attitude of natural humility, which informs the loving relationship between parents and children. They urge that in this most intimate area of personal life we should seek to curb our will to control.

13.78 Given that we are dealing here with only speculative possibilities, and since the likely small effects of individual genes may make accurate predictions of future behaviour very difficult, it is hard to evaluate the disagreement between the conservatives and the liberals. In particular, it may be that the contrast between the liberal's affirmation of a right

to procreative autonomy and the conservative's defence of natural humility is too simple. It might turn out that there are possibilities for modest applications of PGD in relation to the traits considered in this Report which would not seriously undermine the present relationship between parents and their children. **While not entirely persuaded by this conservative line of argument, we do accept that, at present, the case for permitting prenatal selection based on the identification of genetic predispositions for enhanced abilities remains to be made. We recommend, therefore, that the technique of preimplantation genetic diagnosis, which is currently restricted to serious diseases and disorders, should not be extended to include behavioural traits in the normal range such as intelligence, sexual orientation and personality traits.**