

Scottish Council on Human Bioethics

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Date: 11 November 2004 - Human Genetics Commission (HGC)

Choosing the future: Genetics and reproductive decision making

Consultation response on behalf of the Scottish Council on Human Bioethics:

The Scottish Council on Human Bioethics (SCHB) would, first, like to thank the Human Genetics Committee for its invitation to respond to the timely and appropriate consultation on genetics and reproductive decision making.

In addressing this consultation, the SCHB has formulated the following responses:

A. Population screening in pregnancy

Question 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?

Scottish Council on Human Bioethics Response:

1.1. To begin with, the SCHB would like to indicate that the provision of prenatal screening is not ethically neutral, in itself. In other words, the provision of information about the risks for an embryo or foetus to be affected by a disorder, resulting in the possibility of (1) a diagnostic test and (2) subsequent termination creates very grave ethical concerns to a large section of society.

1.2. In addition, it is often noted that the mere provision of reproductive choice in eugenic selections¹ can cause concern. In this respect, three decision events can be distinguished:

- The decisions to undergo a screening test which may be taken very lightly or not at all since it is often considered part of the routine barrage of ante-natal tests.

- The decision to undergo prenatal diagnosis which may, at this stage, already cause some concern to the relevant person(s).

- The decisions to undertake a specific action which is often not foreseen by the relevant person(s) until an unfavourable result is obtained. This can create deep anxieties in the relevant person(s) because of the complex 'life and death' nature of these decisions.

Indeed, parents may find the experience extremely traumatic and overwhelming. For the

¹ The term eugenics is defined as "the science of improving stock, not only by judicious mating, but by whatever tends to give the more suitable races or strains of blood, a better chance of prevailing over the less suitable"; see Choosing the future: Genetics and reproductive decision making, Human Genetic Commission (July 2004), p.5

vast majority, it will be the first time that they are given the grave responsibility of a decision that may influence the very existence of a person.

1.3. It is also the SCHB's experience that differences in the decision making aspects exist. For example, the SCHB is aware that suggestions have been made to some mothers that an abortion would be appropriate when the risk of abnormality was only 5%. On the other hand, a number of parents are not just coldly accepting a termination if tests results are positive but examining, instead, the statistics provided and opting to believe that the window of hope is a more acceptable option.

1.4. With respect to the possibility of an increasing number of conditions being included in screening programmes, the SCHB is very much concerned that this may enable a slippery slope to develop with selection becoming ever more acceptable. This has already happened, for example, in the case of cleft palate for which abortions have been undertaken on the basis that the condition represented a "serious handicap". But a judicial review is now taking place after the procedure was challenged in the High Court since cleft palate was not, initially, considered as a serious handicap².

1.5. In order for society to be better informed concerning developments in the use of PGD and PND, the SCHB would like to see more information relating to (1) the number of embryos and foetuses being destroyed in these procedures and (2) the nature of the genetic disorders being selected out being publicly accessible. This will enable society, as a whole, to give its informed consent concerning any possible future increases in the number of genetic conditions taking place in screening programmes.

1.6. Because of the risk associated with amniocentesis and chorionic villus sampling, the SCHB would also like to see information relating to the number of prenatal tests being performed and their outcome (including whether a termination was performed) being put into the public domain and made accessible to the general public.

1.7. The SCHB notes that prenatal screening and diagnosis have more or less become opt-out systems in the UK and part of 'routine procedures' that one undertakes during pregnancy. It is concerned that if parents do not make a strong and decided stance in order to opt out of the procedures, this routine may just take over.

1.8. The SCHB is also concerned that even though best practice rejects the notion that women will necessarily end a pregnancy after the identification of a foetal abnormality, there will still be some pressure on them to do so from other directions such as society. This was reflected in one of the HGC Consultative Panel Members stating, for example, (page: 5) that "*A doctor once suggested to my mother that I should be sterilised when I was 16 years old... He thought it would be for the best so I would not pass on the disease. Fortunately my parents felt the same way as me and it didn't happen... When my mother was pregnant with me a Ward Sister told her she should be ashamed of herself and that she would not carry me full term anyway...*"

Question 2:

² Curate wins abortion challenge - 1 December 2003 - BBC: <http://news.bbc.co.uk/2/hi/health/3247916.stm>

We are interested in the extent to which you have confidence in the current provision of prenatal screening and diagnostic services. For example:

- ***Is adequate counselling provided?***
- ***Is sufficient and appropriate information offered at all stages of the process?***
- ***Is the information provided fully accessible to all groups in the community?***
- ***Is counselling non-directive?***

Scottish Council on Human Bioethics Response:

2.1. In the experience of the SCHB, the answer to all the above bullet points is ‘yes’ if people are referred to a genetics unit. However, if a couple is only seen by an Obstetrician and Gynaecologist, it is possible that they may well not have been adequately counselled with insufficient information given about the facts. Some foetuses are indeed aborted for trivial reasons with Obstetricians and Gynaecologists being so used to social terminations that they may accept as ‘normal’ the termination of a pregnancy for a mild abnormality.

2.2. The SCHB would also like to indicate that the provision of prenatal screening and diagnostic services are not neutral in themselves. In both cases there is a choice of knowing that a child may be healthy or that he or she may have a serious genetic disorder. The two results are not equal in value. It is not like choosing between two different colours of the same flowers. In the first case, parents will rejoice in expecting a healthy child. In the second, they will be confronted with the possibility of a lot of hardship and distress. Moreover, no health care professional or counsellor would ‘rejoice’ at the prospect of a child being born with a serious disorder (as opposed to a healthy one), and this will be perceived by the parents.

Question 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?

Scottish Council on Human Bioethics Response:

3.1. Most parents recognise that it is not always easy to live with a serious genetic disorder in modern society. Because of this, and since parents want ‘the best’ for their children, many of them would consider terminating a pregnancy if the embryo/foetus proved to have a high risk of being affected by a serious genetic disorder.

This is also reflected in that many persons consider society as being competitive. For example, it has already been suggested by individuals such as Lewontin that “*the presence of such biological differences between individuals of necessity leads to the creation of hierarchical societies because it is part of biologically determined human nature to form hierarchies of status, wealth, and power*”³.

This reflects the belief that for a person to be valued or accepted in our modern society he or she must perform in order to reach a standard set by society, others or oneself. Unconditional

³ Lewontin, R.C., S.Rose, and L. J. Kamin. 1984. *Not in our Genes: Biology, Ideology and Human Nature*, New York: Pantheon, p.68

acceptance by others (except perhaps by the immediate family) is then seen as being non-existent.

On the other hand, if individuals were encouraged to unconditionally accept all other persons that make up society, this feeling of competitiveness would disappear. As a result, the pressures on eugenic selection would also dissipate since they would no longer have a purpose i.e. parents would no longer want to 'maximise' the advantages of their child in a competitive society. Instead, they would accept that each individual can play an important part through his or her differences. Society could then be considered as a system whereby every person exists to complement each other's capacities and gifts (be they genetic or otherwise) in a spirit of mutual dependency and equality.

3.2. Prenatal screening and diagnosis are being offered by health care professionals to prospective parents because they are considered desirable, enabling parents to make a choice which could provide advantages. But this creates the risk that individuals who do not wish to have access to these tests may be perceived as being somewhat irresponsible and careless.

3.3. Because of the complexity and limited understanding of the effects of gene mutations, most genetic diseases will remain untreatable for the foreseeable future. In other words, the only procedures available to health care professionals to address many genetic disorders remains the use of PGD and PND. However, with the improvement of IVF pregnancy rates and a possible increase use of PGD and PND, there is the risk that those born with a genetic disorder will become very few in number. This would result in:

- Society becoming less accustomed to persons that are different. A risk would then exist that individuals affected by disorders could, unfortunately, be considered as 'freaks'⁴. Society is indeed very intolerant of differences be they in the school playgrounds or at work.

- Such disorders being considered as rare or 'orphan' diseases by governments and the pharmaceutical industry. As a result, extensive research to find new treatments for these disorders will be considered as unprofitable with any relevant investments in research remaining minimal.

3.4. The SCHB would also like to indicate that genetic tests cannot always predict with accuracy whether a disorder is prevalent or not. For, example, a test for cystic fibrosis cannot provide any exact details about the expected life expectancy of the affected person.

B. Genetic services

Question 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?

Scottish Council on Human Bioethics Response:

⁴ This happened, for example, with a person characterised as 'elephant man' who was shown off in fairs and circuses.

4.1. It has been suggested that the issues raised by the use of PND and PGD are different⁵ and that whereas selective termination following PND is applied to a foetus that has already implanted and is developing in the womb, PGD is used to select which embryos to implant. In other words, it has been implied that whereas PND would be used to end a life, PGD would, in effect, be 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.

The SCHB, however, takes issue with the above view. It would, instead, like to indicate that the ethical nature of PGD should first be examined before any discussions are considered concerning its use. In many countries such as in Italy, Austria, Ireland and Germany, PGD is prohibited and any health care professional undertaking such a procedure would be committing a criminal offence.

4.2. In Germany, for example, the embryo is protected from the one-cell stage of the fertilised egg until completed nidation in the uterus in the Embryo Protection Act (12.13.1990)⁶. Moreover the legal definition of an embryo is considered as:

- *"the fertilised egg from the moment of the fusion of the cell nuclei of egg and spermium, and*

- *every totipotent cell taken from an embryo since these cells have the potential to develop into a human individual."*⁷.

This means that according to German legislation every cell of the 8-cell embryo (third-fourth day of embryonic development) is under the strongest possible protection of the German Embryo Protection Act since every cell is totipotent and legally qualifies as an embryo⁸. In addition, Paragraph 2 of the Embryo Protection Act leaves no possibility of discretion when it states that it is forbidden *"to dispose of an embryo, or to deliver, acquire, or use an embryo for purposes not serving its preservation"*⁹. Elisabeth Hildt summarises this when she explains that in German law *"a totipotent cell derived from a human embryo in its development is considered equivalent to a human embryo, as long as this cell is able to develop into a human being. Thus it is prohibited to destroy either an entire human embryo or a totipotent cell derived from a human embryo."*¹⁰. This means that all biopsies of totipotent cells for research or analytical purposes such as in PGD are forbidden even if the 'original' embryo is not harmed since the cells used for the analysis and their subsequent destruction can also be considered as embryos.

⁵ Genetics and human behaviour: the ethical context, Nuffield Council on Bioethics, 2002, para: 13.66

⁶ Wolfrum R, Zeller AC, Legal Aspects of Research with Human Pluripotent Stem Cells in Germany, *Biomedical Ethics*, 1999; Vol.4, No.3.

⁷ Wolfrum R, Zeller AC, Legal Aspects of Research with Human Pluripotent Stem Cells in Germany, *Biomedical Ethics*, 1999; Vol.4, No.3.

⁸ Wolfrum R, Zeller AC, Legal Aspects of Research with Human Pluripotent Stem Cells in Germany, *Biomedical Ethics*, 1999; Vol.4, No.3.

⁹ Wolfrum R, Zeller AC, Legal Aspects of Research with Human Pluripotent Stem Cells in Germany, *Biomedical Ethics*, 1999; Vol.4, No.3.

¹⁰ Hildt E.; Preimplantation diagnosis in Germany; *Biomedical Ethics*; 1996, Vol.1., No.2.

4.3. In addition, the SCHB notes that if the biopsy of a single totipotent cells from an existing embryo can be defined as the creation of another embryo (a form of twinning), then the destruction of such a totipotent cell during biological tests would contravene Article 18 of the European Convention on Human Rights and Biomedicine¹¹ which states in Article 18.2 that “*The creation of embryos for research purposes is prohibited*”.

4.4. Another issue associated with PGD is the fate of the spare embryos which are not selected. The SCHB would like to see a study undertaken relating to their prospects and whether they should be discarded, frozen, adopted by other parents, given to research or have any other fate.

4.5. With respect to a persons’ right to request the testing of an embryo or fetus for a particular genetic condition, the SCHB notes that it is not so much the testing for different disorders that may create ethical difficulties but the decisions made on the basis of the information obtained.

Question 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?

Scottish Council on Human Bioethics Response:

5.1. Before answering the question relating to the extent to which people should be able to choose the characteristics of a donor, the SCHB notes that it is important to examine the reasons why parents want children in the first place. Surprisingly as it may seem, this question has still not yet been appropriately investigated^{12,13}.

Childlessness, for example, is often compared to a bereavement rather than an illness. The deep pain through which a couple acknowledges its infertility is severe, long lasting and profound. But in order to understand this distress, it would be appropriate to first discover the origins of the desire for childbearing in couples or individuals.

One of the strongest urges faced by all societies is to “be fruitful and increase in number”, but does this urge relate to some kind of biological trigger in the brains of the couples or persons, or does it satisfy needs which they feel children could fulfil?

Though an enumeration of several reasons are often suggested by hopeful parents for wanting children, the deep urge for child-bearing can remain hidden¹⁴.

5.2. In the light of the above, couples should be supported, from the very beginning of any ‘assisted conception technology’ to consider other ways in which they can use their energy and beneficence. Many will remain childless even after treatment. Could these parents then use their willingness to love a child to address other social needs? They could, for example, help with the education of children in deprived situations if it is perceived as a positive alternative.

¹¹ Convention on Human Rights and Biomedicine, European Treaty Series - No. 164 (www.coe.int)

¹² Murray, T.H. The birth of a child, University of California Press, Berkeley (1996) pp.1-14

¹³ Kettner, M., Schafer, D., Identifying Moral Perplexity in Reproductive Medicine. A Discourse Ethics Rationale, *Human Reproduction and Genetic Ethics*, Vol.4, No.1, (1998)

¹⁴ Marshall, M. Why have Children?, *The International Journal of Applied Philosophy* Vol.3 (1987)

Furthermore, the availability of different treatments should not make couples appear foolish if they do not take up the assisted conception opportunities. If this happened, couples could feel a sense of unacceptable prejudice against themselves.

5.3. In addition to understanding the reasons why children are conceived, it is also important to examine the deep bonds that exist between parents and their offspring.

Many parents, as the responsible partners in the creation of life, know that in some way they belong to the child and the child in receiving life belongs to them. The deep sense of loss or incompleteness felt by parents, unable to be directly responsible for the creation of life in their child, is the essential reason for their interest in assisted reproduction as opposed to, for example, adoption. In other words, the costly and sensitive procedures considered by all families seeking artificial conception are a pointer to the importance they attach to the biology of creation. They apprehend the possibility of their own inability to feel a sense of belonging with the child and the difficulties the child itself would experience in feeling that it did not belong to them.

5.4. This apprehension is also reflected in published reports which suggest, for example, that when Assisted Insemination by Donor (AID) has been used, the commissioning (non-genetical) father is significantly more reticent than the commissioning (genetical) mother of informing the child of its biological origins. Moreover, it has been indicated that only 21% of AID parents, in the Netherlands, have decided to inform their child of the way in which they were conceived compared to 94% of parents who have not used AID¹⁵.

But why do such differences exist? An answer may be found if the deep and important bonds which exist between parents and their child are considered.

5.5. Further examples of the importance of the parent-child bonds can be found in:

- The dilemma faced by the two women Natallie Evans and Lorraine Hadley who lost their High Court battle, in 2003, to use the frozen embryos created with the help of their former partners against the men's will¹⁶. Indeed, it was very clear to all that one of the main reasons why the partners had refused to give permission was that they felt that some kind of bond would exist between them and the child which they did not want¹⁷;
- The assumed strength of these bonds which is reflected in the fears many gamete donors have concerning the lifting of anonymity;
- The fact that UK clinics are expected to strive, as far as possible, to match the ethnic background and physical characteristics of gamete donors to those of an infertile partner; thus, in a way, making sure that the possible child is seen (in a visual sense) to 'belong' to its parents.

¹⁵ Brewaeys, A., Golombok, S., Naaktgeboren, N., de Bruyn, J.K., Van Hall, E.V., Dutch parent's opinion about confidentiality and donor anonymity and the emotional adjustment of their children, *Human Reproduction*, Vol.12, No.7, (1997)

¹⁶ Women lose embryo battle - BBC - 1 October 2003, <http://news.bbc.co.uk/1/hi/health/3151762.stm>

¹⁷ A further example of the assumed strength of these bonds is reflected in the fears many gamete donors have concerning the lifting of anonymity. In addition when UK clinics are expected to strive as far as possible to match the ethnic background and physical characteristics of gamete donors to those of an infertile partner, are they not also, in a sense, making sure that possible child is seen (in a visual sense) to 'belong' to its parents?

5.6. The SCHB is of the opinion that until the above questions are answered concerning the bonds between parents and child, the possibility of considering donated gametes in order to choose the characteristics of a child should not be examined.

Parents who use donor insemination are bringing a child into the world in order for him or her to relate to themselves while often ignoring the relationship the child may want to have with his or her genetic parents. Though the parents may concede to tell their child the truth when they are older, they would then have to understand that the child may wish to see and know his or her genetic parents and express a sort of a 'love' which he or she may already experience. The child may also experience difficulties towards his or her genetic or social parents with the possibility of feeling a sense of rejection.

C. Developments in genetics

Question 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?

Scottish Council on Human Bioethics Response:

6.1. The SCHB notes that recent trends giving ever more choice in the field of reproductive technologies have also increased the number of embryos and fetuses being destroyed. For example, with PGD a number of embryos are created with only a few being selected and implanted (or frozen) resulting in a significant number of embryos being considered as 'waste'. Such a development took place in the case of the Hashmi couple, who fought for the right to have a tissue-matched IVF baby to save the life of their older son. In this case, six IVF cycles were undertaken and a significant number of embryos created but without any success¹⁸. In the same way, the SCHB is very concerned that PGD may enable parents, in the future, to enter into a kind of 'embryonic creation and destruction relentlessness', whereby ever more embryos are created and destroyed with the aim of saving the life of one of their existing children.

Question 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?

Scottish Council on Human Bioethics Response:

7.1. With respect to the regulation of genetics in the rapidly changing field of human reproduction the SCHB concurs that it is important that regulations are undertaken by parliamentary representatives and not through unrepresentative arms-length organisations or quasi-autonomous non-governmental organisations (quangos). This is because the decisions are too important for society to be left to any particular body other than parliament. If this does not happen then any body set up to regulate the field will be seen as making decisions on behalf, but without the informed consent, of the general public.

¹⁸ Hashmis fail in 'saviour sibling' attempt, Bionews 9 July 2004, <http://www.bionews.org.uk/new.lasso?storyid=2180>

The SCHB would therefore prefer a more accountable, democratic and representative decision making body with respect to human genetics and reproduction.

7.2. The SCHB would also like to see better laws being drafted in order to address inconsistencies such as:

- The different manners in which embryos are considered before and after they are implanted into a woman (see Natallie Evans and Lorraine Hadley case in paragraph 5.5.)
- The time difference between the destruction of human and human-animal hybrid research embryos. Indeed, according to the Human Fertilisation and Embryology Act (1990) human-animal hybrid research embryos have to be destroyed at the two-cell stage (one day after fertilisation) whereas an entirely human research embryos must only be destroyed within the 14 day post-fertilisation period.

7.3. The SCHB is concerned about the effect of high expectations on the parent-child relationship which would be heightened by the pain and suffering involved in awaiting tests, expecting perfection and subsequent high demands being placed on the child.

With respect to natural births, a child is often accepted despite any potential drawbacks since the partners may often recognise these same drawbacks in themselves and accept them.

Alternatively, in adoption, the new parents will have a caring and compassionate zeal towards the child since they would often recognise that he or she came from a disadvantaged background.

However, the psychology is different when parents have been instrumental in bringing the child into the world through the design or selection of desirable characteristics. Who would they then blame if the child did not live up to expectations?

Question 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?

Scottish Council on Human Bioethics Response:

The SCHB would like to highlight the following issues related to the topic of the consultation:

8.1. EUGENIC TRENDS

The SCHB is of the opinion that new developments in human reproductive procedures are very likely to result in eugenic consequences or lead to eugenic trends. Furthermore, it is of the view that eugenics, defined as "*the science of improving stock, not only by judicious mating, but by whatever tends to give the more suitable races or strains of blood, a better chance of prevailing over the less suitable*"¹⁹ is associated with a number of very serious ethical concerns. These are:

1 - The destruction of embryos or fetuses

¹⁹ Choosing the future: Genetics and reproductive decision making, Human Genetic Commission (July 2004), p.5

The first serious ethical concern, that may be associated with eugenics, is the methodology in which the selecting-out of disorders is undertaken.

Prenatal screening for diagnosis of potential disorders lends itself to limited management i.e. selecting out via destruction of any affected embryo or foetus.

This procedure creates serious ethical problems for the people who believe that a human embryo or foetus has the same moral status as a person who is born alive. For this section of the general public the act of willingly terminating an innocent human life undermines human dignity to such an extent that the act becomes unacceptable.

For those, on the other hand, who believe that an embryo or foetus does not have the same moral status as a person who is born alive there are probably less ethical problems in this respect.

2 - The possible discrimination against persons with genetic disorders

The second ethical problem, which may arise with eugenic selection, relates to the possible undermining of the social acceptability of genetic disorders and/or disability. In other words, eugenic selections may encourage a perspective of discrimination towards those who are not 'up to standard' or who are not as good or as capable as others in certain aspects. Our world is a competitive one and it is often difficult for governments or other bodies to address any possible discrimination that may arise because of a perceived weakness on the part of an individual.

Egalitarian anxieties do have a genuine basis: a society divided between those possessing enhanced abilities as a result of eugenic 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 on the assumed social and political context. If a democratic context exists, whereby 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 may be no good reasons for thinking that things will get worse with eugenic selections. On the other hand, if society is considered as one in which a talented elite enjoy their good fortune and privileges without any commensurate benefits for the rest of society, then there is no reason to believe that the latter should welcome the creation of a larger and correspondingly more powerful elite²⁰.

3 - The lack of the parent-child bond

Another concern with eugenics would arise if one or both parental gametes were not used to create a desired embryo. This would happen, for example, if a couple used donated sperm (or a donated cell nucleus in the case of cloning) to improve the biological 'quality' of the embryo or the future child. A 'quality' that the parents believe would not be present if they just used their own gametes or cells.

But this gives rise to serious consequences with regard to the relationship which exists between the child and his or her parents. Indeed, many parents, as the responsible partners in the creation of life, know that in some way they belong to the child and the child in receiving life belongs to them.

²⁰ Genetics and human behaviour: the ethical context, Nuffield Council on Bioethics, 2002, para: 13.69

As already mentioned, the deep sense of loss or incompleteness felt by parents, unable to be directly responsible for the creation of life in their child, is the essential reason for their interest in assisted reproduction as opposed to, for example, adoption. In other words, the costly and sensitive procedures considered by all families seeking artificial conception are a pointer to the importance they attach to the biology of creation. They apprehend the possibility of their own inability to feel a sense of belonging with the child and the difficulties the child itself would experience in feeling that it did not belong to them.

In other words, the establishment of such bonds of mutual belonging between the parent and the child are seen as being extremely important. Indeed the idea that blood ties (or gene bonds) are unbreakable, no matter what happens in a family or between parents and children, is often present in the security people obtain from these ties.

4 - The lack of unconditional acceptance

An intuitive objection to eugenic selection is that it 'interferes with nature'. Thus the 'conservative' opponents to eugenics will argue that the kind of interference involved in selection undermines the proper relationship between the parents and their child.

In other words, by inviting parents to exercise their preferences in making a selection, one introduces an element of control over the result of conception, which makes the experience of parenthood very different from the current situation.

At present and in the majority of cases, parents are content to just accept their children as they are. Because there is no possibility of choice, there is therefore no possibility of regret and unconditional acceptance is sustained²¹. The parents are also not under any pressure to make a choice which they can later regret.

For example, when adults 'fall in love', they exercise some degree of choice in selecting their partner, i.e. the person they love. But, unfortunately, adults can also regret the choice they have made and seek to terminate the relationship. Parental love for children, on the other hand, does not include a similar element of choice. If it did the whole relationship between the parents and the child could be undermined²².

This is also reflected in that, at present, parents accept their children as they are in an attitude of 'natural humility' or unconditional acceptance. 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.

In the future, it is the very existence of new procedures in medically assisted procreation that will provide parents with a choice and therefore, undermine this unconditional acceptance.

Moreover, if eugenic decisions were to be made by parents, it is very probable that they would find it difficult to make 'cold' and theoretical decisions which may be in agreement with their real feelings and desires. Indeed, the final decisions may be very different from the ones they thought they would make since parents may choose to conform to societal pressures and decide for increasing amounts of selection.

8.2. PRE-IMPLANTATION GENETIC DIAGNOSIS

²¹ Genetics and human behaviour: the ethical context, Nuffield Council on Bioethics, 2002, para: 13.71

²² Genetics and human behaviour: the ethical context, Nuffield Council on Bioethics, 2002, para: 13.74

Because the definition of an embryo as well as its legal status are so dissimilar between countries, the SCHB would like to note that very different legislations in Europe have been developed concerning Preimplantation Genetic Diagnosis (PGD).

These different legislations also reflect the reality that only a limited amount of scientific information is currently available concerning the 'potency' of human totipotent cell(s) taken from the embryo in PGD. These are then used (and thereby destroyed in the process) to test the 'quality' of the original embryo.

But though no consensus regarding the exact ethical nature of totipotent cells has yet been reached internationally, the fact that these differences exist when considering PGD has frequently been overlooked in some countries.

For example, in the UK, there has often been a nearly unanimous acceptance by scientists and the general public that the moral status of totipotent cells used for PGD has finally been resolved after the 1990 Act. But this is unfortunate since it must be remembered that UK legislation was decided through the means of democratic votes and not after any unanimous scientific demonstration which everyone could accept. Indeed, an increasing number of persons in the UK remain uncertain as to whether the right decisions were made at all²³.

In summary, as long as our whole scientific and ethical decision making process continues to be based on democratic majorities rather than on rational and logical demonstrations, politicians, scientists, health care professionals and many amongst the general public will remain uneasy as to what is really being considered.

Because of this, legislation with respect to totipotent cells should never be seen as being built on unquestionable solid foundations to be used for future discussions concerning embryological research. Instead it should simply be considered as the views of the majority at the time which could prove to be inappropriate when further results and understandings of the biological process are defined.

The SCHB is thus of the opinion that appropriate and responsible discussions relating to the ethical perspective of prenatal screening should not only be limited to the medical practices in the UK. This is because the UK cannot be considered as being the repository of the right unquestionable ethical standards. What may be considered as ethical in the UK by relevant bodies may be considered as completely unacceptable and even as a criminal offence in other European countries.

8.3. THE COMPLEXITY OF GENETIC TESTING

The SCHB notes that the probability of being able to select for children with certain characteristics is very much overestimated. Very few personal characteristics are regulated by a single gene with most of them being multifactorial i.e. determined by the joint effect of many genes and environmental factors: in particular aspects such as height, weight and intelligence. Therefore, the SCHB is concerned that attempts to select for a child with attributes like these may fail with the resultant child being put at risk.

8.4. EUROPEAN CONVENTION ON HUMAN RIGHTS AND BIOMEDICINE

Finally, The SCHB would like to see the UK sign and ratify the European Convention on Human Rights and Biomedicine which has already been signed by 31 and ratified by 19 Council of

²³ Anonymous, Cloning and stem cells, *Wellcome News*, Issue 21 Q4, 1999. p.5

Europe Member States. If this is not done, the reputation of the UK abroad in the field of biomedical ethics would be seriously undermined.