



Editor: Ingileif Jónsdóttir

# **PGD and Embryo Selection**

Report from an International  
Conference on Preimplantation  
Genetic Diagnosis and  
Embryo Selection

TemaNord 2005:591

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Preimplantation Genetic Diagnosis and Embryo Selection  
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© Nordic Council of Ministers, Copenhagen 2005

ISBN 92-893-1259-9

Print: Arco Grafisk A/S, Skive 2005

Design: Zakrisson, [www.polytype.dk](http://www.polytype.dk)

Copies: 400

Printed on environmentally friendly paper.

This publication can be ordered on [www.norden.org/order](http://www.norden.org/order).

Other Nordic publications are available at [www.norden.org/publications](http://www.norden.org/publications)

Printed in Denmark



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### **Nordic Committee on Bioethics**

The *Nordic Committee on Bioethics* was established 1988 to identify and survey ethical issues related to legislation, research and developments in biotechnology in the Nordic countries and internationally. The committee has two members from each of the Nordic countries. It contributes to the public debate by organising workshops on selected items, publishing reports and policy documents, and spreading information to national authorities and national ethical committees

### **Nordic co-operation**

Nordic co-operation, one of the oldest and most wide-ranging regional partnerships in the world, involves Denmark, Finland, Iceland, Norway, Sweden, the Faroe Islands, Greenland and Åland. Co-operation reinforces the sense of Nordic community while respecting national differences and similarities, makes it possible to uphold Nordic interests in the world at large and promotes positive relations between neighbouring peoples.

Co-operation was formalised in 1952 when *the Nordic Council* was set up as a forum for parliamentarians and governments. The Helsinki Treaty of 1962 has formed the framework for Nordic partnership ever since. The *Nordic Council of Ministers* was set up in 1971 as the formal forum for co-operation between the governments of the Nordic countries and the political leadership of the autonomous areas, i.e. the Faroe Islands, Greenland and Åland.

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# Preface

Developments in biotechnology and biomedicine bring hope for improved health and better future. New technologies related to the beginning of life, stem cell research, embryo research and preimplantation genetic diagnosis (PGD) raise challenging ethical questions and concerns. Bioethics deals with principles: When new technologies are applied, are the principles of human dignity, autonomy and justice respected? Bioethics also deals with consequences. What are the consequences of biotechnology, benefits and risks? Bioethics deals with values and norms. The norms vary from one culture to another, from one society to another, the norms change over time, and individual experiences also play a role.

In vitro fertilization (IVF) has been practised for decades, and in modern societies it is generally considered the right of childless couples to have access to IVF treatment. Embryos are generated and selected for implantation and a child is born. The remaining embryos are stored for future use, donated to research or destroyed.

All parents wish to have healthy children. Advances in reproductive technology have opened new opportunities to avoid inherited diseases in offspring. Preimplantation genetic diagnosis was introduced at the beginning of the 1990s as an alternative to prenatal diagnosis, to prevent termination of pregnancy in couples with a high risk for offspring affected by a sex-linked genetic disease. PGD of human embryos permits identification of embryos carrying gene disorders and healthy embryos can be selected for implantation. PGD for medical purposes can be extended, e.g. for identification of susceptibility genes for late onset diseases. When children suffer from severe genetic disorders and require stem-cell transplantation, compatible donors may not be available. Selection of embryos that can serve as donors for elder sick siblings is already a reality in many countries. Embryos with human leukocyte antigens (HLA) identical to those of the elder sibling, can be selected for implantation to become donors of stem cells from cord blood at birth, thus providing cells necessary for therapy of the sick sibling.

Arguments for and against PGD concern the moral status of the embryo, the individual concerned by the implementation of PGD, the consequences of PGD, and in the case of 'savior' siblings, discarding healthy but unsuitable embryos, and valuing savior siblings in them-

selves. PGD for non-medical purposes, such as gender, is more intensely debated and raises additional questions. What are the possibilities and limits of PGD? Which needs are there and should they be met? Who shall decide and who shall be protected? What is the potential harm posed to embryos, children, and society? Is there a perfect child? Which are the rights of disabled individuals? Is a 'sorting' society desirable?

These and many other questions were discussed at an International Conference on Preimplantation Genetic Diagnosis and Embryo Selection organized by the Nordic Committee on Bioethics. There were four plenary sessions: I. Selecting the perfect baby, II. Who shall decide and who shall be protected?, III. Positive and negative selection and IV. Cultural aspects of embryo selection, including sex selection.

The conference was held 28–29 of May 2004 in Reykjavik, Iceland. Iceland's Minister of Education, Science and Culture, Mrs. Þorgerður Katrín Gunnarsdóttir, addressed the participants and opened the conference. Sixteen excellent speakers from different disciplines presented important topics related to PGD and selection of embryos, from ethical, medical, legal, social, cultural, religious and feminist views. The conference was attended by over 70 participants from 21 countries in Europe, the Middle-East, Africa and North America. They had various professional and cultural backgrounds, and many had extensive knowledge and experience in bioethics and biotechnology and participated actively in the lively and interesting discussions.

The chapters in this book are based on the lectures given by the invited speakers. The Nordic Committee on Bioethics wishes to thank the authors for their valuable contribution to the conference and this publication.

Special thanks to Committee members Beate Indrebø Hovland (Norway) and Salla Lötjönen (Finland) and the Committee secretary Helena von Troil for reading and providing constructive comments on different chapters. The expert language checking by Mr. Humphrey Dobinson and Mrs. Kristin Dobinson is duly acknowledged.

The Nordic Committee on Bioethics gratefully acknowledges the support of the Nordic parliamentarians and the Nordic Council of Ministers, providing funds for the project.

*Ingileif Jónsdóttir*, editor

Chairman of the Nordic Committee on Bioethics

# Förord

Utvecklingen inom bioteknologin och biomedicinen ger hopp om bättre hälsa och en ljusare framtid. Nya teknologier i samband med livets början, stamcells forskning, embryoforskning och preimplantatorisk genetisk diagnostik (PGD), ger upphov till svåra etiska frågor och oro. Bioetik handlar om principer: respekteras principerna om människovärde, autonomi och rättvisa när nya teknologier tillämpas? Bioetik handlar också om konsekvenser, vilka är följderna av bioteknologin, fördelar och risker? Bioetik handlar om värden och normer. Normerna är olika i olika kulturer och samhällen och de förändras med tiden. Enskilda individers erfarenheter inverkar också.

Konstgjord befruktning (in vitro fertilization, IVF) har utförts under årtionden och i moderna samhällen anses i allmänhet barnlösa par ha rätt till sådan behandling. Embryon odlas och väljs för implantering och ett barn föds. Återstående embryon sparas för framtida bruk, doneras till forskning eller förstörs.

Alla föräldrar vill ha friska barn. Framsteg inom den reproduktiva teknologin har gett nya möjligheter att undvika att barnet får en ärftlig sjukdom. Preimplantatorisk genetisk diagnostik introducerades i början av 1990-talet som ett alternativ till prenatal diagnostik, för att undvika att graviditeten måste avbrytas i fall det fanns stor risk för att barnet skulle få en könsbunden genetisk sjukdom. PGD av mänskliga embryon gör det möjligt att identifiera sådana embryon som har en genetisk defekt och friska embryon kan väljas till implantering. PGD för medicinska ändamål kan utvidgas t.ex. till identifiering av gener som ger ökad risk för sjukdomar som utvecklas sent i livet. När barn lider av allvarliga genetiska störningar och behöver stamcellstransplantation kan det hända att lämplig donator inte finns att tillgå. Val av embryo som kan fungera som donator för ett sjukt äldre syskon är redan verklighet i många länder. Embryon med humana leukocytantigener (HLA) som är identiska med syskonets kan väljas för implantering och de kan vid födseln bli donatorer av stamceller från navelsträngsblodet och på det sättet ge celler som är nödvändiga för behandling av det sjuka syskonet.

Argumenten för och emot PGD gäller embryots moraliska ställning, individerna som berörs av användningen av PGD och följderna av PGD. I fallet med "räddarsyskon" (savior siblings) handlar det om förstör-

andet av friska men olämpliga embryon och ”räddarsyskonets” egenvärde. PGD för icke-medicinskt bruk, t.ex. val av kön, debatteras intensivt och ger upphov till ytterligare frågor. Vilka är PGD’s möjligheter och gränser? Vilka behov finns det och skall de fyllas? Vem skall bestämma och vem skall skyddas? Vilken skada kan man göra mot embryona, barnen och samhället? Finns det perfekta barnet? Vilka rättigheter har handikappade individer? Är ett ”sorteringssamhälle” önskvärt?

Dessa och många andra frågor diskuterades under en internationell konferens kallad Preimplantation Genetic Diagnosis and Embryo Selection organiserad av Nordisk kommitté för bioetik. Under konferensen ordnades fyra plenarsessioner: I Att välja den perfekta babyn, II Vem skall bestämma och vem skall skyddas? III Positivt och negativt urval och IV Kulturella aspekter på embryourval, inklusive könsurval.

Konferensen hölls 28–29 maj 2004 i Reykjavik. Islands minister för utbildning, vetenskap och kultur Þorgerður Katrín Gunnarsdóttir öppnade konferensen. Sexton utmärkta talare från olika discipliner tog upp viktiga frågor i anslutning till PGD och embryourval ur etiskt, medicinskt, juridiskt, socialt, kulturellt, religiöst och feministiskt perspektiv. I konferensen deltog sjuttio personer från tjugo länder i Europa, Mellanöstern, Afrika och Nordamerika. Deltagarna hade varierande professionell och kulturell bakgrund, och många hade stor kunskap om och erfarenhet av bioetik och bioteknologi och deltog aktivt i de livliga och intressanta diskussionerna.

Kapitlen i denna bok baseras på de inbjudna talarnas inlägg. Nordisk kommitté för bioetik tackar varmt alla författare för deras värdefulla insatser för konferensen och för denna bok.

Kommittén vill också rikta ett speciellt tack till kommittémedlemmarna Beate Indrebø Hovland (Norge) och Salla Lötjönen (Finland) samt kommitténs sekreterare Helena von Troil för att de läst och kommenterat de olika kapitlen. Den engelska språkgranskningen har gjorts av Humphrey och Kristin Dobinson.

Nordisk kommitté för bioetik är tacksam för det stöd som de nordiska parlamentarikerna och Nordiska ministerrådet har visat genom att finansiera detta projekt

*Ingileif Jónsdóttir*, redaktör

Ordförande för Nordisk kommitté för bioetik

# 1 The new reproductive biology – medical and technical possibilities vs. ethical and legal concerns

## **Professor Outi Hovatta, MD, PhD**

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*In vitro* fertilisation (IVF) and treatment options developed on the basis of this methodology have raised ethical questions that have to be answered in an acceptable way. Pre-implantation genetic diagnosis (PGD) and pre-implantation genetic screening (PGS), derivation of human embryonic stem (hES) cell lines and somatic cell nuclear transfer (SCNT) for derivation of ES cells or for reproductive cloning are such techniques.

## **Selection of the embryo for transfer**

The vast majority of eggs are located in primordial follicles in the ovarian cortical tissue, and it has been calculated that a newborn girl has some one million eggs. Small numbers of these immature eggs are constantly being recruited to the growth phase, even during foetal life. They begin to grow during childhood, adulthood, pregnancies, breast-feeding and the use of contraceptive pills. Most of the eggs are never ovulated. They undergo programmed cell death, apoptosis, which is the fate of more than 99% of all eggs. During a normal menstrual cycle, only one egg matures fully, and is ovulated, allowing usually only singleton pregnancies in humans.

The very first IVF treatments were during natural cycles, with only one egg for fertilisation. The results were poor, as also shown later in several studies. Natural cycle IVF results in a pregnancy rate of less than 10% per cycle (Pelinck *et al.* 2002). When follicle-stimulating hormone (FSH) is given to a woman from the beginning of the cycle, all

the eggs which have been recruited two months earlier and which have not yet undergone apoptosis, can be stimulated to maturity. The number of such eggs varies greatly between women, and decreases significantly with age. When all these eggs are aspirated from the ovaries and fertilised, an average of about 12 eggs can be obtained. Some 70% of them become normally fertilised, and some 60% begin further development. From some women, only a very few oocytes (1 or 2) are obtained, and from some up to 50. The size of the egg cohort is an individual characteristic of each woman, and cannot be regulated.

If no FSH is given, it is still possible to obtain more than one oocyte if they are aspirated before maturity and apoptosis. This method is called *in vitro* maturation (IVM) of oocytes. It is developing into an established clinical method because it is so easy for the woman, and all the side effects and costs of hormone treatment can be avoided. In our clinic, an average of seven oocytes have been obtained per IVM cycle. The pregnancy rate has been somewhat lower than during stimulated cycles; in our clinic in 2003, 33% per embryo transfer and 22% per oocyte aspiration (Hreinsson *et al.* 2003, Hreinsson 2003). However, this is much higher than after retrieval of single mature oocytes.

On the basis of practical experience, several morphological factors have been identified which give a good prognosis for pregnancy. After some 16–20 hours, the pronuclei containing the egg and sperm chromosomes are visible in the cytoplasm of the zygote. One of each can be seen in a normally fertilised zygote, and it is a prerequisite for normal development. Forty-eight hours after fertilisation the embryo has normally reached the four-cell stage, and after three days, the embryo has eight cells. Equal size of the blastomeres and less than 20% cellular fragmentation are good prognostic signs. A developmentally competent embryo has only one nucleus in each cell. On the fifth day the embryo should have reached the blastocyst stage. A good quality blastocyst has a clearly visible oval inner cell mass with a good amount of cells, and an expanded blastocoele cavity.

These morphological signs have helped in selecting the best embryo for transfer, hence allowing single embryo transfers, to avoid multiple pregnancies. The complications of multiple pregnancies became particularly evident in large studies carried out in Sweden (Ericson and Källen 2001, Strömberg *et al.* 2002). Single embryo transfers began in Finland and Belgium in the late 1990s (Gerris *et al.* 1999, Vilksa *et al.* 1999, Martikainen *et al.* 2001). In Sweden, Socialstyrelsen (2002) imposed the regulation that only one embryo at a time is to be

transferred, and this transfer policy is now followed. Using the above morphological criteria, the best embryo can be selected for transfer without compromising the pregnancy rate, which is about 30–35% per transfer. The remaining good quality embryos can be cryopreserved for transfer later on. The pregnancy rate is not only correlated to embryo quality, but also to the number of oocytes retrieved, and the number of embryos achieved, even though only one at a time is transferred. If only one embryo is available for transfer, the pregnancy rate is much lower than in elective single embryo transfer, being only 20%.

The fact that it can take a long time before a pregnancy begins during natural non-assisted conception is closely related to the fact that not every embryo transfer results in pregnancy. This can be explained at least partly by the high proportion of chromosomally abnormal eggs in humans. In IVF in general, 20% of eggs are chromosomally abnormal. The proportion increases with age. In women older than 35 years, an abnormality rate of up to 60% has been reported (Kuliev *et al.* 2003). These abnormal eggs can be fertilised, but they seldom result in pregnancy. If they do, the result is most often miscarriage. Hence, one important selection parameter is normality of the egg and the embryo.

### **Pre-implantation genetic screening (PGS)**

This method helps in selecting for transfer the embryo that has the best developmental competence. Chromosomally normal embryos are chosen. The aim is to improve the likelihood of pregnancy. Several chromosomes can be studied from the same cells using this technique.

The normality of the chromosomes of the egg can be studied before fertilisation by examining the chromosomes of the polar bodies (Verlinsky *et al.* 1998). The polar bodies contain the chromosomes that the egg has pushed out as a result of meiotic divisions. The chromosomes of the embryo can be analysed from blastomeres that have been taken out of the embryo at the eight-cell stage. This technique has been studied among older women and among couples with repeated miscarriages and IVF failure (Gianaroli *et al.* 2001, Munne *et al.* 2002, Carp *et al.* 2004, Kuliev *et al.* 2004, Wilding *et al.* 2004). A slight decrease in miscarriage rate has been reported, but there are contradictory data regarding improvement of pregnancy rate among older women. A prospective randomised study in Belgium revealed similar final pregnancy rates with and without PGS (Staessen *et al.* 2004). It is also pos-

sible to carry out fluorescence *in situ* hybridisation (FISH) first on the polar body to check the normality of the oocyte and then to repeat the procedure using embryo biopsy material (Magli *et al.* 2004). The final value of PGS remains to be seen in the future.

### **Pre-implantation genetic diagnosis (PGD)**

Pre-implantation genetic diagnosis has been successfully applied in more than 40 IVF units since the first successful report (Handyside *et al.* 1990). There are now two large international databases regarding the results of this technique. The PGD Consortium of the European Society of Human Reproduction and Embryology (ESHRE, 2002) has collected all the European results, plus those from many other countries. The technique has proved to be feasible as regards numerous known monogenic disorders (Kuliev and Verlinsky 2004, Sermon *et al.* 2004). Chromosomal abnormalities have been studied using FISH, and single gene disorders have been analysed using appropriate DNA analysis methods. The technique is an alternative to prenatal diagnosis from amniotic fluid cells or placenta, followed by termination of pregnancy in cases of an identified severe disorder. In PGD, the diagnosis is usually made by taking two cells out of an eight-cell embryo three days after fertilisation *in vitro*. Chromosomal or DNA diagnostic tests are carried out separately on these two cells in order to control the result because of the very small sample size. With care, the degree of misdiagnosis is small, but the embryo itself may have different chromosomes in different blastomeres. This is called mosaicism. It sometimes makes clinical decisions more difficult.

### **PGD and HLA typing**

Some severe hereditary blood disorders, such as thalassaemia, Fanconi's anaemia and certain forms of aplastic anaemia may result in early death of the child in spite of repeated blood transfusions. The child can be cured by blood stem cell transplantation. Stem cells from a donor who has an immunologically similar tissue type (HLA type) are needed. It may happen that no matching donors can be found. In such cases one possibility is to use blood stem cells from the umbilical cord after the birth of the next sibling, if he or she has the same HLA type as the affected child.

The umbilical cord is normally thrown away with the placenta. It contains, however, foetal blood with many blood stem cells. Using these cells is completely non-invasive for the infant, and does not harm it at all.

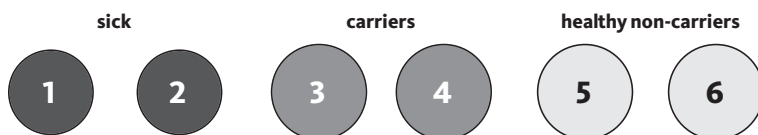
Those few families in such a situation most often have a strong desire for another child, but a healthy one. They do not want to risk having another child who is bound to die within a few years. Hence, PGD to exclude the disease, for instance thalassaemia, is a clear option for them. At the same time it is technically possible to analyse the HLA type of the embryo from the same blastomeres. Transfer of such an embryo would then make it possible to use the blood remaining in the umbilical cord after delivery for stem cell transplantation to the affected sibling. Last year (2004), several reports regarding successful PGD-HLA-typing treatments have been published. Grewal *et al.* (2004) reported a family in which a healthy infant was born after excluding Fanconi's anaemia by PGD, and the cord blood was used for stem cell transplantation to a six-year-old sister, who is now healthy 2.5 years after the treatment. Van de Velde *et al.* (2004) reported two embryo transfers and one pregnancy after PGD for thalassaemia and HLA typing. Verlin-sky *et al.* (2004) carried out 13 treatment cycles among nine couples, and five pregnancies were achieved. Fiorentino *et al.* (2004) obtained a total of 22 embryos among families with children affected by beta-thalassaemia, leukaemia and Wiskott-Aldrich syndrome and found that 14 were healthy and had the right HLA type. Three ongoing pregnancies were achieved.

It has been difficult to find embryos that are both healthy and have a matching HLA type because of the limited number of embryos obtained in human treatments.

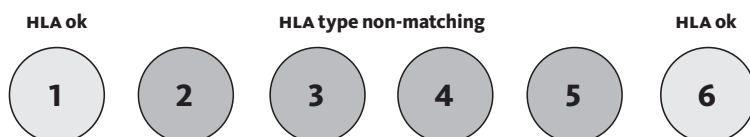
### **“Designer” babies not possible**

The PGD-HLA discussion has raised debate on so-called designer babies. It has been said that if such treatment is accepted, it will result in parents wanting to choose more and more properties of their children. However, the example of the difficulty of PGD-HLA selection demonstrates how difficult it is to “design” any babies using PGD. The cohort of eggs that is developing is always limited. We only seldom get more than six embryos to eight-cell stage. Figure 1 illustrates a scenario from a usual case. Of six embryos obtained, four happen to be free of thalas-

**FIGURE 1.** A scenario regarding the possibility of finding an embryo suitable for transfer, if two genes have to be excluded from the six embryos (a normal average) obtained for biopsy.



Six embryos obtained, and PGD for thalassemia and HLA carried out; an example how it might go



Only embryo, no. 6, is non-affected and has the right HLA-type

saemia. Two are affected, two are healthy carriers, and two are not even carriers. Two of these embryos have a matching HLA type, but one of them is affected by thalassaemia. There is only one embryo for transfer.

If more than two properties are to be selected there will hardly ever be any embryos for transfer. In addition, all such properties that people have imagined parents would desire for their children, such as talent in mathematics, music, or sports, are never regulated by a single gene. Such properties are the result of unknown combinations of several genetic and environmental factors. Even though some of these factors might be amenable to identification, the numbers of embryos obtained would not be sufficient to allow selection. The best way to have talented children is still to choose a talented spouse. Parents usually only wish that their children are healthy. And if they are not, they accept them anyway.

### Embryonic stem cells

When a couple has received the best embryo for transfer to the uterus, and the other good quality embryos have been frozen for transfers in the future, there are sometimes embryos which cannot be frozen because of sub-optimal quality. Again, a couple may have completed

their family, and there are still frozen embryos in storage. Such embryos can be donated to other couples in some countries, or donated for use in research. If the couple does not want to donate them they are discarded. For embryo donation, informed consent from both partners is required. Every research project has to be approved by an Ethics Committee, as is the case with all research involving human beings. In Sweden, derivation of permanent human ES cell lines from donated embryos is legal and is being carried out. In our clinic, 92% of counselled couples have consented to donate such embryos for stem cell research, knowing that the embryo will be destroyed during the procedure, and the possible cell line may continue dividing indefinitely (Bjuresten and Hovatta 2003).

Only 18% of sub-optimal embryos continue developing to blastocyst stage, and these blastocysts are often of such a poor quality that the inner cell mass is hardly visible. However, derivation of hES cell lines even from such blastocysts may be feasible (Hovatta *et al.* 2003), though not frequently. During March 2002–March 2004 we received 57 blastocysts from our unit as donations for ES cell line derivations, and we managed to derive six permanent lines, and 12 additional lines which grew for various periods and then faded away. Similar success rates, a little above 10%, have been reported from other units using embryos that cannot be used in infertility treatment, from the UK, Belgium, Finland, Sweden and the USA.

Better lines, and larger numbers of lines would be obtained if donated oocytes and sperm could be used to establish blastocysts and ES cell lines. Successful derivation of ES cell lines has proved to be strictly dependent on the quality of the blastocyst. If there are no cells in the inner cell mass, there is no hope of a cell line. Chromosomally abnormal embryos cannot give rise to normal ES cells. Supernumerary embryos are most often of very poor quality, for natural reasons.

Research on existing lines has already shown that the promise of differentiating many cell types from hES cells has not been exaggerated. Knowledge of how to regulate and control their differentiation is now accumulating rapidly. Safety issues are being studied in parallel. Our lines have been derived using postnatal human skin fibroblasts as feeder cells (Hovatta *et al.* 2003) instead of foetal mouse fibroblasts used in earlier lines (Thomson *et al.* 1998, Reubinoff *et al.* 2000). The risk of transmitting mouse pathogens is hence eliminated from our lines. Our latest lines have also been derived from the beginning in a chemically defined serum-free medium.

The quality of the lines is improving. There have been numerous reports regarding differentiation of hES cells to different cell types, and much is known about the regulation of early differentiation. This research is actively continuing and progressing.

### **Somatic cell nuclear transfer (SCNT)**

Somatic cell nuclear transfer (SCNT) is a method of obtaining ES cells which will not be rejected by the recipient because the genes, including those responsible for immunogeneity, are from the recipient him/herself. The first fully characterised human ES cell line as a result of SCNT was recently reported by Hwang *et al.* (2004). From 247 donated oocytes the scientists succeeded in obtaining 30 blastocysts. One of them gave origin to this ES cell line. During this project, plenty of new information was obtained on the nuclear transfer process in humans. Future experiments will certainly benefit from these early results.

### **Reproductive cloning**

Human reproductive cloning has been a subject of interest in the media for many years. There have been reports regarding non-serious attempts, and concerns about ethics. But there are clearly also medical indications for reproductive cloning. If one of the partners does not have any germ cells at all, and both agree that SCNT would be a good option for them, it might be an alternative to using donated gametes. This could be an option in those countries and religious groups where gamete donation is not accepted.

Somatic cell nuclear transfer could also be used in the cure of mitochondrial diseases. It could be achieved by transferring the nucleus of an immature oocyte to the cytoplasm of a healthy donated oocyte. This would actually not be cloning, because the oocyte has to be fertilised after nuclear transfer. The ethical concern is that the embryo will have mitochondrial genes from the donor and nuclear genes from the mother. If SCNT in humans proves otherwise safe, it might be an acceptable alternative to all the offspring of a particular woman being affected by a very severe disease.

Copying an individual is not possible by any means. Among the ethical concerns regarding reproductive cloning has been the fact that

some narcissistic individuals would like to copy themselves, even though such couples have not been encountered in the clinics which are persisting in using this technique. The individual born after SCNT will have a mitochondrial genome different to that of the somatic cell used as the nuclear donor. In this respect it would be more different from the parent than identical twins are from each other. In addition, the uterine, postnatal and growth environments would not be similar.

The most serious concerns in reproductive cloning are the safety issues (Simpson 2003, Edwards 2003). Severe health problems have been encountered in many animal species, and the origin is not completely known. Disturbances in meiotic spindle assembly in non-human primates (Simerly *et al.* 2003), and epigenetic changes (Alberio and Campbell 2003) have been suspected. Because it has already been possible to obtain blastocysts and an ES cell line after SCNT in humans (Hwang *et al.* 2004), some clarity may result as regards these phenomena in the near future. For the time being it cannot be regarded as a safe infertility treatment in humans.

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## 2 Genetic diagnostics – what can it predict?

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When we are discussing a sensitive and pioneering subject such as preimplantation genetic diagnostics, it is good to know for every contributor about his or her background, biases, and point of view. Mine is that of an active scientist trying to identify genes that are important in disease pathogenesis. I believe that susceptibility genes are important for improved diagnostics of diseases and for designing new pharmaceutical therapies. But I also believe that all the evidence so far shows that susceptibility genes will not be useful population screening targets and they are too imprecise for predicting disease with any useful accuracy. I shall review here some evidence that makes me believe that this is a fair statement for the time being, and perhaps for the foreseeable future.

### **Genetic effects in disease**

When do we suspect that genetic variation plays a role in a disease? One of the familiar signs is familial clustering, the observation that a disease occurs more often in children (or other relatives) of those affected with the disease than one would expect by chance. How often it is expected by chance can be assessed by knowing the incidence or prevalence of a disease in the population, and then comparing the familial occurrence to those figures. Traditionally, twin studies have been used to assess the genetic component in a disease. The measure in twin studies is the concordance ratio, i.e., how often the members of a twin pair either both have or both do not have the disease. A genetic component is suggested whenever the concordance of disease is much higher in monozygotic twins than in dizygotic twins. Twin con-

cordance studies give information on the genetic component of disease, but they do not inform us about where in the genome one or more disease genes are located, and not even how many genes there might be. In some families, a disease seems to be inherited as a simple dominant or recessive trait according to the distinct patterns of Mendelian inheritance. Any such observations suggest that only one or possibly just a few genes are critical for disease causation.

Genetic diseases are often classified in categories depending on the gross mechanism of causation. One category is Mendelian or monogenic disorders. These comprise over 8000 disease entities known in humans, many of them rare and not all occurring in all populations (in different populations, geneticists often talk about ‘disease heritages’). As a group, these disorders affect 2–4% of people at some age, but each distinct disease is relatively rare (up to 1:500, most in the range 1:100,000–1:10,000). Monogenic disorders are characterized by a predictable recurrence risk, and precise molecular diagnosis is available for many of them (but not all). Their severity varies from antenatal lethal to fully treatable.

A second large group of genetic diseases comprises those with a gross chromosomal background. Trisomy 21 is the most common example, but otherwise this category includes numerous rare types. In this group, there is a known and presently manageable concern for reproduction with a high risk of lethal or malformed babies born to healthy carriers of chromosome translocations. In such cases, the recurrence risk is predictable, and a precise cytogenetic diagnosis is available in most cases. These disorders are as a rule severe, varying from antenatal lethal to multiple malformations or developmental retardation.

The third major group of genetic diseases is that including complex disorders. Many of these are common, and they result in major health care costs, mostly late in life. This group of diseases is of high interest for today’s discussion, because there are definite genetic risks, but also uncertainty for prediction due to environmental effects and chance. We know much less about the genes for complex disorders at the present time: genes are being found, but their predictive value may remain low. However, these genes may become highly relevant for directing therapeutic choices in the future.

Let us discuss in more detail one example of a common, complex disease, that of the genetics of asthma. Asthma is a chronic airway inflammation that is associated with periodic episodes of reversible

airway obstruction and mucus production, causing characteristic wheezing when air passes through the narrowed lung airways. Asthma is also associated with other atopic disorders, such as hay fever and skin rash or eczema. A laboratory measurement of interest is serum immunoglobulin E, IgE, that is typically elevated in atopy. Asthma occurs in 4–6% of people in industrialized countries, and twin studies have repeatedly revealed much higher concordance ratios in monozygotic than dizygotic twins (19–88% vs. 4–63%, respectively). The risk of developing asthma is 2–3 times higher than the average population risk for children with one asthmatic parent, and still higher (up to 50%) if both parents are asthmatic (Laitinen *et al.* 1998; Illig and Wjst 2002; Weiss and Raby 2004).

Presently, four genes have been positionally cloned for asthma, even though weaker and often inconsistent evidence has been presented for tens of other genes as possible asthma susceptibility genes. The four strong candidate genes for regulating the genetic risk of asthma are ADAM33 (Van Eerdewegh *et al.* 2002), DPP10 (Allen *et al.* 2003), PHF11 (Zhang *et al.* 2003), and GPRA (Laitinen *et al.* 2004). It is noteworthy that the relative risk for each of these genes separately is at most about 1.5; for example, among healthy individuals the risk gene may occur at 30% frequency, whereas up to 40–50% of asthma patients may carry it. When asthma as a disease (about 5%) is much rarer than the carriership of the gene in the population (about 30%), we say that the gene has reduced penetrance. The causes of reduced penetrance are not understood in detail for almost any gene at the present time, but are thought to result from the effects of other genes (polygenic inheritance), environmental effects (such as exposure to pollen and other allergenic agents), and chance (referring to stochastic events) – in one word, multifactorial causes.

At the present stage of knowledge, the roles of the different asthma susceptibility genes in different populations are still uncertain. There is some evidence that their relative roles in different countries may vary, depending simply on the fact that different alleles (alternative forms) of genes have happened to reach different frequencies in different populations. But for the time being, we also do not know exactly what kinds of interactions or joint effects there are between these genes. We do not know whether having certain combinations of the risk forms of these genes cause additive or multiplicative risks. These questions, of course, are subjects of currently ongoing genetic-epidemiological studies.

Asthma research is quite representative of the field of complex disease genetics in general, although the contributions and roles of genes are different in diabetes, inflammatory bowel disease, rheumatoid diseases, Alzheimer's disease, schizophrenia, etc. Can we then make some generalisations about the current and even more importantly, future applicability of genetic tests in complex diseases? My interpretation is that we can, even though our ability to assess this question is likely to improve a lot when currently ongoing large-scale genetic association studies covering the larger part of the whole genome in large population samples will start to yield insights. My argument starts with the lesson provided by genetic susceptibility in twins. In most of the common complex diseases listed above, concordance ratios are much higher in monozygotic twins than dizygotic twins, providing a good argument for an important genetic basis or contribution. On the other hand, the concordance ratio for monozygotic twins in almost no disease exceeds 50–60%. Essentially, this result means that even in individual twin pairs, matched identically for all their genes and all DNA between their genes (including regulatory DNA elements), our ability to guess whether the second twin is going to get the disease after the first got it, is not better than 50–60% on average. The uncertainty, of course, is due to the environmental effects and chance (stochastic events), because genetic effects are discounted in monozygotic twins. This rate of success for prediction is not going to be very useful for predictive genetic diagnostics for most purposes. It might be acceptable if the risk of disease can be further reduced by simple and acceptable measures, such as dietary counselling. However, for late-onset treatable diseases, such as diabetes, I don't believe that any form of prenatal diagnostics would be interesting for the vast majority of couples.

Very much the same argument applies then also to even more exotic genetic tests often discussed in such a context, such as choosing babies for their predicted height, intelligence, behaviour, beauty, or other poorly-defined but arguably partly genetic properties. Their predictability will always remain rather poor, because the number of different gene combinations of the many contributing genes (every one with little influence by itself, as suggested by the asthma case), the endless variation in environmental effects and social experience (which is undoubtedly important for many of the cognitive and behavioural phenotypes) and the random nature of chance will keep us in the dark about the future. Just as astrology, palm reading, and other techniques, some applying crystal balls, have always been on the agen-

da for people trying to manage the future, genetic testing is not going to help or provide mankind with any more accuracy to predict the future of an individual.

So what is the future likely to bring us in terms of scientific developments? Some trends are clear and already in progress. The technology of genetic analyses continues to develop rapidly. It is now possible to assay 10,000 variable, fixed bases (SNPs) in the genome for a cost of  $\approx$  €500, and one specific assay costs today about € 0.5–1 at any qualified analytical laboratory (many claim that they can make the analyses much more cheaply). Large, population-based research projects are being performed or planned worldwide, including as examples the UK Biobank, Geenivaramu in Estonia and DeCODE genetics in Iceland. Recently, the director of the NIH Human Genome Research Institute called for a similar, large-scale prospective population cohort study in the United States, to involve approximately half a million people (Collins 2004). Similar studies have also been proposed in Canada and Sweden. All these studies aim at considering the effects of both environmental factors and biomarkers, including genes in prospective cohorts, for their relative roles in contributing to common, complex diseases. The results from prospective studies, of course, are first to be expected within 10–20 years, or whenever a sufficient number of events have been recorded and analysed.

Thus, it appears likely that our knowledge for data interpretation accumulates more slowly than the technology to assay genes. It will therefore be important to have a critical attitude toward any applications of predictive genetic testing. The medical profession is likely to incorporate any useful information as part of the diagnostic schemes and procedures, because as accurate a causal diagnosis as possible is a mainstay of the medical paradigm, and an improved accuracy in diagnosis is likely to guide more accurate therapeutic measures. Genetic tests are likely to become part of routine diagnostic procedures as new biological markers that can help in specifying a diagnosis more accurately, but whether we will see disease-specific panels or general diagnostic panels with gene tests, remains to be seen. These developments will pave the way for personalised drug therapy and possibly health counselling. As gene tests are incorporated in routine medical use, it is also expected that the accumulation of new knowledge and evidence may continue to shape people's attitudes and views on what is useful and good and what is unacceptable.

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# 3 The Ethics of Embryo Design\*

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## Introduction

In this paper, I will first shortly discuss the notion of design as I understand it in this context and ask whether is useful to discuss that from the viewpoints of science and ethics. I will secondly discuss the values at stake in the debate about embryo design. Thirdly, I will present and critically evaluate two positions that have been prominent in this debate: the liberty argument and a version of the child welfare argument. Finally, I will argue that both these arguments are too individually oriented and that we need to situate this issue in a wider context of social concerns and in relation to issues of justice in health care, not only in our affluent countries but also from a global perspective.

## The Notion of Design

The notion of design implies “to plan and make something in a skilful or artistic way”. This has both ‘negative’ and ‘positive’ implications. It is negative in the sense that design can be an art of removal, when something is made by taking away that which conceals the desired result (as in the art of sculpturing). Design can also be ‘positive’ insofar as it is an art of addition when something is made in order to reach the end state intended. In the present context, the notion of design is as a rule used in the ‘positive’ sense; as Mary Warnock writes: “Those ... who talk of ‘designer babies’ are thinking of babies, whether cloned or born by in vitro fertilisation, who are engineered not to avoid a severe disease or disability but in order positively to come up to some sort of ideal held by their parents”.<sup>1</sup> It would be negative design to

\* Nordic Committee on Bioethics: Conference on Preimplantation Genetic Diagnosis and Embryo Selection, May 28–29 2004, Hotel Nordica, Reykjavik.

1. Warnock, *Making Babies*, p. 107.

engineer babies “to avoid a severe disease or disability” and, therefore, it is often associated with therapy. Positive design, on the other hand, is typically described in terms of enhancement of desired traits. But then it is important to point out that enhancement can both be disease-related and not. “Children will be ‘designed’ to be, for instance, more resistant to disease, more intelligent, physically stronger or more ‘physically attractive’.”<sup>2</sup>

In light of this, it is sensible to distinguish between enhancement and *benefit* where the latter is relative to health and disease. Enhancement of memory is not an obvious benefit in that sense, while increased resistance to disease would be such by definition. This shows the importance of the notions of health and disease in this context. The more broadly we define health, the wider becomes the scope of benefit. This is one reason of many – which I cannot discuss here – to keep the notion of health relatively narrow, for example in terms of normal bodily functioning.<sup>3</sup> I have in mind here the notion of normality used routinely, for example, by paediatricians when examining children. Hence, the notion of benefit would clearly apply to an attempt to change a condition from abnormal to normal, while the notion of enhancement could be reserved for attempts to engineer a condition from normal to supernormal. I will restrict the notion of design to enhancement in that sense.

## Science and Morality of Design

Given that I will be using the notion of design as nondisease-related enhancement, it needs to be asked whether it makes any sense from a scientific viewpoint. After reminding us of the inexactness of medicine, W. French Anderson writes about this: “In short, we know too little about the human body to chance inserting a gene designed for ‘improvement’ into a normal healthy person. ... There is no point to a scientific discussion of eugenic genetic engineering at present—there is simply no science to discuss.”<sup>4</sup> Anderson points out, however, that the present scientific futility of these issues does not exclude the importance of moral questions about them. There is still a need for both con-

2. Nordgren, *Responsible Genetics*, p. 200.

3. “The line between disease and impairment and normal functioning is thus drawn in the relatively objective and nonevaluative context provided

by the biomedical sciences, broadly construed.” Buchanan et.al. *From Chance to Choice*, pp. 121–122.

4. Anderson, “Human Gene Therapy”, p. 345, 347.

ceptual and critical analysis of the ideas which constitute the discourse about embryo design. It is also important to consider justifications for the normative framework which society should construct in dealing with this controversial aspect of biopolicy. Should research in this direction be encouraged at all or do we have good reasons for drawing limits and head in other directions?

This question implies both what might be called the defensive and the constructive aspect of ethics and it is important to strike an appropriate balance between them. If ethics becomes overly defensive, it focuses only on the negative implications of the new biotechnology, raises the fences so high that there is no vision of future developments. If ethics, on the other hand, is overly 'constructive' it becomes preoccupied with increasing the speed on the road to progress and forgets to protect the values that need to be preserved. In both cases, the questions about where we are heading and what is the value of going in that direction are ignored. In order to discuss this further we need to consider the values at stake in this context.

### **The values at stake**

The values at stake in the discussion about embryo design and the principles protecting them can be divided into three main categories: (1) The life of the embryos that are the subject matter of the design; a commonly evoked principle is the sanctity of life. (2) Liberty and the welfare of the people concerned; the corresponding principle is respect for people. (3) The interests of the human species and of mankind; here the principle of justice is most important. I will discuss the values of liberty and welfare in relation to the liberal argument below and still later the interests of the human species and of mankind. But before I come to that, I will briefly discuss the issue of 'life itself' which often is the focus of the moral debate in this context.

The principle of sanctity of life often referred to in this context concerns the moral status of the embryo. I cannot discuss this complex issue in any detail here but I will distinguish between three positions. The first position regards human life as an *absolute value* much in the same sense as people are regarded inviolable. Obviously, this position is adopted by those who argue against any use of the human embryo for research or therapeutic purposes and, indeed, against any 'manipulation' of human life. This position has many problems which

critics have relentlessly unveiled.<sup>5</sup> However, in arguing against this position, critics tend all too often and too quickly to assume an instrumental view towards the human embryo. But if the embryo has only *instrumental value* then it becomes too easy to argue for an extensive use of human embryos for the desired objectives. I opt for a more sensible and cautious approach which regards the human embryo as a *prima facie basic value* which should not be manipulated with or disposed of unless we have strong overriding moral reasons. These reasons could be either related to the interests of the people concerned (e.g. the prospective individual and his/her parents) or to the interests of the human species and of mankind.

### The liberal argument

In this context, the liberal argument concentrates on the negative freedom of individuals from state intervention for practising procreative autonomy. This freedom should preferably be maximised so long as other individuals are not harmed. Hence the term ‘liberal eugenics’ “refers to a practice that entrusts interventions into the genome of an embryo to the discretion of the parents”.<sup>6</sup> These are special choices because they concern the way in which people lead their lives and form their families: “[Liberals] argue that the sorts of choices that are at stake in human reproduction are not mere choices, but that they are peculiarly intimately bound up with our deepest individual nature, and that they are central to individual autonomy, robustly construed.”<sup>7</sup>

It is striking how limited this viewpoint is. By concentrating on the negative rights of autonomous individuals concerned in each case, it loses sight of all other issues of importance. The notion of reproductive liberty seems to be spoken of with complete disregard for the unique features of the particular issue under scrutiny. Clearly, there is a major difference between ‘liberal eugenics’ and reproductive freedom from coercion as in cases of sterilisation (as practised by the ‘old authoritarian eugenics’), the right to control fertility by the use of contraception or even a woman’s right over her body exercised in the act of abortion. There are also important differences within the scope of

5. For example, Harris, *Clones, Genes and Immortality*, Ch. 2 “Research on Embryos”.

6. Habermas, *The Future of Human Nature*, p. 78.

7. O’Neill, *Autonomy and Trust in Bioethics*, 60. She mentions John Harris and Ronald Dworkin as representatives of this position.

the procreative right to choose among reproductive technologies, depending on what kind of options are under consideration. This is because, “reproduction is unlike both contraception and abortion, in that it aims to bring a third party – a child – into existence”<sup>8</sup> and the moral rightness of reproductive autonomy must be evaluated in the light of the interests of the child. However, the interests of the child are considered very narrowly from the liberal point of view which concentrates on the moral rights of individuals.<sup>9</sup>

### A child welfare argument<sup>10</sup>

“The designer, choosing according to his own preferences (or social habits), does not violate the moral rights of another person,” Jürgen Habermas argues. “Instead, he changes the initial conditions for the identity formation of another person in an asymmetrical and irrevocable manner.”<sup>11</sup> By this Habermas tries to demonstrate the limits of the liberal view which restricts the notion of harm to violation of moral rights. He directs the attention to the conditions for “identity formation” of the prospective child which “may suffer from the consciousness of sharing the authorship of her own life and her own destiny with someone else”.<sup>12</sup> On this level, there are two different points in Habermas’ argument. The first I call the *happiness thesis* which implies that subjective preferences of the designer and social habits influencing the design are no guarantees for what is to the advantage for the child. Each individual’s future life history is unpredictable and values are bound to a first person perspective. This is reminiscent of Kant’s position: “I cannot do good to anyone in accordance with *my* concepts of happiness [...], I can benefit him only in accordance with *his* concepts of happiness.”<sup>13</sup> The other I call the *responsibility thesis* which implies that a designed individual has a reason not to shoulder responsibility for her life, because she “could regard her own genome as the consequence of a criticizable action or omission”.<sup>14</sup> This would change

9. The foetus, for example, need not have any rights, but that would certainly not preclude us from having moral duties towards it.

10. I choose here to draw upon Habermas’ position but other authors emphasising the interests of the child

are, for example, O’Neill and Warnock.

11. Habermas, *The Future of Human Nature*, p. 81.

12. *Ibid.*, p. 82.

13. Kant, *The Metaphysics of Morals*, p. 203.

the basic precondition for human moral self-understanding that each person is in principle responsible for her life.

On the individual level these arguments are not immediately convincing because they seem to imply ‘genetic exceptionalism’ with respect to human freedom and responsibility. In Sartrean terminology, one could see genetic make-up as any other aspect of the facticity of the individual’s condition which has “meaning only in and through my project”.<sup>15</sup> It is a fact about human freedom that simply by responding to his situation the individual gives it meaning and significance and thus transcends it through his project. I don’t think there is a good reason to believe that the existential freedom of giving shape to one’s life is radically affected by design. If the designed person chose to blame her parents for their actions or omissions, she would still be responsible for that choice.<sup>16</sup> This could be compared to a religious person blaming God for creating him in a certain way. A person would still be free to pursue happiness in the way she sees fit in the life situations in which she will find herself. In fact, dominating upbringing and socialisation could be much more influential in this regard than genetic design. The happiness thesis and the responsibility thesis are not sufficient arguments against such interventions.

In addition to these considerations, Habermas introduces “a regulative idea that establishes a standard for determining a boundary ...: All therapeutic genetic intervention, including prenatal ones, must remain dependent on consent that is at least counterfactually attributed to those possibly affected by them”.<sup>17</sup> But such a *consent thesis* is not likely to serve as a sensible boundary for genetic engineering. Of course, parents and designers believe that they will be benefiting the prospective individuals by improving their genome and have no problem with anticipating their counterfactual consent. This standard shows, however, how individualistic Habermas’ analysis is, at least in part, which is all the more striking since he is countering the liberal argument that is limited by its preoccupation with the individual person as a legal entity.

14. Habermas, *The Future of Human Nature*, p. 82.

15. Sartre, *Existentialism and Human Emotions*, p. 53.

16. I do not accept Sartre’s radical notion of individual sovereignty and

I don’t think that we are ever more than co-authors of our lives, but I believe that he is right about the notion of responsibility.

17. Habermas, *The Future of Human Nature*, p. 91.

## Moral Status of the Species and Social Concerns

The problem with the three theses I briefly discussed is that they are too much on the individual level. But Habermas' argument also proceeds at another and deeper level, namely the moral status of the human species: "It remains a horrifying prospect that a eugenic self-optimisation of the species, carried out via the aggregated preferences of consumers in the genetic supermarket (and via society's capacity for forming new habits), might change the moral status of future persons."<sup>18</sup> This is a vision beyond the effects on possible individuals to the "unintended side-effects" on the ethical substance of human society. From this perspective, different questions emerge. They are no longer restricted to "whether the consequences of [parental] decisions infringe upon the objectively protected well-being of the child"<sup>19</sup> but what the social effects of taking an 'instrumentalising attitude' towards human life would be in the long term.

Habermas places his discussion of this point in the history of the important distinction between the made and the grown, the technically manufactured and the organically and socially cultivated. This distinction has, of course, been long obliterated in the breeding practices of plants and animals where man attempts to optimise other living beings for his use and pleasure. A further step in that direction would be to extend the production attitude towards human beings and enable parents to have designer babies. I have already argued that it is not impossible that those children could be both happy and responsible agents. But that is not a sufficient response at this level of the analysis. Here we need to reflect wisely and carefully about a much more pervasive effect this could have, for example upon our *mode of thinking*, on notions of *parental responsibility*, and on our ideas about the *goals of health care* and the role of *health care institutions*. It is an irresponsible exercise to think only about these serious things as individual possibilities because they might eventually have radical effects on our social practices.

I must be brief about this; the mode of thinking that is bred by aspiration for designer babies seems to be based on a mistake, namely that changing the genetic makeup of individuals will result in some desired

18. *Ibid.*, p. 93–94.

19. *Ibid.*, p.77.

and ‘better’ individual characteristics. Apart from the science fiction of this view, it ignores the complex interplay between genes, between genes and the environment and about the relevant connections between aspects of human personality. Such genetic determinism is likely to reduce emphasis on responsible parenthood which arguably is one of the two single most needed attitudes in the Western world. Responsible parenthood implies emphasis on improved pedagogical conditions, which does not square well with eugenic expectations. To the contrary, eugenic design strictly invites transgression of boundaries which could be seen as the baseline of responsible procreation: “In particular, it involves going beyond the parameters set by current scientific knowledge, shared normative assessments, and regard for first person judgements of worth.”<sup>20</sup>

Finally, if the aspiration for designer babies is to have any real relevance, it must be seen as a function of resource allocation which competes with other societal tasks. And once it is related to public policy, we need to discuss both available resources and the desirable as well as fair use of them. There are two basic options here: either embryo design would be a ‘privilege’ for the rich or it would be made publicly available. Generally, I am in agreement with the view “that the benefits of reprogenetic medicine should not merely become a privilege for the rich”.<sup>21</sup> In this case, however, there is no medical benefit so perhaps it is more correct to ask whether it should become a consumer’s choice. That categorisation is misleading, however, because of the nature of the matter which both affects our scientific resources and the shaping of society. If my arguments about the long term societal effects are sound, the question about availability of embryo design is to be answered in the negative. To them could be added the more existential thought that some options are worse having than not: “having an option can be harmful even if we do not exercise it and – more surprisingly – even if we exercise it and gain by doing so”.<sup>22</sup> I leave it as an open question for the thoughtful reader whether the option for parents to design their babies would be of this nature or not.<sup>23</sup>

20. Graham, *Genes*, p. 180.

21. Nordgren, *Responsible Genetics*, p. 222.

22. Velleman, “Against the Right to Die”, p. 34. See also Dworkin, “Is more choice better than less?”

23. Along similar lines, Habermas writes for example: “Each new

authorization of a prenatal therapeutic genetic intervention constitutes a tremendous burden for those parents who have principled reasons for not wanting to make use of the license.” *The Future of Human Nature*, p. 91.

## A Question of Justice

The other most needed attitude in the Western world is an increased responsibility to other members of the human species in destitute parts of the world.<sup>24</sup> The discussion about embryo design is a clear example of the ‘luxury problems’ of people in the affluent countries. Again, if this discussion is to be more than philosophical gymnastics, there is a need to relate it to a possible public policy and institutionalisation of health care options. This societal level is not reached by discussing the issue merely in terms of the value of life, individual autonomy or respect for persons. Here, issues of social justice and fair allocation of resources come to the fore. Resources devoted to developing genetic enhancement are resources *not* used for known beneficial therapies. This sacrifice cost must be assessed not only in relation to the medical needs of the citizens but also to the survival needs of people across the globe. Assessed from that perspective, it must be crucial that the ambitions of embryo design have no connection to the inherent and commonly accepted goals of medicine and health care.<sup>25</sup> And these goals must also be seen in the light of the enormous health care tasks at a global level.

Placed in this context, the dominant moral discourse about childrens’ future in the light of ‘genetic dilemmas’<sup>26</sup> becomes rather narrow sighted. This point can, however, be easily exploited and overstated. Weighed against the destitution of millions of people, a beneficial therapy for a single child in the affluent world seems of little significance. But this thought is misleading. The key word here is ‘beneficial’; it both reminds us of the thin but crucial line between therapy and enhancement and also links the action to the goals of medicine. In the effort to design a more just world – and a better society – a beneficial medical act must never be discounted. But actions which would merely satisfy the subjective desires of the affluent and have no link to the

24. I witnessed a striking example of a neglect of this attitude at the Sixth World Congress of Bioethics in Brasilia in 2002. John Harris opened his invited speech by playing with the wonderful promises of genetic research which might increase the human life-span by about 20 years. One wonders whose life-span is meant here. It was all the more

striking that the theme of congress was “power and injustice” and a major emphasis had been on the pervasive lack of basic health care for people in many parts of the world.

25. Cf. Hanson and Callahan, eds. *The Goals of Medicine*.

26. Cf. Davis, *Genetic Dilemmas*.

accepted goals of medicine, are of no significance. In the context of public policy, such wants and wishes have no fair claims on us. The question is not whether the system can adapt to preferences which would maximise particular interests, but whether a public system attends fairly to legitimate claims.<sup>27</sup>

## Conclusion

In this paper I have considered arguments in the debate for and against embryo design. The thrust of my thesis, which is preliminary and needs more refinement and elaboration, has been the following: If we are to address adequately biopolitical questions about procreative liberty, we need to consider not only the effects genetic policies might have upon the particular children that would be created but also the effect on the society and the world in which they will be raised. Therefore, the liberal and the child welfare arguments about embryos are too individualistic and the issue has to be discussed in a much wider context of social institutions, just health care and global health care policies.

27. Cf. Kymlicka, *Contemporary Political Philosophy*, p. 119.

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## 4 Is life worth living if you have a disability?

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I was invited to talk about life with disabilities and its value. The question given me “Is life worth living if you have a disability?” is on the surface almost a non question, but at a different level a deeply challenging one. I will start with the superficial elements of the question, then move on to talk about the social context of disability and how we can look at disability within society from the perspective of two broad models. I will share with you some findings of my research into the social construction of young disabled adulthood. I will apply the social model of the disability perspective and take both the concepts “adulthood” and “disability” to be socially constructed.<sup>1</sup> The findings suggest that it is not diagnostic labels or degree of impairment, but social exclusion coupled with disempowerment that casts some of the young disabled people in the study into marginalized, socially oppressed “eternal childhood” roles, while inclusive processes coupled with adequate and flexible support counteract this. I will proceed by arguing for finding a balance in the use of the new prenatal technologies, and give you one example from my current study, which is a comparative study of three generations of parents of disabled children, and their experiences of professional and personal network support. My example is of a couple whose unborn child was found to have an impairment and the context they found themselves in when making their decision to have the child. In conclusion I will try and tackle the question; “Is life worth living if you have a disability?” from my perspective.

1. Both the status of adulthood and the status of a disabled person is most often correctly assumed as part of a tacit exchange of complex information

through the interactive elements of language, social context and cognitive interpretation of relevant information. (1, 2, 3, 4).

## Introduction

Let us first look at the question “*Is life worth living if you have a disability?*” For some an answer to the question may be a simple *No*. Such an answer is given from the point of view of stereotypical thought about impairment, and its implications for disability. The prejudice that disability makes life not worth living, or that it is better to be dead than disabled, is old and may have its origin in both individual and collective human **angst** of suffering or the loss of autonomy; or as in the eugenics movement of the last century, in preventing particular groups of people from reproducing, thus maintaining the quality of “the race”; or to reduce the presumed cost of supporting people who are not expected to put anything back to society.

For others, the answer may be the exact opposite, a firm *Yes*. Arguments for such an answer are diverse in the literature and in the context of everyday moral discourse. They may rest on the somewhat fundamental moral, philosophical or religious premise that defines each and every human life as infinitely valuable including the life of unborn babies. Many disabled people and disability activists take this view, and for example argue strongly against prenatal testing and selective termination of impaired fetuses. They argue that the new prenatal technologies are primarily meant to prevent the birth of “people like themselves”. Furthermore, that their application may send out the powerful message to disabled people and to society at large, that the lives of disabled people are worthless, and they should never have been born. (5)

I am not persuaded by either a *Yes* or a *No* answer and their accompanying arguments.

For me, this question appears at first glance almost a non-question. Would any of us ask whether life is worth living if you are old, poor, unhappy, or if you belong to a disadvantaged minority group? There is no one clear answer to such a question. It rests upon a stereotypical “ideal type” assumption about what it means to be old, poor, unhappy or simply different. We all know people who can be described as old, poor or different who will tell us that they lead good fulfilled lives, and many disabled people report that they are on the whole content with their lives, as happy as the next man, proud of their achievements and loved by their friends and family. (6, 3, 7). So we need to listen and

learn from what it is in people's social context that supports a good life from their perspectives.

For the past 20 years I have collected stories from and about disabled people in my own society and around the world, and been fascinated by these stories, and the way in which each one is both essentially unique and also by how similar themes seem to run through them. Many stories are about exclusion, social marginalization, stigmatisation, and various forms of oppression, but also about inclusion, friendship, successful struggle for personal rights and active participation. Most of all, these stories are about hope, dreams and a common humanity.

If faced with the question you have given me; "*Is life worth living with a disability?*" I believe that each and every person I have spoken to might reflect upon his or her own life – and look puzzled. This is no different from how most of us would tackle such a question. Yet, we have probably all had occasions in our own lives to ask ourselves if our lives are worth living, not because of who we are but because of the context we have found ourselves in. We can be certain that we will all die eventually, but most of us hang on to life despite its challenges and would not swap it for another person's life even if we had the chance. We may well wish for a bit more of what we think may increase our quality of life, but essentially we get used to ourselves with or without characteristics such as impairment.

So why is such a question under discussion in the early 21st century? Are we entering a brave new world where the concern is not so much about who reproduces, as in the 19th and 20th century, but who is to be born? (8) Has the eugenics ideology reared its ugly head yet again, but in a different disguise, connected with fear of impairment or of the economic cost of supporting people with special needs? (9, 10)

The new genetic science and reproductive technology is here to stay, whether we like it or not. But we should be cautious; "The new genetic research is not so much about science and the identification of genetic anomalies as about the place of difference in society." (10) The new genetic science and prenatal technologies have brought questions about the value of life with disabilities into focus. Such questions need to be dealt with in a balanced and nuanced way and within the social context of life with impairment.

## The social context of disability

I approach my question from a sociological point of view and as a disability studies scholar. Sociologists ask questions about what is, rather than what ought to be, and try and understand the interplay between individuals, groups and the socio-cultural context within which people find themselves. (11) From the point of view of interpretivist sociology, reality can be viewed as a process of social constructions. One way of describing research methodology within the interpretative paradigm is to say that “it is the systematic collection and analysis of stories people tell about how they interpret reality.” (12) Telling stories is not enough; they have to be firmly embedded in thick description (13) and in the more explicit discussion of the interpretivist theoretical assumptions. Because of the paradigm’s firm belief in multiple realities of social construction, the goal of interpretivists is to describe, interpret and understand. The Weberian concept of ‘*Verstehen*’ conveys this deeper kind of understanding and appreciation of the meaning of actions becoming meaningful in the context of relationships and interpretations at a given time and space in history.

### Two models of disability

My work is located within *a social model of disability*. From this perspective, disability and impairment are not seen as synonymous. Impairment is seen as a biological variation or attribute of the human body, but disability is seen as the product of relationships, attitudes and structures within society. (2, 3, 4, 14) Thus *disability* is the twin burden of prejudice and discrimination that constitutes the real problems of disability, not the particular impairment. (11)

Disability studies employ “the social model of disability”, placing the disablement in the realm of society, its values, structures and politics. Disability studies contain a range of paradigmatic positions, but come together around such questions as “Who are disabled people, and who should speak for them?” (15, 16) Disability studies do not only seek to understand the meaning of disability within a social context. They include a political purpose; to work for a more inclusive society and against marginalization, segregation and social oppression of disabled people. (17, 18, 14, 2, 4)

By contrast “an individual/ medical model” of disability concentrates primarily on the physical or intellectual impairment of the person (or the prospective impairment of a foetus), and about curing or caring. Thus, the focus is on bodily ‘abnormality’, disorder or deficiency, and the way in which this, in turn “causes” some degree of “disability” or functional limitations. (19) This perspective places the disability within the individual. Disability and impairment are taken to be synonymous. Further, this widespread perspective within our culture includes the view that disability as the characteristic of the individual is a more salient characteristic than any other in a person’s life, and that it is more problematic than any other social or intrinsic restriction or suffering. (11) Disability is thus seen to provide a perfect explanation for the afflicted person’s diverse problems – from health problems to learning problems, unemployment, poverty, social isolation and loneliness.

With medicalisation of disability in the 19th and early 20th centuries, the individual/medical model of disability was firmly in place both in the scientific world and the perception of the common people in the West. Because the individual/medical model’s approach to disability sees the diagnosis of impairment and its solutions in medical terms, the emphasis is on rehabilitation, cure, prevention and caring, rather than social support, anti-discrimination and human or civil rights. (20) However, attempts to define disability from the individual/ medical model’s point of view have been made for a variety of social, organisational and economic purposes, where a social model perspective seems more appropriate. This has been done, for example, for programmatic or administrative purposes, such as for policy and fiscal initiatives and planning and for providing welfare benefits and services at community, national, international or global levels. The 1980 International Classification of Impairments, Disabilities and Handicaps (the ICIDH classification) from WHO provides a good example. (21) This has resulted in a debate on technical and measurement issues that revolves around how to count persons with impairment, how to rate their needs, and how to predict all kinds of service needs for the future. The current international WHO classification (ICIDH-2) from 2001, even though still located within the individual/ medical model perspective, includes criteria of activities, social participation, community resources and personal preferences. Thus the new ICIDH-2 stretches far into the social model perspective. (21) Obviously, the individual/medical model’s perspective is essential, when the focus is on

managing pain, rehabilitating the human body or saving lives, but it can be misleading, or harmful when applied to disabled persons in a broader social context.

I argue that “the individual/ medical model of disability” provides *a priori* assumptions and prejudices about normality and full human existence. This seems too often to be the case, despite the fact that empirical evidence regarding what constitutes a fulfilled life suggests otherwise; “Intellect does for example not make life more valuable *per se*, and most impairment is neither inevitably a serious harm, nor qualitatively different from other problems or restrictions in human life”. (22, 6)

Professional perspectives are too often anchored in such prejudice and may affect the professional and scientific perspective, for example on the use of the new reproductive biology of the late 20th and early 21st centuries. If professionals believe that disability and impairment are synonymous and inevitably the source of serious harm to the disabled person and his or her family, their advice, remedies and programmes will reflect such views. The authority vested in such professionals often tips the balance when parents (or prospective parents) seek professional advice to help them make difficult choices, affecting the fate of their disabled child and family.

### **The social construction of young disabled adulthood**

Next I want to argue for the importance of the social context and necessary and sufficient support for the quality of life of disabled people. I will summarise some findings from my recent research into disability and young adulthood. Some of these findings provide an insight into the lives of young disabled people in Iceland, and the way in which different social contexts shape their lives. These findings help to retrace the question; “*Is life worth living if you have a disability?*” in a nuanced way, as I attempt to do in my conclusion.

The study is qualitative and focuses on the perspectives and experiences of 36 disabled young adults (aged 16–24), some of their parents, teachers and friends (108 interviews in all), on coming of age as a disabled person in Iceland. The subjects belong to the first generation of disabled youth to grow up with normalization and inclusion as the law of the land. (23, 24, 25, 26) A broad diversity of socio-economic status, place of residence, and diagnostic labels was built into the sam-

pling. The young people had in common that they were all diagnosed with *significant* impairment. They carried a broad variety of diagnostic labels; physical or sensory impairment, mental retardation or mental illness. Many had more than one such diagnostic label such as mental retardation, epilepsy, spasticity, blindness, deafness, autism or mental illness. The study was located within the interpretivist theoretical tradition and the social model of disability. The purpose of the research was to describe, interpret and build a theoretical framework about the social construction of young disabled adulthood, thereby hoping to clarify issues such as how schooling, family and friendship relations impact on the young people's perspectives, hopes and dreams for their futures. (2, 3, 4)

#### Summary of the findings:

The findings can be presented in terms of a metaphor of the young disabled people as travellers along two different roads; on the highway with the rest of us towards "interdependent" adulthood, or on a special lane for special people towards "eternal childhood", or nomads in the wasteland between the roads. The findings are reported in more detail in a number of conference papers and articles in scientific journals, and a book reporting the study is imminent. (2, 27) Here a brief summary will have to suffice.

Three things stand out from the findings, as having the greatest significance for placing the young people on the different roads to adulthood, according to the metaphor:

1. Neither the diagnostic labels nor their degree or significance *per se* explained much of what happened to these young people and their families during their childhood and youth. On the other hand, the type and quality of support given to the parents from family, friends and professionals seemed to explain much of what happened to them from early childhood onwards. The exception from this was the case of two young people with autism, where the labels seemed to help explain their apparent isolation and lack of friends.
2. Parents' choices of services: special segregated services or generic services (or the availability of services in the more rural areas), explain better than the diagnosis and its severity, how the young people perceived their situation and future prospects as young disabled adults.

3. A number of problems that the young people experienced in childhood and youth, such as lack of friends, bullying, loneliness and isolation, problems of access in the community and schools, problems related to finding a place to live and earning a living as young adults, resulted much more from social barriers and exclusion, than from the nature of their diagnostic label. (28, 29, 2, 3)

All the young disabled participants in the sample, who allowed themselves the luxury of dreaming, shared a similar vision. (One young man knew he was dying and said that he had “swept his dreams of adulthood under the carpet.”). This vision involved living in one’s own home, having a job and meaningful leisure or a hobby. Most hoped for a partner and maybe a child. Neither disability labels (diagnostic labels) nor a disabling society managed to stifle that dream, which they share with most other young people. For the young disabled people on the highway (14 in all), some kind of supported adulthood based on interdependence rather than independence was well within reach or already achieved. For youth on the special lane (15 in all) adulthood remained a far-away dream, obtainable sometime in the future. Finally, for the few nomads (7 in all) there was much greater uncertainty as to whether they would reach adulthood at all or whether they wanted to. Social factors, in particular, the type of social networks and relationships – within segregated special or generic settings – that have enmeshed the young disabled adults at home, in school, friendships and, for some, at work, coincide with their approach to adulthood.

All the young disabled people had difficulties in their lives, difficulties due to access problems, exclusionary programmes and segregating support structures, but they led their lives with courage and pride in their abilities. Despite difficulties and at times pain or disease, all but one embraced their future with optimism. Even the young man who knew that he was dying, and said that he had “swept his dreams under the carpet”, talked optimistically about the coming sport season. Only one person, Jóna (in the nomad group) was not sure whether her life was worth living with her impairment. Her fate had changed from that of a bright and popular schoolgirl, when an accident rendered her body almost useless and robbed her of the ability to speak (she could communicate with the help of a communication board). Despite her predicament and her long hospitalisation, she was proud that she managed to pass the competitive national exams at the end of her 10th compulsory school year while in the hospital. However,

when she got out, the social services failed her dismally. At the time of the interview she lived alone in a flat provided by the disability services, and spent much of her time on the internet, where she felt she could be herself. After the accident she lived first with her mother, and then by herself with personal helpers in her childhood home. This was considered too expensive and the professionals in charge of her case suggested she should move to a small flat nearer to services. Her mother explained:

There was hardly a day when something did not go wrong. This was sheer horror, I almost moved back in. They forgot her on the stairs for a whole day, they did not notice when she fell on the floor and lay there. They found the service too expensive ... This is how it went for almost two years. She did not know for two years if somebody would come for the shift or not. It was truly a nightmare.

Finally Jóna moved to a flat next to a group home, but things did not improve dramatically according to mother and daughter. The mother said:

It's better, but ... now she does not get necessary help at night and has to sleep with a diaper ... horrible humiliation at her age ... We have no choices, the services never ask what she wants or needs ... She is so much alone ...

It is clearly not the impairment that is robbing Jóna of her lust for life, but the social context within which she found herself.

### **The new prenatal technology**

Genetics will affect all of our lives in the 21st century. We need to understand how this may happen, and the nature of the social and ethical decisions that we have to make as individuals and collectively. The new advances in genetic science, the technology and the research that is its basis can be viewed from different perspectives and fields. (30) These technological advances give rise to a host of challenging and fascinating questions about the biology of the human species, human reproduction and even the blueprint for human life. They may well be, as Tom Shakespeare, a disabled British sociologist puts it "... a genuine milestone in the development of the planet Earth". (31) He writes:

“Understanding genetics enables scientists to understand disease and potentially to develop therapies and drugs that alleviate conditions. In the future this will lead to better treatment for cancer, hypertension and a range of everyday problems. When there is no treatment for a disease, the major application of genetics will be in prenatal testing and selective termination of pregnancy.” (31)

Shakespeare reminds us that “1% of births are affected by congenital impairment, while 12% of the population is disabled. This of course indicates that environmental factors, lifestyles and aging are the major causes of impairment. Yet 4 in 10 will develop cancer, and cancer is often a genetic disease” and a cure for or prevention of cancer would be a major leap forward in medical science, improve the quality of life and reduce healthcare expenditure. Thus he urges us “to put genetic knowledge into appropriate perspective and disbelieve both the “hype” and the hysteria.” (32) With Shakespeare I argue for gradual application of the new technology and for caution.

### **Parental choices?**

The sociological moral stance tends towards tolerance of individual choices, and the sociological perspective looks beyond individuals and the morality of their actions, towards the social context in which they make decisions. I will thus not discuss parents’ choices from a moral standpoint, but argue for parents’ choices from a sociological interpretivist stance.

Professional work contains many *a priori* assumptions and prejudices about normality and full human existence. From the individual/medical model’s perspective, disability is inevitably a serious harm and a significant infringement of the autonomy of the future child. Thus prospective mothers (and their partners) are often encouraged by medical practitioners to have their pregnancy terminated when prenatal scanning and a subsequent battery of tests indicate certain genetic deviations such as Down’s syndrome, Fragile X syndrome, Huntington’s disease and others where there are no effective treatments or cures available. But the perspective also encourages scientists and medical practitioners involved with prenatal screening or the

screening of babies to search for ways in which to alleviate possible pain and suffering by preventive treatment or symptom management through the use of drugs, other preventive methods and gene therapy, such as in the case of cystic fibrosis, PKU (Phenylketonuria) and others. (20)

Medical staff, trained to alleviate suffering and prevent harm, tend to favour screening and the termination of pregnancy when the foetus is found to be impaired. Prospective parents are more than likely to share this view. Such prospective parents are likely to take upon themselves the suffering of abortion in order to save their future child and the family from suffering, stress and harm, and to prevent the unborn foetus having to face the future loss of opportunities. This is more likely if the information given to prospective parents, and the verbal or nonverbal attitudes of the professionals, both support such decisions, and when society does not provide sufficient and necessary support for disabled children, adults and their families.

Shakespeare found in his survey of British parents of children with restricted growth, that most said that they were glad that prenatal diagnosis had not been an option for them. (33) My current study on how and on what premise 30 Icelandic parents of a broad variety of disabled children aged 4-6 and 10-15 made decisions and choices regarding their disabled child and their families promises a broad picture. Some of these mothers had prenatal screening indicating that the foetus was impaired, but decided to have their disabled child even against professional advice. Others did so with the full support of the professionals, and still others did not know in advance that the foetus was impaired. Either the mother had not gone to prenatal screening, or she had done so and been told that everything was in order, but subsequently gave birth to a disabled child.

#### An example from research in progress

Young parents of a six year old daughter with a genetic impairment described how they experienced the prenatal services and the birth of their daughter. The pregnancy was normal until some bleeding occurred in the 16th week. The mother had her first prenatal screening and the couple was assured that everything was fine. Then in the 19th week they went again for screening. The mother said:

I had not planned to go, but you see somehow everybody went. This is a kind of family meeting, people come out with pictures and there is lots of excitement and joy. So we went like everybody else, very excited . . . All of a sudden the atmosphere changed . . . A woman came in and started talking to the others . . . We were sent out of the room. . . I had no idea what was coming, not even when we were told to wait for the doctor, and have another scan done. . .

**Dóra:** And?

**Mother:** Then the obstetrician came and I realised that something was wrong. . . something wrong with the brain . . . When I got home it seemed to me that more or less all the baby's brain was missing . . . You don't listen properly, maybe they do not tell you clearly enough, or maybe you cannot comprehend what you are being told . . .

**Dóra:** ?

**Mother:** My husband was there, they [the medical staff] were looking at some books with pictures. I just lay there kind of numb . . . and they [said]... can it be this or that? . . . leafing through, comparing pictures, getting out some more books, trying to figure this one out . . . I was lying there and he [my husband] was sitting by me on a chair. It was as if we were nothing. Then they sent us home. We went home, and decided to have the child, impairment or not. This was our child.

**Dóra:** Why?

**Mother:** I don't really know. This was always our child . . . it was as if the medics were silly, I saw them as a bit stupid. We knew that this was our child, never mind what they said about it. It was the 19th week, I had milk in my breasts, I had stopped working. We were ready, I was over thirty and ready to have a child. . . and my husband agreed 100%. . . But the doctors did not mention the word child. All they talked about was "a picture", "the brain", "the foetus" . . . Nobody mentioned a child until we went later for information to a paediatrician . . . he used the word child. . . We went home and nobody called us up . . .

**Dóra:** What did the doctors advise?

**Mother:** They did not advise anything, they just expected that we would go for an abortion.

When the parents returned to the hospital two days later they refused more tests because they feared that they would harm their unborn baby.

**Mother:** The doctor asked us if we were going to have the child.

I answered, yes. And he asked; Do you know what this costs, do you know what this means, and do you know anyone who is disabled? He went on and on ... in a nervous blabber. I tried to explain that we knew disabled people, and that we had made our decision. Then someone got our obstetrician. He came directly from an operation, with blood on his coat. He heard our story and said; Yes, sometimes this happens, that we discover such things. We will try and do all we can for you for the rest of your pregnancy. He supported us and respected our decision, and the other doctor calmed down.

The father described the birth so:

**Father:** Her water broke in the early evening. I took her to the hospital, but we were asked if we would mind if the birth was delayed so that some people could be there. We did not refuse, we did not know... Then, the next morning when we went into the delivery room, it was lined with people... It was as if they expected a monster. I did not know what to say. Then the obstetrician entered. He looked around, obviously angry, and told everyone not directly involved to get out. That was a big relief ... Then our daughter was born and looked beautiful, nothing like the children in the pictures...

These parents described their six year old daughter with great love and pride. She could read and could not wait to start school. She had suffered a life threatening illness, and been in and out of hospitals for almost four years, but got through that with excellent medical help paid for by the National Insurance. Life was again good for the small family. Yet, the mother said that if she got into the same situation once more she could not say beforehand what they would decide.

The context in which this data is anchored begs a lot of questions. How come that the parents envisaged their unborn child, but the professionals saw it as a brain damaged or an impaired foetus? Did the fact that the parents knew some people with disabilities whose lives were worth living make a difference for their decision? How can one

explain the different perspectives of various medical staff? Why did the couple have to witness the consultation of medical books, and why did they feel that they were treated like objects? Further, why did they not get adequate counselling, and how come that the delivery was delayed and that the delivery room was filled with people? Many more questions come to mind, but I argue that this data reflects contraries in peoples' perspectives, and that the individual/medical model, held inappropriately, caused the hurt and the clumsiness that the data lays bare.

The parents interviewed so far do not speak with one voice about their and their child's predicament during the prenatal period. Those who had gone through the prenatal screening and been told that the foetus was fine, and yet had a disabled child, faced a difficult dilemma. On the one hand some of them felt cheated by the prenatal services, or by God or fate, on the other hand their disabled child was their child first and foremost. All the parents interviewed so far (6 couples, 3 single mothers and 1 single father), said that in retrospect they could not imagine their families without their disabled child, but many acknowledged that they would make use of prenatal screening and possibly choose not to have a second impaired baby. For all the parents interviewed so far this has proved a painful and delicate subject.

Personally, I do support women's (and their partners') right to choose. I agree with Shakespeare that "social policy should restrict itself to enabling couples to exercise choices to continue or terminate pregnancy in cases where significant genetic or developmental conditions are diagnosed." (11) But "all choices are situated in social contexts, and we have the duty to ensure that those contexts are supportive of both possible decisions in the widest possible sense". (11) That goes also for their (and their partners') right to choose prenatal screening and tests, obtain *full and adequate* information if impairment is a significant characteristic of the foetus, and to terminate pregnancy if they believe that this is the best option for the potential child and the family, *but I do worry about the context in which choices are made*. Are the medical professionals and the prenatal counsellors helping the parents adequately informed by the social model perspective as well as by the medical knowledge, or are they locked within the more common individual/medical model? The answer to that question may decide who is going to get born and who is not.

## **Conclusion: Disability is neither measles nor a syndrome**

Disability is neither measles nor a syndrome. Disability has more to do with how we as individuals and society relate to people with impairment and their families and close friends. I hesitate in the face of questions such as who should have the right to decide who should live and who should die or not be born, and in what situations such decisions are permissible. Personally I do not think that all life is worth living, but this is a dangerous position to hold. There are those who are destined to live with great pain, despite all medical knowledge, but fortunately they are not many. It is debatable whether a child should be born if that is the prognosis. There are people who spend a long time in hospital, apparently brain-dead and hooked up with machines. In such cases I think that it is the role of the doctor, in consultation with the patients' immediate family, to decide whether or not to extend such a life. But almost everybody else, despite significant impairment, can, with adequate support (which involves doing whatever is needed when it is needed), live a valued, dignified and fulfilling human life within society, as a child, youth, or "interdependent" or in some cases fully independent adult. Research within disability scholarship has provided adequate empirical evidence that even people with significant impairment, who need support at all times, day and night, due to physical or intellectual disability, can and do become full active participants in their society. They can go to school, find friends and hobbies, and later work, and they can live in their own homes as fully fledged interdependent adults. (2, 4)

Human diversity is at the core of all human society. A society that employs highly trained scientists, doctors or other medical staff, that advise parents to abort their unborn child if the foetus is found to have genetic or other impairment, is driven by prejudice and ignorance. For me such single minded advice is like advising parents to abort a child due to its sex, colour or, if that were possible, due to its future sexual orientation. The prenatal screening technologies are there and will be refined and used. However, prospective parents should be given a broad picture, including information from families with similarly impaired children and from disabled adults, and then be supported in their own choice. Different parents will then make different choices.

Personally, I believe that disabled people form an integral part of human society, like the chorus in Beethoven's 9th symphony, or the

strings in Mahler's work. The quality of life and the human rights of disabled people are not just their private problems, but important public issues. (34)

I have struggled with the question you gave me: "*Is life worth living if you have a disability?*" for a long time and in a different context. Many years ago, in my ignorance, I came close to answering that question in the negative. Such an answer would have changed my fate and that of my son, as well as being extremely simplistic. New questions, versions of that long forgotten thought, have proved much more challenging and rewarding. I am thinking of questions such as:

What does it take to live a good life with impairment?

How can we counteract disability?

What does it mean to be a disabled young adult?

and

How can we strengthen inclusive and counteract exclusionary processes in our schools and society?

Such questions have challenged me, given me an exciting field of study and friends in many places around the globe. (See no. 6)

## Acknowledgements

I am very grateful to Dr. Tom Shakespeare, who generously lent me some of his unpublished notes and papers, and suggested other references to help me prepare for this talk.

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# 5 On the moral status of unborn babies and supernumerary fertilised eggs

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**Prologue:** “The fundamental issue in embryo research is the morality of doing research on human embryos. To address it we must ask and answer the question of the moral status of human embryos. There is a wide range of articulated views on this issue, from arguments that such early stage embryos are mere tissue with no greater moral status than cells we can scrape out of the inside of our cheeks, to arguments that early stage embryos ought to enjoy the same moral status as any of us living, breathing people”.<sup>1</sup>

## Introduction

This paper contains four preliminary claims questioning the legitimacy of posing old questions in order to answer new problems. Furthermore, it contains an account of a 'conceptionalist' view of the moral status of unborn babies and supernumerary fertilised eggs, held by two Norwegian scholars, as well as a discussion of problems involved in such a view. The discussion is organised around six different scenarios; two scenarios formulated by the well-known English bioethicist John Harris and four scenarios formulated by a young Norwegian philosopher, Anne Maria Skrikerud. The third part of the paper directs attention to possible trait-oriented (additional) conditions for ascribing a being with moral status, and to problems involved in such an approach. This part is followed by a brief presentation of end-oriented (additional) conditions for ascribing someone with moral status, pro-

1. J. Kahn, “What’s at issue in the Stem Cell Research Debate?”, *Bioethics Examiner*, University of Minnesota, 8,1, 2004.

posed by two Norwegian bioethicists, Berge Solberg and Bjørn Myskja. Finally, the question, ‘What does it imply to treat a fertilised egg, embryo or foetus in a dignified way?’ is briefly addressed. Also in these parts of the paper I rely heavily on views put forward by other scholars. Only in the selection and sifting of views and arguments can I claim originality. I have tried to keep as close as possible to the structure of my original presentation.

## I. Four preliminary claims

CLAIM 1: The fundamental moral question debated in prenatal medicine today is: *When does human life begin?* This question and its corollaries (*Is the human embryo a human being? Is the human embryo a person? When is the human embryo a person?*) are not modern, but classical questions raised anew in the context of prenatal medicine.<sup>2</sup>

CLAIM 2: An answer to these old, metaphysical questions will not necessarily make us more able to cope with the ethical challenges raised by today’s prenatal medicine.

CLAIM 3: What has happened is not just that a classical question has re-emerged; a *transposition* of this question from a philosophical or metaphysical context to a scientific or medical context has also taken place.<sup>3</sup>

CLAIM 4: The fundamental question that prenatal medicine (and medical ethics) is faced with is not ‘When does human life begin?’, but rather ‘When does life begin to matter morally?’<sup>4</sup>

“Many people have supposed that the answer to the question ‘When does life begin to matter morally?’ is the same as the answer to the question ‘When does human life begin?’ The moment of conception may seem to be the obvious answer to the question of when life begins. Over any rival candidates it seems to have the decided edge that it is an identifiable event from which point the egg begins the continuous process that leads to maturity.”<sup>5</sup>

2. For a substantiation of this claim, see J.H. Solbakk, ‘Why is the human embryo considered *persona non grata* in medical research today?’, *BioLaw*, Vol. 2, Nos. 41/42, 1990: 483–489.

3. Solbakk 1990.

4. J. Harris, “Beings, human beings and persons”, *The value of life*, 1995, p. 8

5. Harris 1995, p. 10.

“But of course the egg is alive well before conception and indeed it undergoes a process of development and maturation without which conception is impossible. The sperm, too, is alive and wriggling. Life is a continuous process that proceeds uninterrupted from generation to generation continuously ... evolving. It is not, then, that life begins at conception. But if not life, is it not at least the new *individual* that begins at conception?”<sup>6</sup>

## II. The moral status of unborn babies and supernumerary fertilised eggs.

### A 'conceptionalist' view

“A fertilised egg is a *human, biological life in its earliest stage*. When humanistic and Christian traditions of morality furnish each human being with a unique self-value, it is impossible to avoid the question from which moment this self-value is present. In our opinion there exists no other identifiable [moral] boundary when it comes to evaluating human physical life and bodily integrity than the [moment of] conception”.<sup>7</sup>

“Any attempt at establishing a morally relevant distinction between fertilised eggs and foetuses on the one hand and human persons on the other hand, is futile. Such attempts make use of an a-historical conception of normality to determine who qualifies as a human being. Consequently, only adult, rational individuals are able to comply with this conception. Such a view is at odds with the heterogeneity that in general exists between human creatures”.<sup>8</sup>

Problems involved in a 'conceptionalist' view:

PROBLEM 1: The *identity-thesis*, i.e. the view that there is a *genetic* as well as *numeric* continuity between conception and birth.

6. Ibid.

7. L. Østnor, T. Rognum, in *Stamceller fra aborterte fostre og befruktede egg – medisinsk forskning, klinisk anvendelse og mulige alternativer* [Stem cells from aborted foetuses and fertilised eggs – medical

*research, clinical application and possible alternatives*], Report from a working party set up by The Norwegian Ministry of Health, 2000, p. 15.

8. Østnor and Rognum 2000, s. 21.

Six scenarios to illustrate the problem of the identity-thesis:

FIRST SCENARIO: “A number of ‘things’ may begin at conception. Fertilisation can result not in an embryo but in a tumour which can threaten the mother’s life. This tumour, called a hydatidiform mole, would not presumably be invested with all the rights and protections that many believe spring fully armed into existence at fertilisation”.<sup>9</sup>

SECOND SCENARIO: “Even when fertilisation is, so to speak, on the right tracks, it does not result in an individual even of any kind. The fertilised egg becomes a cell mass which eventually divides into two major components: the embryoblast and the trophoblast. The embryoblast becomes the foetus and the trophoblast becomes the extraembryonic membranes, the placenta and the umbilical cord. The trophoblastic derivatives are alive, are human, and have the same genetic composition as the foetus and are discarded at birth”.<sup>10</sup>

THIRD SCENARIO: “Let us say that during copulation an egg becomes fertilised. The zygote that has been created is in possession of all the genetic traits which Tom is going to possess in his adult life, if Tom happens to be born [and grow up]. Tom starts to divide into two cells, four cells etc. On the eighth day Tom divides into two identical entities, i.e. twins. Approximately nine months later two identical twin brothers are born who both are in possession of the same genetic code as Tom. Shall we then call one of them ‘Tom’ and the other one ‘not-Tom’?”<sup>11</sup>

“The process of division that gives rise to monozygotic twins is completely symmetrical. Consequently, to name somebody ‘not-Tom’ is at odds with the first part of the identity thesis which says that genetic continuity is present from the moment of conception. On the other hand, if we give to both of them the name ‘Tom’ we end up in conflict with the second requirement of the identity thesis, ‘numeric continuity’: We started out with one zygote named Tom and now we have two new-born babies called Tom. Alternatively, one could say that Tom stopped existing on the eighth day and that instead Lars and Kristoffer cropped up. But that would imply that Lars and Kristoffer actually did not exist from the moment of conception. And what has become of Tom?”<sup>12</sup>

9. Harris 1995, p. 10.

10. *Ibid.*, p. 11.

11. A.M. Skrikerud, *Embryonale stamceller – Bør man tillate forskning på befruktede egg?* [Embryonic stemcells

– should research on fertilised eggs be permitted?], MA Dissertation (philosophy), University of Oslo, Oslo 2003, p. 36.

12. Skrikerud 2003, p. 36-37.

FOURTH SCENARIO: “A man and a woman conceive, but the result is not just one zygote, but two independent zygotes, i.e. heterozygotic twins. Let us call them Line and Trine. On day 6 the two of them, i.e. Line and Trine, enter into a symbiosis. What has now been created is a so-called chimeric entity, and they – it or she – will continue to develop as *one* organism. What is it we have now? Who will be the forthcoming child? Line or Trine? If the one who is born is Line, does that mean that Trine has stopped existing?”<sup>13</sup>

FIFTH AND SIXTH SCENARIO: “Another argument against overemphasising the identity-thesis derives from considering what may happen if the embryo starts dividing *after* day 14.

Two things may then happen: One will get either siamese twins or what is called in English ‘fetus-in-fetu’ (‘foster-i-foster’).<sup>14</sup>

PRELIMINARY CONCLUSION: Genetic and numeric continuity are necessary, but not sufficient conditions for ascribing either moral status or *full* moral status to a human embryo. Additional conditions must be in place as well.

### III. Trait-oriented (additional) conditions for ascribing a being with moral status

In the literature at least seven different conditions have been suggested:

- to be God-like (to be created in God’s image),
- to be man-like (to be *formed*),
- the ability to sense and perceive (e.g. to see, to hear, to taste, to feel desire, love, lust and pain),
- the ability to move,
- *rational capacities*,
- *self-awareness, self-consciousness*,
- *free will*.

Problem 1: The ‘diagnostic’ problem:

“The question about moral status is mainly a philosophical question. Medical and biological research may answer questions concerning empirical characteristics of a foetus, while its moral status remains a

13. Ibid., p. 37.

14. Ibid.

normative question. No empirical investigation is capable of determining its moral status unless we first know what empirical characteristics or traits are relevant for the ascription of human dignity or human rights. The controversy [about the moral status of unborn babies] is not caused by any lack of knowledge about the foetus; no new embryological data will be able to resolve this controversy”.<sup>15</sup>

“The controversy concerns what are the distinguishing characteristics or traits that provide a being with moral status on a level equal or similar to you and me. What is it that makes *us* members of the moral community? What is it that makes us belong to the class of individuals with dignity and towards whom moral beings have direct moral duties? ... What is it that gives us a right to life?”<sup>16</sup>

Problem 2: The problem of inclusion and exclusion:

If we start including in – or excluding from – the moral community members of the human race, we risk excluding some who many do not want to exclude, while including others who somebody else perhaps does not want to ascribe moral status or human dignity to.<sup>17</sup>

#### IV. End-orientated (additional) conditions for moral status

“... in the case of in vitro fertilisation every fertilised egg is initially treated as an evolving end in itself. The supernumerary embryos only become supernumerary after the process of quality control and implantation have taken place. Each of them could have been the embryo that was implanted and became a human being ...”<sup>18</sup>

“... supernumerary fertilised eggs are embryos that statistically speaking one may say *were given a chance to become a child*. To treat with respect an embryo outside a woman’s body implies in our view to give it a (statistical) chance of developing into a child. Research on embryos is only permitted when the embryo has been created with the intention of becoming a child. This is the case when only chance made the egg redundant or supernumerary with regard to the achievement of

15. J. Saugstad, “Abort” [Abortion], in K.E. Johansen (Ed.), *Etikk [Ethics]*, Oslo 1994, p. 282.

16. Saugstad 1994, p. 282.

17. Ibid.

18. B. Solberg, B. Myskja, “Terapeutisk kloning og instrumentalisering av livets begynnelse” [Therapeutic cloning and the instrumentalisation of the beginning of life], *Kritisk Juss*, 28, 2001, p. 264.

a successful pregnancy. Only in such situations should research on embryos be considered acceptable”.<sup>19</sup>

## V. On moral status, human dignity and the notions of porosity and vulnerability

What does it imply to treat a fertilised egg, embryo or foetus in a dignified way?

FIRST ANSWER: There exists no definitive or content-full answer to this question.

SECOND ANSWER: Because the concept of ‘man’ is a *porous* concept ‘human dignity’ becomes a *vague* concept.

“Porosity is often used in relation to physical objects to emphasize that one may never be sure that a concept which describes a physical entity is completely defined. In this way it is signalled that a situation may always occur where something one would call a ‘man’ bears a trait that should not be attributed to human beings, or simply that science figures out something about human beings which today would be unthinkable for any one of us”.<sup>20</sup>

“Human dignity is a concept that describes a value that is attributed to human beings, to all human beings and to everybody to the same extent. What this implies and what this means has varied and still varies. The strength of ‘human dignity’ is exactly this sort of vagueness. It is not in the need of a more precise definition, not even within the framework of an argument aimed at persuading us that research on fertilised eggs should not be permitted”.<sup>21</sup>

### Concluding remarks

In this paper I have been focusing the attention on just a small selection of the diverse views about the moral status of unborn babies and supernumerary fertilised eggs, which appear in the literature. Person-

19. Solberg and Myskja, 2001, p. 264.

21. *Ibid.*, p. 35.

20. Skrikerud 2003, p. 31.

ally I hold the view that well-founded doubt about the rightness of our moral deliberations, practices and visions is always better than unjustified confidence and conviction, even when we strive to decipher the moral status of unborn babies and supernumerary fertilised eggs. Consequently, I feel it is justified to remain in doubt about the exact nature of their moral status.

**Epilogue:** “Twice man starts his life: when he takes his first step and when reality becomes a mystery which he seeks to resolve. Not everybody experiences fully the second awakening to life, although everybody once was close to it”.

“Brother man, try not to grasp the roots of the water lily. Do not descend into yourself to bring forward what dwells in your depth. Remain a mystery to yourself”.<sup>22</sup>

22. Albert Schweitzer, *Philosophical Nachlass*.

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# 6 Autonomous Decisions in Embryo Selection

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## Introduction

The expansion of genetic testing has presented physicians (and society) with difficult questions about the choices that should be available to parents when selecting embryos for implantation. The most controversial choices relate to selection based on information not relevant or necessary to the proximate goals of a successful pregnancy and birth of a healthy child, such as gender (in the absence of sex linked genetic diseases), cognitive abilities, physical appearance and tissue typing. While some advocate liberal policies that are highly deferential to parents and reproductive autonomy,<sup>1</sup> others recommend limiting the availability of tests and some choices through regulatory bodies like the Human Fertilisation and Embryology Authority (HFEA) in the UK.

In this paper I will explore the role of autonomy in embryo selection for implantation and address these questions: What is an autonomous decision in regard to embryo selection? Whose autonomy is involved? What limits are or should be placed on the options of the decision makers involved, and who is or should be responsible for setting those limits?

Before answering these questions, I think it is useful to describe and compare two possible contexts in which decisions related to embryo selection may be made: a medical model and a consumer model. A medical model is relevant because pre-implantation genetic diagnosis of embryos is one of the services offered by specialists in reproductive medicine. Consideration of a consumer model is prompted by the fact that assisted reproductive technologies and genetic testing (at least in the United States) are relatively unregulated other than by

1. J.A. Robertson, Procreative Liberty in the Era of Genomics, *American Journal of Law & Medicine* 29:439–487 (2003).

market forces.<sup>2</sup> I will use this comparison to draw attention to the effects of incorporating features of a consumer model into this area of medical practice and not because I think it is the better model for providing services related to PGD.

## Medical versus consumer model

A medical and a consumer model differ in regard to the actors, goals and values that are involved. Decisions and behaviours in each model are also guided by different ethics and standards. In the medical model, the primary actors are physicians and patients who are involved in a personal and intimate relationship. Because of their unequal knowledge and skill (in medicine) and the patient's need to trust the physician, the relationship is defined as fiduciary in nature with the physician having an obligation to put the interests of the patient above his or her own. This is consistent with the overarching goal in medicine to do what is best for the patient to achieve health.

By contrast, in a consumer model the actors are sellers who market their goods or services to buyers or consumers. These sellers and buyers interact primarily as strangers in what is sometimes described as arms length transactions and sellers do not have fiduciary responsibilities to consumers.<sup>3</sup> The primary goal in a consumer model is maintaining profitability by providing goods and services responsive to consumers' needs, desires and purchasing power.

Whereas medicine places value on things like health, compassion, trust and fairness, in a consumer model profitability, competition, and efficiency are valued. These core values are reflected in the ethical principles and normative rules that guide behaviours in each model. In medical ethics discourse, the principles of non-maleficence, beneficence, respect for persons, and justice are often referred to in analysing dilemmas and determining the right course of action.<sup>4</sup> It is

2. K.A. Byers, *Infertility and In Vitro Fertilization, A Growing Need for Consumer Oriented Regulation of the In Vitro Fertilization Industry*, 18 *J. Legal Med.* 265 (1997) at 295; New York Task Force on Life and the Law, *Assisted Reproductive Technologies, Analysis and Recommendations for Public Policy* (1998); D. Adamson, *Regulation of assisted reproductive*

*technologies in the United States, Fertility and Sterility*, 78: 932–942 (2002).

3. Although those who serve in various capacities within a business organisation may have fiduciary obligations to shareholders and investors.

4. K. Madison, A. McCall, G. Laurie, *Law and Medical Ethics* 6th Ed. (Butterworths 2002), at 6.

beyond the focus of this paper to elaborate on the issue of principlism in medical ethics since my audience is familiar with it.

Ethics in a consumer model is rather different. In business courses and texts, the core ethical principles are identified as: freedom, honesty, truthfulness and promise keeping. And the business community seems to generally recognise these principles in forming codes of ethical conduct. However, judging by examples of the principles of ethical business conduct of some companies, discourse on ethics within business relies less on the identification of core principles and their application to dilemmas to arrive at the “right” thing to do, and more on the development of codes of personal behaviours that relate to responsibilities individuals have toward the business organisation, not consumers.<sup>5</sup> In this commercial context it appears that freedom refers to respecting the freedom of others to enter into contracts of their own choosing and not manipulating or coercing others into transactions. It also requires avoidance of situations where independent business judgment might be compromised, for example by placing oneself in conflicts of interest. Attention to honesty means not distributing false information and promise keeping means following through on commitments made to clients, for example to deliver goods and services as contracted for.

In both a medical and a consumer model, ethics and law play a role in setting standards for behaviour. Which of these plays the more dominant role in either model may be difficult to assess in part because law (unlike ethics) is jurisdictional and the degree to which the law intervenes and imposes standards will vary from jurisdiction to jurisdiction. Nevertheless, if we view law as setting minimum standards that must be adhered to, while ethics includes standards and ideals that one aspires to, I think it is possible to make some general conclusions about the relative influence of ethics and law on standards in medicine versus commerce.

Medical professionals tend to take their obligations to patients seriously, to commit to doing the right thing, and to strive for the highest level of ethical practice. This is not to say there hasn't been the need for the law to step in and impose standards and rules in medi-

5. For discussion of how this is evident within the managed care industry see, W. Mariner, *Business vs. Medical Ethics: Conflicting Standards for Managed Care*, *J of Law, Med & Ethics*, 23:236–246 (1995) at 238. Examples for other industries can

readily be found on company websites. e.g. Prudential Insurance at <http://www.prudential.com/index>; The Walt Disney Corporation at [http://corporate.disney.go.com/corporate/conduct\\_standards.html](http://corporate.disney.go.com/corporate/conduct_standards.html)

cine. On the contrary, the law has imposed rules on medical practice as evidenced by the establishment of patient rights. However, commitment and concern over ethics and doing the right thing (in regard to consumers) is much less evident in a commercial model. Business ethics rarely demand more than what the law (or the need to appeal to buyers) would require. Consumer protection laws therefore become necessary to level imbalances between sellers and buyers and to ensure at least in some circumstances that consumer welfare takes precedence over sellers' interests. This is achieved for example by laws requiring sellers or manufacturers to disclose information about goods and services that might not be readily apparent to the consumer, and by setting product safety standards.

### Autonomous decisions

Autonomy basically means "self-rule"<sup>6</sup>, regardless of whether we are talking about autonomy in medicine or in commerce. An autonomous decision is one made by an individual with capacity to act from reasons, values and goals that are one's own. Autonomy also requires that the individual accept responsibility for his or her actions and choices, even if adverse consequences result.<sup>7</sup>

In medical ethics, discussions of autonomy usually focus on patient self-determination and the obligation of physicians to respect patient choices, particularly when they differ from the physician's recommendations. It is the patient who makes the ultimate decision to proceed with treatment or not, but patients can neither demand nor order treatment that deviates from the relevant standard of care, nor can they dictate how procedures are performed. For example, patients have the right to refuse life saving treatments such as blood transfusions if they prefer to do so. Such patients do not, however, have the right to insist that surgeons perform a procedure that is likely to lead to the need for life saving transfusion despite such refusal and physicians are not obligated to go along with such choices.<sup>8</sup> Likewise,

6. B. Lo, *Resolving Ethical Dilemmas, A Guide for Clinicians* (Williams & Wilkins 1995) p. 17.

7. G. J. Annas, *The Rights of Patients* (Southern Illinois University Press 2004) at 78.

8. However, the law would not necessarily view a physician's performance of a procedure in reliance upon such refusals and the patient's assumption of the risk as evidence of negligence. See for example, *Shorter v. Drury*, 103 Wn.2d 645, 694 P.2d 116 (1985).

physicians are not obligated to comply with patients' requests for prescriptions for drugs simply because patients want them. Laws that regulate abortions and assisted suicide place additional limits on patient autonomy. Thus, regardless of the dominance of patient autonomy in American medical law and ethics<sup>9</sup>, it is not an absolute value or right.

Furthermore, patients do not exercise autonomy in isolation, but in the context of a relationship with another autonomous actor – the physician.<sup>10</sup> The autonomy of physicians is limited by their ethical obligations to respect patient autonomy<sup>11</sup>, the law and the organisational structures in which they practise. Nevertheless, physicians are chiefly responsible for setting standards of care. Professional standard doctrine in tort law even defines standard of care in terms of professional custom.<sup>12</sup> In summary, decision making in a medical model is an interactive process between two sets of autonomous actors: patients and physicians who share the goal of doing what is best for the patient.

In a consumer model, we also have two sets of autonomous actors: providers of goods and services (sellers) and consumers (buyers). Sellers are prevented from exercising limitless “self-rule” by laws that prohibit or restrict the sale of certain goods (e.g., firearms, tobacco, alcohol, pharmaceuticals and other drugs), governmental price controls (in regard to some goods) and the market. Some of these restrictions can also affect consumer choices (and hence their autonomy). Consumers can also only exercise free choice in the market to the extent that they have the ability to pay for goods and services. But in general, once a product is legally on the open market, whether or not an exchange of goods or services occurs is up to the decisions of willing sellers and willing buyers.

Having described these two different contexts for decision making, I will use the example of screening embryos to identify those with genes for perfect pitch to explore how conducive to a consumer model of autonomy reproductive medicine should be.<sup>13</sup> I realise that no

9. R. Dworkin, Getting What We Should from Doctors: Rethinking Patient Autonomy and the Doctor Patient Relationship, *Health Matrix* 13:235–296 (2003), at 239.

10. For discussion of the process of decision making in medicine, see J.Katz, *The Silent World of Doctor and Patient* (1984).

11. See supra note 9 and E. More, The Remains of the Profession, or What the Butler Knew, *Annals of Internal Medicine*, 134:255–259 (2001).

12. G. Annas, S. Law, R. Rosenblatt, K. Wing, *American Health Law* (Little Brown and Company 1990) at 411.

13. I choose this example because of its effective use by John A. Robertson supra note 1 at 464–466.

gene encoding for the ability to identify and recall musical notes has been identified and that the likelihood of any embryo having any such gene would be relatively rare.<sup>14</sup> Nevertheless, this cognitive ability represents screening for characteristics or traits unrelated to health and provides an opportunity to consider what, if any, limits should be placed on parents' access to pre-implantation genetic screening (PGD) and the role of physicians in assisting parents who want a child with particular traits.

Perhaps the strongest case for not restricting the use of PGD to screen for perfect pitch has been made by John Robertson, a leading advocate for procreative rights. Yet even he does not support the notion that parental autonomy in this regard should be absolute or that parents should be able to screen and select embryos on any basis. Instead he would require that available screening and selection techniques serve important reproductive interests and not cause unacceptable harm (to offspring or others in society).<sup>15</sup> Consequently, he would place a burden on parents to demonstrate (presumably to the physician) that they have a "strong enough" case for selection on the basis of perfect pitch (or any other trait unrelated to health). What suffices as a strong enough case by parents in his view, however, is not entirely clear. The strongest case would be "if they would not reproduce unless they could select that trait, and they have a plausible explanation for that position."<sup>16</sup> That burden being met, he would additionally require that the trait relate to a reproductive goal that deserves respect, and that the trait be consistent with respect for the resulting child. In his view having a child with perfect pitch relates to a reproductive goal and wanting a child with that trait is consistent with respecting such a child. Finally, since there is no societal stigma attached to persons who lack this trait, he concludes that selections based on this trait would be acceptable.<sup>17</sup>

While Robertson readily envisions parents meeting their burden for selection for perfect pitch, he reaches a different conclusion about traits like eye and hair colour. Basically he finds it implausible that any parents would not reproduce unless they could select for eye or hair colour and therefore unlikely that any parents could make a sufficiently strong case for selection on the basis of such characteris-

14. Robertson supra note 1 at 464 citing D. Drayna et al, *Genetic Correlates of Musical Pitch Recognition in Humans*, *Science* 291:1969–1972 (2001).

15. Robertson supra note 1 at 446.

16. *Id.*

17. *Id.* at 465.

tics. On the off chance that some parents would hold eye or hair colour in such high regard, however, he nevertheless suspects that providers might reject such requests as trivial and this becomes critical in drawing the line between acceptable and non-acceptable uses of PGD.

Robertson's distinction between these traits on a scale of triviality doesn't hold up and personally, I think it just as plausible that some parents would place the same significance on physical features like eye colour, as on perfect pitch. But what I find most troubling about the criteria he has developed is how closely it resembles a model of assisted reproductive services more in keeping with a consumer model than a traditional medical model. What I think he has done is confuse desire and longing for a particular type of child with respect for that potential child and elevated that desire to such a degree that the legitimate goal of reproductive medicine – helping couples have a healthy, genetically related child – is transformed to a goal that more closely fits with a consumer model – helping parents select *the* child that fits their ideals. The embryo – and therefore the potential child – becomes a commodity and the parent-child relationship itself is trivialised.

What he has described, however, is not far off from what is emerging as the applicable standard: if the procedure is safe and the physician obtains the informed consent of the prospective parents, the screening can be performed and selection made on the basis of results. The physician's role in assessing the triviality of the parents' choice under the Robertson standard is more like the role of a broker and less like a medical professional. Decision making draws further away from the shared process described in the medical model and approaches simple consumer choice.

If Robertson's justifications and criteria are unsatisfactory, what then would I offer in its place as a standard for selecting from among embryos for implantation? I don't have one. But I am convinced that a standard in keeping with a consumer model should be carefully avoided. The answer lies not in encouraging physicians to focus more concern on fulfilling the desires of parents, but in requiring that they focus more intently on the potential child. The critical question therefore becomes: What if any obligations do they have to the potential child? Are they fiduciary obligations? In other words, should the prospective child be viewed as a patient? The more they are treated as patients, the less likely it is that PGD will become just another consumer service.

## Conclusions

No one (including John Robertson) would seriously recommend that reproductive medicine should wholeheartedly embrace a consumer model. But if we are to avoid its dangers and keep PGD well grounded in the traditional values, goals and ethical standards of medicine, the profession has to accept responsibility for developing standards. If it does not, then that responsibility will fall to the law and regulators.

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## 7 The child's perspective and the parents' – who should decide?

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Every day a paediatrician must try hard to understand the child's perspective when taking decisions involving children. So what is a child? A child from a paediatric point of view is a growing human being physically and psychologically immature and therefore dependent on adults for survival. Dependency means vulnerability. For most adults, national states and authorities officially claim that a child like a grownup human being has a right to full integrity i.e. not to be used bodily or mentally for any other purpose than the child's own well-being. A child has however, a limited but growing autonomy to protect this right to integrity and thus a child's autonomy must be substituted.

Ten years after the UN Declaration of Human Rights it was clear that children were still less protected than adults and needed a separate declaration, which was delivered by the UN in November 1959 (The Declaration of the Rights of the Child) in which it states "The child by reason of his physical and mental immaturity, needs special safeguards and care, including appropriate legal protection, before as well as after birth". Thirty years later it had become clear that the declaration was not being followed but children continued to be used and abused for hard unpaid labour, prostitution and as child soldiers. In November 1989 the UN decided on the Convention on the Rights of the Child (1) and today all member states except two have ratified this convention, meaning that the states have a legal obligation to follow this declaration. One important article relevant to the present discussion is article 3 which states: "In all actions concerning children, whether undertaken by public or private social welfare institutions, courts of law, administrative authorities or legislative bodies, the best interests of a child shall be a primary consideration".

When discussing the child's perspective in the field of preimplantation genetic diagnosis (PGD) and embryo selection there is a range of different problems; from PGD for carrier identification of a severe disease with Mendelian inheritance where the families already have a severely ill or perhaps already deceased child, to the potential use of this technique for selection of e.g. sex or eye-colour. In the first case it is not difficult for me to be positive about using prenatal diagnostic instead of foetal diagnostic tests, thereby avoiding perhaps repeated abortions whereas it is clear to me that using these tests for selecting a child for non-medical purposes has severe ethical consequences, especially in relation to our view of the child as a subject and a goal in itself. More difficult problems arise in the grey zone in the middle of these two extremes and I have chosen to discuss the child's and the parents' perspective on the problem of using PGD for HLA diagnostics to create a child who could become a stem cell donor for a child in the family who is already sick.

The debate started in the year 2000 when Adam Nash was born after PGD-HLA analysis to provide cord blood stem cells to his sister Molly who was suffering from severe Fanconi anaemia. The public debate, especially in the US, was intense, and different ethicists, natural scientists and doctors took part in the debate both in the public media and in scientific journals. Indeed, in February last year (2004), this very case was publicised again to show that both children survived and were healthy. Clearly this case has increased the optimism worldwide about using this technique for treatment of many diseases which could be treated by bone marrow transplants and even more efficiently by cord blood (stem cell) transfusion.

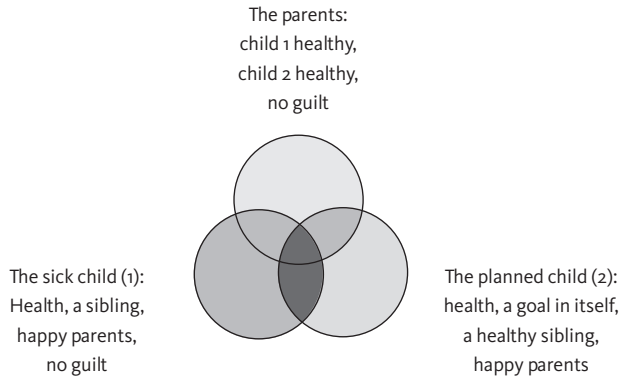
Indeed, the Article 3 is relevant here but in Article 6 in the Convention on the Rights of the Child it is stated that:

"1. State Parties recognize that every child has the inherent right to life, 2. State Parties shall ensure to the maximum extent possible the survival and development of the child". In the case of Molly and Adam clearly two children are involved but the question is – should one child be born to become a cell donor for another child and if so, on what premises?

Figure 1 shows the conflict of interest between the three involved parties. 1. The parents, whose interests obviously are firstly to help their sick child to become healthy, might also primarily be wishing to have another child whom they wish to be healthy.

**FIGURE 1.**

PGD-HLA: The conflict of interest



The parents have an obligation to do the best for their children and in this situation they clearly want to fulfil this obligation and have no guilt for not doing so.

The sick child has an interest in being healthy. She might also wish to have a sibling. She will clearly have happy parents and not feel guilt herself.

The planned child has an interest in being healthy but also to be a goal in itself (this is the main humanity rule: that every human being has a right to be a goal – not just a means for others!). Clearly also this child will have an interest in having a healthy sibling and happy parents.

In analysis, these three dimensional conflicts of interest, primarily for the potential benefit of the recipient child, must be identified, and then balanced against the potential risks for the donor child. Risks and benefits have several dimensions including statistical risks (absolute and relative), risks experienced and also certainly there may be other risks which are still unidentified. With regard to the benefits for the recipient child, a recent paper in the international scientific journal Bone Marrow Transplantation (Benito *et al.*) reviews outcomes achieved after cord blood transplantation (2). The review is mainly based on the results from the International Cord Blood Transplantation Registry (ICBTR) and EUROCORD, which together now cover up to 70,000 cord blood units, from which more than 2,000 CB transplants have been performed, mostly in children, for treatment of a variety of malignant (mainly leukaemia) and non-malignant (mainly immune deficiency, myelodysplasias and other inborn errors of metabolism) diseases.

Clearly the results differ between related cord blood transfusions (in which overall survival was reported to be 63% after one year and 46% after two years) in contrast to unrelated cord blood transfusions where overall survival in EUROCORD was reported at 29% at the follow-up after one year and the Minnesota/Duke Hospital reported up to 40% after two years. Positive prognostic factors were non-malignant underlying disease, HLA-identity, young age, and cell dose. In the case of an HLA identical donor and a recipient having a non-malignant disease, one year survival could be up to one year. On the other hand, at two years of observation, even in this favourable group only 80–90% were event free (free of relapse) at two years follow-up. In this broad review each result depends on rather small data samples and short follow-up times, but clearly for some of the non-malignant diseases such as combined immune deficiency the results seem very promising.

With regard to the risks for the donor child there are two categories of risks:

1. The physical risks depending on the IVF and PGD procedures:

Today much knowledge has accumulated regarding the risks for children born after in-vitro fertilisation (IVF) for infertility reasons. The major risks are prematurity, which in turn to some degree depends on multiple births, the latter occurring in 40–50% of children born after IVF procedures. Risks are greater since premature birth, especially before 32 weeks of gestation, is associated with high risks of neonatal complications such as lung complications, cerebral haemorrhage and severe infectious diseases, all of them which might lead to chronic handicaps. In addition, an increased prevalence of malformations has been observed.

In a very large population-based study using pre-recorded data on 5,680 children born after IVF and 11,360 matched controls, perinatal risk factors recorded in the Swedish Medical Birth Register were compared with data from the records in the Swedish Rehabilitation Centres (3). It was then shown that children born after IVF were significantly more likely to need rehabilitation services when followed up at 1–14 years of age (factor 1.7). Forty-three per cent of the IVF children were born in multiple pregnancies, which is a clear risk factor for all types of neurological and other handicaps such as blindness. When looking at single births only, the risk for neurological handicap was still increased (factor 1.4), the most common diagnosis being cerebral palsy, which affected 0.37% versus 0.14% of children of the general population. Overall the excess risk for prematurity was high even with single births, 11% versus 5.4% and severe prematurity 2.6 ver-

sus 1.2%. The risk of malformation has also been shown to be slightly but significantly increased (5.4%) (factor 1.5) (4). A three-fold increased risk was seen for neural tube defects, alimentary atresia, omphalocele and hypospadias.

The increased risk of neurological handicaps, from all causes, did not disappear after adjusting for possible confounders such as maternal age, male sex, low birth weight or low gestational age, whereas the increased risk of malformations largely disappeared after adjustment for year of birth, maternal age, parity and period of unwanted childlessness.

It is thus clear that the IVF procedure is not harmless although a large proportion might be explained by a high frequency of multiple births and to some extent by maternal characteristics (3, 4). These figures might not be representative for mothers who undergo in-vitro fertilisation when not being infertile, but some of the excess risk might still be there especially if the IVF procedure includes more than one embryo implantation. The PGD procedure itself could add to these risks but the magnitude of these is still completely unknown. The series published on the outcome of the child as to e.g. gross malformations and birth characteristics are much too small to give any statistical basis for the detection of less common handicaps which might still be severe.

Clearly even less is known about the psychosocial effects of being born using the PGD-HLA technique to design an ideal cord blood donor to a chronically sick child. However, some information could be extracted from the rather extensive literature on siblings of severely handicapped children. In well controlled, adequately based studies of siblings of severely handicapped children it has been shown e.g. that there is a greater risk of aggressiveness and depressive symptoms and also of social isolation at follow-up 11–23 years (5). It has also been shown that different background factors such as birth order, age spacing, sex and socio-economic status affect the psychosocial risks for these children (6). It is notable that being a younger sibling close in age to the handicapped child scored higher in psychological impairment at long-term follow-up.

There are several different possible outcomes for both children i.e. the chronically sick child could either be cured by the cord blood stem cell transfusion but alternatively – depending on the nature of the disease – the child could continue to be sick and need repeated bone marrow transplants, and in the worst case this child could die. The child who is born as a donor would, in the majority of cases, be

physically healthy and be donating only cord blood. However, it must be considered that this child may be repeatedly donating bone marrow when the sick sibling is not cured by the cord blood. In the worst case this child is also born with neurological and other handicaps due to the IVF and/or PGD procedures. Thus we have six possible scenarios to consider when evaluating the risk-benefit relationship.

**FIGURE 2.** The possible combinations

• Child 1 healthy,	Child 2 healthy (ideal)
• Child 1 sick,	Child 2 healthy
• Child 1 dies,	Child 2 healthy
• Child 1 healthy,	Child 2 sick
• Child 1 sick,	Child 2 sick
• Child 1 dies,	Child 2 sick

All other scenarios than the ideal will add on negative effect on child 2 (who was born to cure)

In the case that both children become and remain healthy, probably the potential psychosocial consequences of the procedures for all family members will be minimal and perhaps only positive for the donor child. However, in all other scenarios the psychosocial consequences are different and increasingly hazardous. When considering these scenarios in relation to the risks and benefits in the light of the Convention of the Rights of the Child, I would conclude that:

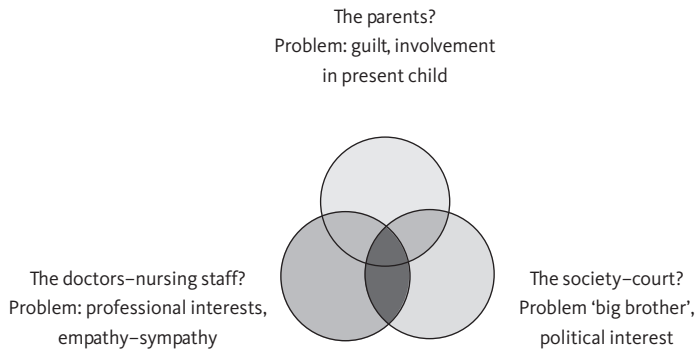
- Many different aspects of risks and benefits must be considered in the individual situation from the child's perspective before using PGD-HLA to design a potential stem cell blood donor for a chronically sick child.
- The physical risks and outcomes for both children will clearly potentially affect the long term psychological and social aspects of life and may become a life-long handicap.
- In the analysis and decision-making stages, most emphasis must be put on considering the planned child whose interests are least well protected.
- Finally it must be remembered that society will break a fundamental ethical boundary by creating a human being for the benefit of another and we must consider the slippery slope we are embarking on.
- It is also very important to consider and support the present and potential alternatives.

Thus a strong support should be offered for developing cord blood banks and associated HLA-registers for effective searches for HLA-compatible but unrelated stem cell donors. Moreover, in the future, stem cell lines may be created from an HLA-identical embryo as identified by PGD. This would be an alternative for parents with a sick child without taking any risks associated with the creative of a potential donor child, and it may work much faster and thus increase the chance of benefit to the sick child.

### Who shall decide?

Figure 3. illustrates the three different potential decision makers and the problems with each of them.

**FIGURE 3.** Who shall decide?



Clearly the parents must be involved in the decision and their refusal should be fully respected. On the other hand the parents cannot be left alone with the final decision to create a child with HLA identity to a chronically sick child. The parents' strong wish to help their chronically sick child will dominate and their guilt may become an overwhelming problem if there is a negative outcome i.e. any of the five non-ideal scenarios discussed above occurs.

Should then the doctors and/or the nursing staff decide? The doctors and nursing staff are also involved with the sick child and their family and they will not be unbiased in their decision since they are both professionally and emotionally involved with the family and espe-

cially the sick child. Their dominant professional interests are primarily to cure the existing patient. The third possibility would be that a societal body e.g. a specific health authority or even a court should make the decision. In this case some people might feel that the power is put too far away from the individual family. On the other hand, when new technologies are developed that can be potentially harmful, politicians, in a democratic society, must take the responsibility to set the limits. It is a societal duty to set principles, guidelines or even laws to protect the members of their society, taking into account both national traditions and views and international declarations and conventions. In this case, the society has the responsibility to protect and do the best for present and future children. The weakest person in this specific case is the planned child. A model of decision-making, as practised in the UK by the Human Fertilisation and Embryology Authority, might be considered. As a paediatrician I will say that the parents can never be blamed for their wishes but they cannot be left alone with a decision like this. In a famous book on medical research with children edited by R.A.M. Nicholson (7), it is stated that "We recommend that parents and guardians should be considered as trustees of a child's interests rather than having rights over the child. The prime consideration in any research involving children should be that it is not against the interests of any individual child". The same idea about the parents' role could be adopted in this case.

In conclusion it is my view that an independent board consisting of both experts and lay people should, for each specific case, analyse the risks and benefits for all involved and make the final decision, after careful interviews with both parents and the team caring for the affected child.

Finally I would wish to state my personal views on whether we should or should not allow PGD-HLA for cord stem cell donation with the present knowledge as to risks and benefits as follows:

- PGD-HLA for stem cell donation involves taking a clear step towards making an individual child, a means rather than a goal, offending a basic and widely accepted ethical principle, and involves potential psychological, social and also physical risks for the donor child. According also to the principle of caution the technique may only be considered in carefully selected cases of severe life threatening situations of diseases with a Mendelian trait, meaning that the PGD procedure per se will also benefit the planned child who will thus not have the risk of carrying the disease gene.

- Society should provide the means for alternative treatments and support existing sources such as cord blood donor banks and registers. The use of PGD-HLA for complex diseases or for other purposes should not be allowed. The possibility of using human embryonic stem cells made HLA identical to fit an existing sick child may provide a future solution.

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# 8 The ethics of PGD-regulation

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## **Introduction**

The development of preimplantation genetic diagnosis (PGD) has received a lot of attention since its commencement at the beginning of the 1990s, not only in the fields of reproductive medicine but also among lawyers, philosophers and politicians. Parliamentary committees and ethics committees specially assigned for dealing with issues related to PGD have assumed the task of balancing the interests and values believed to be at stake. (1, 2) In this article I will concentrate on the interests by different policy-making groups to regulate the practice of PGD. I will discuss some of the ethical arguments that have been used in the debate and by regulators, but I will not do this in a systematic way. There are already good and fairly comprehensive overviews concerning the ethics of PGD available elsewhere. (5, 6, 7) The focus in this paper is on the ethics of PGD-regulation.

## **Who is primarily concerned?**

For me it really started as a kind of fascination. How can one explain this great interest among policy-makers, lawyers and philosophers for a practice that is of direct concern to only a very limited number of people? I do not deny that PGD may be of concern to many others but it is useful to first consider the situation of those directly affected. They are not that many. The practice of PGD has evolved in clinics for assisted reproduction. The third report of the European Society for Human Reproduction and Embryology (ESHRE) has presented data from 25 centres performing PGD. (8) By the year 2000 there had been 886 referrals for PGD resulting in 163 pregnancies and 162 children born. In 2001 data from 12 centres were added giving a total of 1,516 referrals resulting in 459 pregnancies and 279 children born. In Sweden the most recent figures available are from Sept–Oct 2003 indicat-

ing in total 78 treated couples at two centres with 181 IVF-cycles resulting in 20 pregnancies. (9)

In addition to giving the numbers the data from ESHRE and others also provide a detailed account of who these individuals are, that is, the patients undergoing PGD. (3, 8) They are patients who have experienced repetitive miscarriages, they have previously given birth to affected children or they have experienced serial terminations of pregnancy. Genetic risk and objection to termination of pregnancy are the most important reasons for PGD. A high number of PGD cycles have been performed on patients carrying chromosomal abnormalities – they feel that PGD is their only hope of having a healthy child. (8, p. 243)

There is a relatively small number of individuals and couples directly concerned. They have a history of involuntary childlessness and a desire to have a healthy child, a perfectly legitimate desire which they share with many others whose chance to have their desires fulfilled is greater. Nevertheless, this practice is the issue for parliamentary discussions, regulation, and special ethics committees assigned to handle the sensitive ethical, legal and social issues believed to be at stake.

### **Different concerns**

In this context, as in all ethical and policy discussions, moral and social concerns should be taken seriously. However, one must realize that different parties may have different concerns. Taking the intense debate into consideration it seems that those situated at some distance from the actual practice of PGD have one set of fears and concerns while those directly involved have other kinds of concerns and fears. Those at a distance (e.g. politicians, ethical committees, parliamentary commissions and media) seem to be concerned with the, from their perspective, rapid development of reproductive technologies. The first groundbreaking report of PGD is not older than 14 years. A future of “designing babies” with whatever characteristics desired by the parents is a recurring theme. (10,11,12) That PGD will be used for non-medical reasons, such as selection of the sex of a child, constituting an unjustified discrimination against individuals based on sex, is another fear. Several examples of the use of PGD for this purpose have also been demonstrated. There may also be concerns in some quarters about who should “play God”, i.e. deciding who should live with what characteristics.

Those directly concerned may have other concerns. From the perspective of involuntary childless couples with a history of increased genetic risk and repetitive miscarriages, reproductive technology does not develop fast enough. Parents with a suffering and dying child looking for an HLA-identical donor with the help of PGD may fear that someone will eventually come up with an argument strong enough to prevent them from helping their child.

In order to sort out the arguments around the ethics of PGD-regulation different frameworks are possible. One may focus on i) the technology, ii) the situation of the couples, iii) the best interests of the child to be born.

### **Technology-related fears**

It may be feared that because of the rapid development of new technologies, reproductive decisions may be taken lightly. Sooner or later, it is believed, couples will come to PGD clinics with desires about hair colour, eye colour, sexual orientation, a perfect musical pitch and a variety of other non-medical traits. (5) However, there are no empirical facts available that can sustain this fear. Taking part in an IVF-procedure is a long, troublesome and winding road for couples. There is now good empirical evidence available to support the claim that participation in IVF involves difficult and serious decisions, not at all something taken lightly. (13) For PGD-couples it is, as described, an even more serious matter. In a study investigating the attitudes of 38 PGD-couples after taking part in a PGD programme, it was found that only 48% would use PGD for future pregnancies and 41% found it extremely stressful. (14)

It may be feared that even if serious defects leading to premature death are acceptable reasons for taking part in a PGD programme, there is comprehensive designing of babies around the corner. However, designing babies is not a feasible option, for several reasons. Firstly, in addition to the trouble and pain associated with the procedure, it is a fact that even when several oocytes are retrieved and fertilised there will only be a limited number of embryos of sufficient quality available for analysis and selection. PGD-couples experience even lower success rates compared with other IVF-couples due to their history of chromosomal or genetic defects. Seven viable embryos represent a high number for a couple. (15) It is therefore only possible to look for a very limited number of abnormalities or genetic character-

istics during one cycle. Even enhanced technological methods in the future using detection of single nucleotide polymorphisms and microarrays, will not overcome the limit that is set by the availability of viable embryos. (3) A second reason why designing babies is not a feasible option is the fact that the human characteristics believed to be objects of interest are the result of more than one or two genetic factors. These phenotypic traits are the result of several genes expressing their information together with environmental factors and the effects of pure biological chance. (16)

The best method to design babies is and will be to select your partner. Designing babies through PGD is simply not a feasible option, not now, nor in the foreseeable future. Since this is the case, using the argument about “designer babies” in preventing the development of PGD is a sign of lack of moral integrity.

The argument about “designer babies” is sometimes framed as a “slippery slope” argument. (17) The basic idea behind this argument is that there is an action A that may be morally permissible on its own grounds (e.g. using PGD for conditions associated with premature death). However, allowing this action to take place implies that one enters a slippery slope that inevitably will lead to the action B, an action that cannot be justified with the arguments in support of A (e.g. using PGD for any supposedly trivial design purposes). One clearly does not want to end up in B so therefore one should not do A either. It is a forceful but dubious argument. It can actually be conceived in two different ways: as a logical argument and as an empirical argument. As a logical argument it is too good. There is not even in natural science a process where one will inevitably end up in B by doing A since there are a host of influencing conditions that may change the course of development.

The slippery slope argument gains more support as an empirical argument. The idea then is that a moral degradation will take place as one gets used to intervening in and manipulating human life. However, in order to carry its presumed weight, the argument needs to be empirically sustained. The same kinds of fears were voiced in connection with the development of foetal diagnosis. One was concerned that reproductive decisions should be taken lightly, that it would lead to discrimination against those individuals carrying the characteristics that became reasons for termination of pregnancies and that disabled individuals with those features would not be taken care of properly. There is, however, no evidence that these fears have come true. On the contrary, few couples will terminate a pregnancy for trivial rea-

sons and there has been a growing concern for and attention to the needs of disabled persons in most societies. Regarding the care of disabled infants, it seems that a basic parental duty comes into play. All parents have wishes for their children. They want foremost a healthy child. Once born, however, the child is not an option. It is taken care of and loved for its own sake with all its individuality.

### **Focusing on the couple**

Taking the current regulations into consideration there seems to be a fear that couples will request PGD for non-serious reasons, if not for trivial reasons. In a report by a committee of the Swedish parliament in 1995 it was proposed that PGD should only be allowed for serious, progressive inherited diseases leading to premature death, conditions where there is no cure or treatment available. (18) An ethical consultation group argued against this but still proposed that PGD should only be available for couples carrying a specific monogenic or chromosomal defect with a high risk that the child will have a genetic disease or defect. (2) What is to be considered as 'high' is not explained. The problem here is who shall decide about the seriousness of the disease or the significance of the risk.

A couple with a child with galactosaemia, an autosomal recessive disorder, asked for PGD. They love their child and take full parental responsibility for it but they strongly feel that they would not manage to have another child with the same disease. A 38-year old woman with a history of several miscarriages strongly feels that she will not manage a child with Down's syndrome. She wants to take part in a PGD programme. A 36-year-old father suffering from hereditary prostate cancer, an autosomal dominant disease but with no genes yet identified and characterised, requests PGD. He is infertile and suffering from incontinence. There are frozen sperms available. A son would have a 50% risk of getting the same kind of cancer while a daughter would have a 50% risk of being a carrier. The father strongly feels that he cannot pass on such a condition to his son. There is no law prohibiting PGD in these cases in Sweden today but doctors are usually accommodating to decisions taken by the parliament and to the guidelines issued by ethical consultation groups. Taking the available rules and guidelines into consideration, all three cases mentioned would be disqualified for PGD.

Who should judge about the seriousness of a disease or a defect and about the significance of the genetic risk? An argument from the abortion debate may help as an analogy. As in PGD there is an ethical dilemma associated with abortion, even if it is judged by most people to be more serious to terminate a pregnancy in week 12 or 18 in comparison with discarding an embryo six days old. Much of the abortion debate rests on a false dichotomy. The interests of the child to be born are set against the interests of the pregnant woman, and the couple. This dichotomy seems, however, not to be a good description of the moral dilemma experienced by the women and couples involved. Janet Farrell Smith suggested that a better description of the dilemma is to consider the conflicts of interests between the woman and the foetus as a conflict between the need of a foetus for care and nurture in order to attain a healthy life as an infant and the ability of the pregnant woman to supply such care. (19, p. 269) Instead of a dichotomy one may perceive the situation, both with regard to abortion and PGD, from a premise of connection. The woman, and the couple, try to balance their duty to a child to be born with other duties they have in life, e.g. duties to each other and duties to living siblings. Since they will carry the burden of whatever the decision will be, they are the ones that should decide. (20, pp. 158ff) Each couple and each family history is unique. The couples themselves are best suited to assess their situation, what burdens they are willing to bear, and how serious the condition is. The couples should decide, aided by professional doctors, nurses and genetic counsellors with good knowledge of the specific case. Ethics committees and members of parliaments are too distanced.

### **From the perspective of the child**

The perspective of the child has been a major focus of ethical discussions related to PGD. (3, 5, 6, 7) I will not review the different arguments here; I will only discuss two specific aspects. It may be feared that the individual child born will not receive the same care as a healthy child. This fear has been expressed regarding selection of an embryo according to its HLA-type in order that a child born out of a PGD cycle can be a stem-cell donor for a sick sibling. (3, 4) There is, however, no empirical evidence sustaining this kind of fear. The premise of connection seems to be deeply grounded in the psychology of parenthood. The parental duty is strongly felt and once a child is born it is not a matter of choice. There are no indications at present that parents would

not love and take care of the child born under these circumstances to the same extent that they do for their other children. (7) From the perspective of the child to be born all medical risks must be appropriately assessed. Aggressive early cord clamping may deprive the donor of placental blood, and is a procedure that may harm a premature newborn. (21) Information of this kind should of course be communicated to the parents in order for them to make their assessment. This situation is, however, not new. The same kind of assessment is made by parents contemplating to volunteer their child as a bone marrow donor.

Regarding the use of PGD in order to help a sick sibling, it has also been feared that this would constitute an instrumentalisation of the child to be born. (4) A first response to this fear may be that concerning the actual love and care the child will receive there are no indications of this sort, and this is what really matters. There are too few cases available for an empirical investigation but lessons might be learned from other situations when children are volunteered as donors of tissue and organs for their siblings. One may also wonder what parents generally will answer their children when they ask why they were born. Will a child born because the parents wanted a sibling to their only child, or a boy after having three daughters, experience only an instrumental value? Or will a child not planned, just born out of an "accident" feel a victim of an accident? Presumably not, since in normal families each child born will be loved and taken care of as an individual.

### **Information about carrier status**

In Sweden the practice today is that information is not given about carrier status of the embryo since, even if it is a serious condition, it will not affect the child born. The common position seems to be that one cannot start selecting for non-carriers since we are all carriers. Each individual is carrying genetic dispositions that have no effect on the individual because there is only one copy of the gene. There is an unknown risk for everyone that the combination of one's own genes with the genes of another carrier will result in a child with a recessive disorder. In practice this position implies that if a couple with dystrophic dysplasia, a serious autosomal recessive disorder, is going through a PGD cycle that results in three perfectly viable embryos, A, B and C, where A is carrying two copies of the defect gene, B is car-

rying one copy and C has no defect gene, C will not be selected in favour of B. Whatever the choice is between these two, the child will not be affected. However, there is a risk that the child B will meet another person with one copy of the same gene and get pregnant, resulting in a sick child in the next generation. It should be observed that child B would not have a legitimate cause for complaint, either towards its parents or towards the clinic. The alternative for this child would be to not exist at all. (22) However, the parents of child B may have such a claim to make when their grandchild is born since they were denied the information about a possible future risk they may have wanted to consider. Now they are expected to care for this child according to duties of grandparenthood.

It is true that all people are carriers and most of us are ignorant about our status as carriers. In the case described the situation is, however, different. In this case there is information available about the risk, and if the risk occurs the condition is serious. In all other areas of life it is assumed that one should try to minimise risks and exposure to risk. There is also a specific responsibility, as far as possible, to try to control for both short term and long term risks, e.g. environmental risks, nuclear waste. There is also a growing concern about the need for prevention in order to control future health risks. Individuals are recommended to adjust their risk behaviour and to take part in different kinds of health promoting activities in order to reduce long-term health risks. The (grand) parents may rightfully claim that they did not receive all relevant risk information, even if a child who is a carrier for a recessive defect has a very low risk of getting a child with this defect (less than 1%). It should be observed that selecting C instead of B does not imply a discrimination against individuals living with this condition, in analogy with the argument proposed earlier in this paper.

From the perspective of the embryos it does not matter. Two embryos will be discarded whatever the choice will be. It should also be observed that with regard to foetal diagnosis, couples also have a right to know about additional findings. My conclusion is that, unless other and better arguments are presented, the practice of not disclosing carrier status is not ethically justified. It should be observed that from a practical point of view there may be other reasons why selection of non-carriers is not a desirable road to take. A selection of non-carriers would imply a decreased chance for a couple to get pregnant since instead of having 75% of the embryos for transfer one would only have 25%. In practice, selection of non-carriers may therefore not

be desired by the couples. However, *if* there are two equally viable embryos to select between, I still can not see why one should not select the one without any defect gene.

## **Policy and ethics**

It may be argued that because I consistently side with the involuntary childless couples against the efforts by legislators, parliamentary committees, ethical committees and consultant groups to regulate PGD I rest my argument on a “problematic separation between policy and ethics,” implying that in the end it is all up to individual choice. (23, p. 219) However, I have not argued this. On the contrary, policy and ethics, as I see it, are closely intertwined. What I have argued is that there is an ethics of PGD regulation and accordingly an ethical responsibility on those trying to make a policy by setting rules and guidelines at a distance of those most directly concerned, i.e. the couples involved in PGD programmes. The couples are the best to judge about the seriousness of genetic risks and disease conditions. The couples are the ones who will bear the burdens of any decision and policy. The children to be born are important stakeholders but I regard their parents to be the best suited to take their interests into consideration.

Furthermore, policy is not just a matter of legal and political decision-making. A policy about reproduction is something that evolves in the everyday life and decisions made by the citizens of a society, guided by social conventions, moral norms and previous legislation, adjusted as technology develops. The policy of reproductive technology is formed by involuntary childless couples, and by their doctors and their nurses. What is remarkable in the debate about PGD is the view that there is a need for an entirely new policy, to be issued by specially assigned policy makers, i.e. politicians, philosophers, lawyers and medical ethicists of various disciplines. One seems to have forgotten that PGD is part of a long development, preceded, for example, by foetal diagnosis. One strange effect is that decisions completely within the jurisdiction of individual couples in association with foetal diagnosis, e.g. decisions about reasons to terminate a pregnancy within accepted time limits and the right of access to all information, are denied PGD couples. There is also in most countries already an accepted policy with regard to the handling of surplus human embryos with permission to perform research on them until day fourteen, several

days after they are usually discarded in association with a PGD cycle. There is no new policy needed, and no interventions needed in clinical decision-making.

### Acknowledgement

I would like to express my gratitude to the participants of the conference for valuable comments on my presentation and also to Elisabeth Blennow for reading and giving valuable comments before submitting this article.

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# 9 The concept of selection: When are you selecting? Is it discriminatory?

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The word “sorteringssamfunnet” (the sorting society) is in Norway a word with enormous power in the bioethical debate. Norway, which in 2003 got one of the strictest Acts in Europe on medical use of biotechnology, has legitimized this law mainly with reference to the fact that we do not want “the sorting society”. What is fascinating in public debates is that the debate is not so much about what the “sorting society” is and why it eventually is a very bad thing – rather this catch phrase enters into the debate to demonstrate that you have the ethics on your side if you are sufficiently against the “sorting society” (1).

Whether it is the public debate on the “sorting society” or whether it is for other reasons I do not know, but the fact is that Norwegian women have been and continue to be rather modest in their demand for prenatal diagnosis and selective abortion. All pregnant women over 38 years are offered an amniocentesis in Norway, but only 40% take the test (2). A recent study from the National Centre for Foetal Medicine, showed that in the last five years, the number of selective abortions in the middle counties of Norway has not increased, compared to the five previous years (3). In fact, the number had decreased. That means that several pregnant women have carried babies with lethal anomalies to term. It also means that some pregnant women have carried to term babies with, for instance, Down’s syndrome.

I think it is good that the women carry these pregnancies to term. This is not because a high demand for prenatal diagnosis and selective abortion is necessarily problematic, nor because a high demand is a proof that women do not have a free choice. But rather the opposite, in a way; low demand for prenatal diagnosis, and the fact that women carry to term babies with severe disabilities, is a proof that it is possi-

ble to choose differently. It is a proof that the policy of non-directiveness in genetic counselling is implemented.

Some Norwegians would claim that there is cultural pressure in Norway not to have a selective abortion. But I don't think there is empirical evidence for this claim, and we should remember that the huge majority still choose abortion when serious conditions are detected.

Let's return to the concept of "a sorting society". Sorting has something to do with selection, and of course there are some implicit vague references to the selection between fit and unfit in Nazi Germany during the Second World War. With PGD you literally are sorting fertilised eggs – sorting between fit and unfit, sick and healthy. Consistently, since there are more obvious "sorting elements" in PGD than in prenatal diagnosis and selective abortion, there has been even more resistance in Norwegian politics to PGD than to prenatal diagnosis – although there is much scepticism about prenatal diagnosis in the influential groups that have been called "the moral minority" in Norway. According to the ethicist Knut Erik Tranøy and the geneticist Kåre Berg, a minority in the Norwegian public and parliament with a strong, explicit "value-commitment", has managed to present their values as universal values in these questions (4).

Is it then, possible to articulate a basis for this scepticism and fear of sorting and selection? If PGD is discriminatory in a way, who is the victim of discrimination? Who is being harmed by this selection? Is it the embryo with a disease gene that is discriminated by an unequal treatment compared to the healthy embryo? From prenatal diagnosis and selective abortion this argument is well known: if the abortion limit in a country is set for instance at the end of 22nd week of pregnancy, and abortion after that is forbidden, then it should be forbidden for abortions based on genetic indications as well as on social indications. If abortion after this is considered to be murder, then to allow abortions for a foetus with a serious disease or disability, would be an illegitimate unequal treatment of this foetus (5). But in Norway, as well as in many other countries, there is a limit for all kinds of abortions, so the problem of unequal treatment does not occur.

It is of course possible to argue this way about the embryo stage too. But that presupposes that the embryo is a person in the moral and legal sense. A powerful group in Norway, does not believe that the embryo is a moral person. These persons also support abortion on demand. How then, is it possible to give meaning to the point of view that PGD is discriminatory, from their point of view?

Here, I think the controversial so-called expressivist thesis plays an important role. Prenatal screening, for instance for Down's syndrome, can be accused of expressing a negative quality-of-life judgement on existing people living with Down's syndrome (6). These people and their families might feel that the national health service and their society judge their lives and their family relationships as (maybe) not worth living or not worth realising. And although this does not have to lead to actual discrimination (in fact it is possible that extra stress is put on realising the inclusive society in an era of prenatal diagnosis), it is plausible to perceive the "message" from such a screening as offensive from the perspective of someone with a disability. Again, it is important to stress that it is not an empirically proven fact that people with a disability are worse off economically, or less included in society. As I said, the opposite is probably the case. But it can still be said that there is a "message" from prenatal screening programmes and the "message" can be said to affect us all, in the sense that some people in society more and more will be seen as "living abortions" – those lucky or unlucky few that survived the screening programme. The message from the screening programme shapes our perceptions of existing people with severe disabilities. A new category of people arises; the category of those who maybe shouldn't have lived.

Now, if this is an articulation of the sorting or selection-critique of prenatal screening programmes, disability activists have argued that the critique is even more suitable for PGD. "Sorting is sorting", it has been argued, and with the only addition that earlier sorting is worse than late sorting because earlier sorting means *more* sorting (7). With PGD there will not exist any binding ties between the embryos and the mother, and the embryos will be judged by a cold and detached look, this position argues, both from the doctors involved and also from the mother. Selection will now be easier from an emotional perspective. And since the focus is not on the moral status of the foetus, but on the "message" to people with disabilities, the message gets stronger if early selection means more selection.

A statement from the Norwegian Handicap Association in 2004 confirmed this interpretation: In a comment to a much discussed saviour-sibling case in Norway Lars Ødegaard, the leader of the Norwegian Handicap Association announced that the Association could accept PGD in this situation where you are creating a new child to rescue the life of an existing sibling with a serious disease or disability. But the Association could not accept PGD in any other circumstances (cases where parents "just" wanted to create children without serious

diseases) because this would be to permit sorting of human life (8). In the same announcement Ødegaard was positive to medical research on spare embryos from IVF. He was in fact quite consistent if we interpret him in this way: The negative selection sends the message that a certain life is not worth realising. The selection of a positive sibling saviour sends no offensive message – but rather the inclusive message that society will try hard to prolong the life of a child with beta thalassaemia major. The same applies to research on spare embryos: No offence is given – there is just a possible benefit for people with serious diseases or impairments.

But is it really possible to defend such a position? I will give two arguments to show why it is difficult. Firstly I will draw attention to the relation between screening and offence. Secondly I will argue that there is, and necessarily has to be, a relation between offence and a certain view on the moral status of the foetus or the embryo.

### **The relation between screening and offence**

In many western countries there has been a tradition for viewing prenatal genetic services differently when they are offered to parents that already have got a child with a severe disability or to high risk couples, compared to when they are offered to every single pregnant woman. Among disability organizations this difference is recognized, and parents with children with severe impairments are frequent users of prenatal diagnosis in later pregnancies. Screening always means routinisation, automatisisation, effectiveness – all these elements that are so hard to combine with extensive counselling and informed choices. In high-risk strategies, burdens are more the core issue than likes/dislikes or prejudices. The disease may be well known in the family. The burdens and the blessings might be well known, too. PGD is ‘made for’ such risk couples; it presupposes IVF and it should be easy not to get out onto a slippery slope, if we do not want to. In general we could say that PGD has an *anti-screening character* and the anti-screening character of PGD means that the ‘message’ sent from PGD-services should be perceived as far less offensive than the ‘message’ sent from, for instance, a prenatal screening for Down’s syndrome (or other conditions) in pregnancy.

## Offence and the moral status of the embryo

The other limit of the offence-argument arises from the following question: – Is it possible to address the sorting/selection problem as independent from the problem of the moral status of an embryo or a foetus? In my opinion the answer is no. That does not mean that I think this is solely a question of the moral status of the embryo or the foetus. But I think it is easy to show that the moral status of the embryo has *something* to do with an eventual critique of PGD.

In order to show that, we could use a creative variant of Derek Parfit's famous example (9): A woman wants to become pregnant but she suffers from a temporary condition that could cause severe impairments to her child if she chooses to conceive now (for instance German measles). If she waits three months, she will probably conceive a healthy child. It is possible to argue that if the woman is advised to wait three months before conceiving, this advice sends an offensive message to existing people with equivalent impairments, suggesting that such lives should not be realised. However, to argue this way would be absurd to most people. The right thing to do seems to be to wait three months. Offence is not a relevant perspective here, because no problematic action is taken in order to achieve a healthy child. To wait before conceiving is not morally problematic.

You could reply "What then with a carrier screening programme before pregnancy?" Is it impossible to claim that it is offensive, since no foetus or embryo is involved? Well, one problem with carrier screening is that it is closely connected to prenatal diagnosis and abortion, or that it has a kind of compulsory nature in suggesting that certain people should not have children or not marry the person they love. In some way or other there has to be something 'morally problematic' added to the choice between health and disease. If not, all medicine would be offensive to certain people.

In my opinion, then, the more choosing of the healthy before the diseased is connected to some 'ethically problematic' act, the more plausible the argument of offence gets. This could be labelled 'a gradualist view on offence'. And what is interesting is that a gradualist view on offence would be a defence of PGD as a negative selection service to high-risk groups.

My conclusion is that the 'message' from selection is dependent on when the selection takes place and how the selection-service is offered to the public or to certain groups.

If we accept ‘children of choice’, to use John Robertsons phrase (10), through prenatal diagnosis and selective abortion, then negative selection through PGD cannot be morally more problematic, probably it is less problematic.

If we say yes to PGD for serious inherited diseases because we do not find it offensive, it does not necessarily follow that we should say yes to PGD and HLA-typing as a kind of positive selection. In other words, if we believe that PGD is not discriminatory and not more offensive, but rather less, than prenatal screening and selective abortions, we still have not solved the problem of using PGD and HLA to save a sibling. It might be correct to say that such use of the technology is not considered offensive by people having a serious disease or disability. But there might be other and far more important ethical problems in such cases as well as the problem of offence. In my opinion PGD used to create a new child in order to save a sibling, is a bigger ethical challenge than PGD used ‘just’ to create a child without an inherited condition. What was fascinating in Norwegian politics in the year 2004 was that the opposite seemed to be the political reality.

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# 10 The bio-politics of pre-implantation genetic diagnosis. A Norwegian case

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## **Introduction**

The case of Mehmet Yildiz recently provoked an intense public and political debate in Norway about the ethics and bio-politics of PGD. This account is structured around three main headings: the private case of Mehmet Yildiz; the *public* narrative of Mehmet's case; and the politicisation of Mehmet's case. The change in the law which followed the discussion of the case in the Norwegian parliament in May 2004 is also presented. Finally, the question, 'Why did the Mehmet case become political dynamite?' is addressed.

## **The private case of Mehmet Yildiz**

Mehmet Yildiz, aged 6 years, is a Norwegian-Turkish boy suffering from a serious genetic disease, beta thalassaemia major. The only existing curative treatment is stem cell transplantation (bone-marrow transplantation) from a genetically related, tissue-compatible living donor. The success rate with such treatment is well above 90%.

In Mehmet's family no compatible donor was found. The only alternative source for the stem cells Mehmet needs is umbilical cord blood (eventually in combination with bone marrow) from a newborn, tissue-matching sibling.

The alternative of undergoing a succession of pregnancies in combination with prenatal diagnosis and selective abortion until a matching foetus is traced has never been an option for the Muslim couple.

On the other hand, preimplantation genetic diagnosis (PGD) and the discarding of affected and/or tissue-incompatible fertilised eggs prior to implantation, is something the couple consider morally acceptable.

Although Mehmet's parents want to have a new child that is unaffected by thalassaemia, they want as well to be sure that the child is tissue compatible with Mehmet. Therefore, they started to pursue the possibility of having access to PGD of thalassaemia in combination with HLA-typing and IVF.

The lack of this kind of *explorative* treatment in Norway combined with the strict legal situation, compelled the parents to privately seek access to such treatment abroad.

In December 2003 they were offered treatment in Turkey. At that time the case was still unknown to the news media in Norway as well as to Norwegian politicians and the public.

On December 8, 2003 17 eggs were harvested from Mrs Yildiz. Out of 11 fertilised eggs, 8 were eligible for blastomere biopsy on day 3. Two embryos were found to be an HLA match and healthy thalassaemia *carrier*. These two embryos were transferred to Mrs. Yildiz on day 4 and pregnancy was obtained. She had an early miscarriage due to extra-uterine pregnancy.

### **The public narrative of Mehmet's case**

Approximately three months later I was contacted by Mehmet's physician. She informed me that one of the leading television companies in Norway – TV2 – had got hold of Mehmet's story. She had agreed to comment on the boy's present treatment situation. However, before she did that she wanted to be updated on the legal situation about PGD in Norway.

On January 1st, 2004, the newly revised Act on Biotechnology came into force. According to § 2.14 of the Act, PGD is permitted only in situations of serious, X-linked disease where there are no possibilities for treatment. According to § 3.1 of the same Act, research on fertilised eggs and human embryos is forbidden as well.

On February 28th and 29th the story of Mehmet's sickness was broken by TV2. The core message broadcast was that Mehmet would soon be at risk of dying if he was not offered stem cell transplantation. Secondly, that the kind of symptomatic treatment he was undergoing (monthly bloodtransfusions in combination with peritoneal infusion

of desferrioxamin 5–6 nights per week), represented a big strain on the boy.

Besides interviews with Mehmet’s physician and a specialist on IVF who had helped the family to trace treatment contacts abroad, the leader of the Parliament’s Social Affairs Committee, a prominent representative from Fremskrittspartiet (FrP) (‘The Progressive Party’), was interviewed. His message was clear: “The law must be changed immediately so that Mehmet’s life can be saved. Mercy should prevail over the law”. A few days later the FrP proposed a Bill to change § 2.14 of the Act on Biotechnology to enable Mehmet and/or children with other forms of *serious* diseases (genetic as well as non-genetic diseases) in need of stem cell transplantation to have access to this kind of explorative treatment.

In the following days and weeks a stream of newspaper articles, interviews and debates about the case involving politicians, health professionals, patient representatives and ethicists were published and broadcast

### **The politicisation of Mehmet’s case**

The Minister of Health strongly defended the strict regulation of PGD and he deemed it to be irresponsible behaviour if the parliament decided to change the law just a few months after the revision of the Act on Biotechnology had taken place. With explicit reference to an expert Report on thalassaemia, PGD, HLA-typing and IVF delivered by the Directorate of Health and Social Affairs just two weeks after the story of Mehmet had been broken, the Minister of Health characterised the treatment Mehmet’s family was requesting as *experimental research* and stated that the boy received the best *established* treatment currently available.

The Minister’s interpretation of the report was correct as far as concerns Mehmet’s current treatment, but his characterisation of the PGD-HLA-IVF alternative as *experimental research* was at odds with the verdict issued in the Report: namely that it is a treatment that is *explorative* but not hazardous.

The Sosialistisk Venstreparti (SV) (‘Socialist Leftist Party’) that had sided with the parties forming the government coalition in the course of the parliamentary debate on the revised Bill on Biotechnology came under heavy pressure to change their newly adopted stance on PGD.

Approximately one week after the Directorate of Health and Social Affairs had delivered their Report the Party gave a press conference to announce that they had changed their mind on PGD as well as on PGD and HLA-typing in combination with IVF.

## Lex Mehmet

The core element in the Party's new stance was that the current ban on PGD except in situations of serious X-linked diseases without treatment possibilities, should not be formally lifted. Instead § 2.14 of the Act on Biotechnology should be supplemented with new subsections to make possible an *exemption* from the ban if and when 'particular considerations' speak in favour of a case. By 'particular considerations' were meant the presence – or the risk – of *serious, genetic disease without treatment possibilities*.

An *independent* medical ethics committee empowered to grant exemption from the main rule on PGD should be set up and given the responsibility to evaluate individual applications for PGD in combination with IVF in order to have a child not affected by the serious genetic disease in question, as well as for PGD in combination with HLA-typing and IVF in order to have a child that is both unaffected by the actual disease and a tissue-compatible donor for a sick sibling.

On May 11th 2004 the FrP's Bill, as well as the Bill proposed by the SV, were debated in the parliament. After three hours fierce and heated debate the first Bill was thrown out, while the second Bill won a majority vote against the three parties forming the present government coalition.

## Critical afterthoughts

The case provokes two pertinent questions: Why did the Mehmet case become political dynamite? and What made the SV change its strict stance on PGD? Below I give seven possible answers to these questions.

ONE: The Mehmet case became political dynamite because the revised Act on Biotechnology did not contain a *complete* ban on PGD. By exempting serious X-linked diseases from the ban on PGD the parliament had left behind a ticking time bomb waiting to be detonated by a case such as Mehmet's.

TWO: SV changed its stance on PGD because of a massive media campaign against the Party's position. As expressed by the Party's main spokesperson in the parliament's Social Affairs Committee: "No politician is able to stand up against a storm that rages for weeks."

THREE: SV changed its stance on PGD because of a series of poor showings in the opinion polls. A fierce stance in the Mehmet case during the first days of the debate made the party bleed seriously.

FOUR: SV changed its strict stance on PGD because it proved not to be able to pass the first reality test. The Party's chairperson said during the debate in the parliament on May 11th: "What the parliament does today is to remove the provision that makes it impossible to go into the difficult matters of judgement raised by individual cases".

FIVE: SV changed its strict stance on PGD because it became convinced by the strength of the *better arguments* launched during the debate.

SIX: SV changed its strict stance on PGD because it had the political courage to *openly* express its *moral doubt* about the rightness and wisdom of its original position.

SEVEN: SV changed its strict stance on PGD because it found the idea launched during the public debate of establishing an independent medical ethics committee to review individual cases, a viable resolution of a biopolitical problem too complex and difficult to be handled by the parliament on its own.

In the power-struggle between ethics and biopolitics at least two different outcomes are possible. One is a *politicisation* of bioethics. A disturbing example of such an outcome is witnessed in the epilogue of this presentation. The other alternative is an *ethicisation* of biopolitics. I take the Mehmet case to be an instructive illustration of that possibility.

**Epilogue 1:** "How might perceived bias in a federal commission such as the Bioethics Council affect the ability of the nation to receive the best available scientific information on which to base policy decisions? Will researchers be unwilling to provide their expert opinions regarding their field of research for

fear that they will be used to promote a particular view held by the Council? I am afraid that this effect is already occurring. I was recently contacted by a world leader in research involving neural stem cells from adults; he was considering withdrawing his agreement to provide his expert opinion to the Council, for fear that the potential of research involving adult stem cells would be overstated as a justification for a continued ban on federal funding for promising research on embryonic stem cells. When prominent scientists must fear that descriptions of their research will be misrepresented and misused by their government to advance political ends, something is deeply wrong ... There is a growing sense that scientific research, which, after all, is defined by the quest for truth – is being manipulated for political ends” (E. Blackburn, "Bioethics and the Political Distortion of Biomedical Science", [www.nejm.org](http://www.nejm.org), March 18 2004: 1379–1380).

**Epilogue 2:** “Die Bioethik in den Vereinigten Staaten ist politisiert, dahinter gibt es kein Zurück mehr. George Bush will sich nicht von seiner konservativen Basis entfremden, ... Wird Busch im November wiedergewählt, ist ein Ringen im Bioethikrat um Randgebiete der biomedizinischen Forschung ... abzusehen. Nicht zu erwarten hingegen ist, dass das Gremium als zuverlässiger und fairer Vermittler in einem bioethischen Dialog aller Amerikaner dienen wird. Vielmehr ist es eine – vom Staat finanzierte – Waffe der Parteipolitik geworden” (A. Caplan, 'Süberung im Ethikrat', *Die Zeit*, 6.05.04).

**Epilogue 3:** Approximately one month after the Norwegian government had lost the vote on the Mehmet case in the parliament, the Minister of Health took the opportunity not to re-nominate the members of the National Advisory Board on Biotechnology that had been publicly criticising him for his fierce stance on PGD. Whether this act will result in further politicisation of Norwegian bioethics remains to be seen.

# 11 Ethics of PGD/HLA typing for stem cell donation

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The term “assisted reproduction” has become associated with some procedures, which have captured the public imagination and preyed on widespread fantasies. This particularly applies in cases where embryos are manipulated outside the body, or are the object of research; here society’s concern has been most vocal with the inevitable consequence that legislation has been passed in many countries to provide the watchdog deemed necessary to reassure all parties. This happened in the UK in 1990, when the Human Fertilization and Embryology (HFE) Act (HFE Act, 1990) was passed by Parliament. Central to the spirit of the Act is the requirement that the practitioners of assisted reproduction consider the “welfare of the child ... born as a result of the treatment (including the need of a child for a father), and of any other child which may be affected by the birth”. It also set up the Human Fertilisation and Embryology Authority (HFEA), which, among other roles, licenses human embryo research and all fertility treatments involving the creation of embryos outside the body, which include pre-implantation genetic diagnosis (PGD), and its variations.

The availability of multiple embryos created *in vitro* is essential in order to perform PGD. This procedure may be described as the ultimate step in antenatal screening, retrogressing from screening the foetus *in utero* to the embryo *in vitro*. As far as PGD itself is concerned, it may be appropriate to introduce the term of pre-gravid diagnosis, as indeed the mother to be is not pregnant until a fertilised embryo(s) (after PGD or not) has been implanted *in utero* following the necessary IVF.

The ethical questions which arise from PGD are not dissimilar to those of antenatal screening. The phrase “promotion of informed reproductive decisions” (Modell and Kuliev, 1991) is indeed a caring and sensitive expression to describe this pre-gravid diagnosis. Needless to say counselling is of great importance in all these decisions.

The eugenics debate must also be mentioned, as it has been argued that some couples would demand, after pre-implantation diagnosis, the assurance of a “perfect” baby. Actually, in practice, couples say they want a “normal” rather than a perfect baby. But is the basic philosophy of preconception and pre-implantation diagnosis akin to eugenics, in that it selects gametes or embryos? Concerns that “a more and more restrictive definition of normality and humanity” (Testard and Sele, 1995) would ensue from a wide application of PGD must be at least considered, but it must be said that if eugenics is defined by its focus on population, and not individual couples’ choice to reproduce, the term ‘eugenic practice’ does not apply.

Furthermore, some writers would actually wish to find new terms rather than ‘eugenics’ in view of the tainted historical background of the field, and in particular the radical eugenics movement of the beginning of the 20th century (Missa, 1999).

Some specific ethical problems of pre-implantation diagnosis are also linked to its particular constraints, especially the need to undergo IVF. There is particularly here a concern for justice, as both nationally and internationally access to IVF and PGD is very patchy, especially if subsidised. In practice, it is for the time being a matter of rather restricted choice, as the number of units performing the technique worldwide is extremely limited (about 1,000 babies worldwide currently), and the technique is only available to a few prospective parents. The need for long-term surveillance of this particularly “precious” offspring in turn entails recording the births and follow-up details of the children with their specific dilemmas already described in detail (Milliez and Sureau, 1997).

### **PGD and ethical concerns**

PGD was originally developed as an alternative to prenatal diagnosis for couples at high risk of transmitting a genetic defect. It allows scientists to check specific genetic defects of the embryo obtained through IVF so that only embryos not affected by the tested disease, or balanced for the tested chromosomes can be implanted. It is also used for sex determination in case of X-linked disease, and counting of chromosomes for couples at low risk of transmitting a genetic disease within the frame of their ART-treatment, called aneuploidy screening (looking for unbalanced pairs of chromosomes which like Down’s

syndrome, may lead to abnormalities in the fetus, or an increased risk of miscarriage in older women).

One of the fundamental ethical principles to observe (ESHRE Taskforce 5, 2003) is the need to demonstrate safety: there is no evidence at the present time that the removal of one or two cells for the biopsy affects the embryo. It is nevertheless wise to plan follow-up appointments for children born after PGD in order to prospectively assess this.

The other two main principles are: increasing the welfare of the future child by avoiding harm (an interest of both future parents and practitioners), and respecting the autonomy of the parents. Parental autonomy is increased as it allows them to choose a technique that better fits their moral principles (PGD rather than termination of pregnancy). Providing information (the tool which promotes patients' autonomy) is essential. This should include genetic counselling, and details related to all the different steps of the IVF procedure and this then enables the future parents to give informed consent to the procedure.

### **PGD and HLA matching: specific ethical concerns**

Choosing by PGD an embryo free of a disease which may also become a child who would be a HLA match (ESHRE Taskforce 9), is a new dilemma.

The main argument against this kind of request by the parents is the instrumentalisation of the future child. But the fact that the well-being of the existing sibling is endangered serves as the compelling reason to accept the technique. Even from the point of view of the future child, it may be seen as beneficial to be able to save its sibling *as a matter of solidarity* between siblings, a value generally fostered and viewed positively by both the family and society at large. Sensitive counselling may help the parents to foresee difficult events, for example, the failure of the initial aim: what if the planned child does not save the life of the elder sibling, how can the feelings of guilt be assuaged in a situation where good will was assumed on behalf of a future person who is necessarily left with some grief feelings?

A practical point that must be stressed is that cord blood donation is only possible if the affected child weighs less than 25 kg.

Another problem is the acceptability of the parents' motives for the selection of embryos: there the 'postnatal' test is useful, as it states that it is ethically acceptable to enable the birth of a child by PGD/HLA who can be used for a certain goal if it is acceptable to use an existing

child for the same goal (i.e. if it is acceptable to volunteer an existing child for stem cells donation to a sibling, then it is also acceptable to enable this birth by PGD/HLA). But adults' self interest is not acceptable (i.e. not for the use of parents themselves).

### **The welfare of the child**

With the welfare of the future child and of "any living child" in mind, one has to prove that the benefits for the receiving sibling whose life can be saved outweigh the disadvantages (if any) for the future child. It is felt that this solution is morally acceptable if the use of the unborn child as a donor is not the only motive for the parents to have the child. This condition obviates the Kantian argument against using someone as a 'mere' instrument, as it is the word 'mere' which is important. However, parental motivation is particularly difficult to assess, and thus the postnatal test is preferred, as long as the parents "intend to love and care for this child to the same extent as they love and care for the affected child" (ESHRE Taskforce 5). This Kantian objection particularly applies to two different cases which may arise: when the child conceived by PGD and Embryo Transfer (ET) is also at risk of the genetic disease affecting the older sibling, or when this future child has no such risk and PGD is solely performed for HLA typing. This was recently illustrated in the UK by two cases, which were subjected to intense public discussion via the media: the cases of the Hashmi family and of the Whitakers.

In the UK each PGD case must be licensed by the HFEA, and the Hashmis' request was accepted, as they wished for an embryo to be matched to their son who was seriously ill with thalassaemia, for whom all other treatment had become ineffective. However the Whitakers' was refused, because their sick child suffered from Diamond-Blackfan anaemia, a disease which is mostly non genetic, and thus the future planned child was not at risk of this condition and would be planned perhaps 'merely' to save the older sibling. It seems the rationale behind this decision may have been in the realm of the Kantian imperative, although the ESHRE taskforce reflections did not make this distinction, but used the "love and care" of the future child condition as a rationale.

Another important criterion is the planned operation for the future child. The creation of a child for the purpose of harvesting non-regenerating organs seems extremely difficult to justify in view of the risks

involved for the donor child. It seems acceptable if the future child's operation involves minimal risk (e.g. cord blood or bone marrow donation).

Finally one may argue that the benefits also include "family welfare" in the general sense where the family at large is seen as an entity, which benefits from solidarity between its members. But an unavoidable dilemma concerns the fate of healthy non HLA match embryos, which may be cryopreserved for further pregnancy, used for research or disposed of, as it is not advisable to donate them to another couple since there is no certainty about the ultimate safety of embryo biopsy to date.

## Conclusion

Generally most societies function on the presumption that parents will act for the benefit of their children. In the case of PGD/HLA typing the dilemma for the parents is that they have to balance the interests of both children. They may judge that the possible harm to the future healthy sibling is outweighed by the probable gains for the sick child. Moreover, the acceptability of this balance can be argued by referring to the notion of hypothetical consent: the future sibling on whose behalf the decision to donate is made, would agree with the present decision when he/she becomes autonomous.

For the children, future and present, one can argue that although there may be some psychological benefits for the donor child, no medical benefits result from the donation. However, the risks and inconveniences of human stem cell donation for the donor are considered as minimal. These risks are outweighed by the benefits for the receiving sibling whose life can be saved. This is a decision to be made by the fully informed and counselled parents.

Thus the use of a child as a donor of stem cells in itself is not considered disrespectful towards the child. This is demonstrated by the fact that the parents may volunteer an already existing child to serve as a bone marrow donor for a sibling. One way to check whether the interests of the future child are respected is by applying the postnatal test: if it is acceptable to use an existing child for a certain reason, it is also acceptable to create a new child for the same reason.

Finally, since the parents' intention to conceive a child to cure a sick sibling is morally acceptable, the collaboration of the physician in the project is also morally justified.

The parents respect the child's autonomy if his/her use as a donor is not the only motive for the parents to have the child. They should intend to love and care for this child to the same extent as they love and care for the affected child. If this condition is fulfilled, the future child is not created merely as an instrument for the benefit of the elder sick sibling. The lack of instrumentalisation is even more obvious when the parents request PGD primarily to avoid having another child affected by the same disease and the wish for HLA matching is only added afterwards.

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# 12 Legislation and regulations in the Nordic countries Is there a Nordic dimension?

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## 1. Introduction

The purpose of this paper is to address the issue of embryo and foetus selection from a legal perspective and to consider whether there is a Nordic regulatory dimension.

By way of introduction, it must be stressed that this is a very complex field of law, where well-established legal regimes are confronted both with new technologies and with new forms of ethical thinking. Furthermore, it is an area where medical discretion and law are closely linked, which all in all may cause some difficulties in getting a clear and sound picture of the legal landscape. Finally, it is important to notice that it is often complicated and demanding to make a comparative analysis. The legal situation in different countries may vary considerably.<sup>1</sup> Issues addressed in family law in one country may be dealt with in constitutional law or health law in other countries. Practical obstacles such as language barriers and possibilities to get access to legislation and governmental policies may also cause complications. Even in a supposedly homogeneous cultural setting as the Nordic area, legislative traditions and language have made it difficult to get a clear picture of the legal situation. In particular, it has been difficult to find information on Finland and Iceland. Consequently, this presentation should not be considered an in-depth comparative legal analysis, but rather a more modest introduction to a complex legal issue.<sup>2</sup>

1. Legislation on biotechnology in the Nordic countries – an overview. The Nordic Council of Ministers, Copenhagen, 2005.

2. The author wishes to thank PhD Salla Lötjönnen, PhD Riitta Burrel, Head

of Department, Gudridur Thorsteinsdottir and Professor, Jur Dr Elisabeth Rynning for having provided important information. All faults and errors are the author's responsibility.

## 2. Legal framework

Foetus and embryo selection are embedded in slightly different legal frameworks. *Selection of fetuses* is not only a question of diagnostics and regulations regarding the criteria to be used as the basis for diagnostics. Prenatal diagnosis is closely linked to abortion and to women's right to bodily self-determination. Consequently, legislation on abortion has an immense impact on foetus selection.

*Embryo selection*, on the other hand, does not involve the female body – at least not in the same manner as abortion – thus establishing a more straightforward situation of selection.

## 3. Selection

Looking into the question of selection, various issues could be addressed. In this paper, the focus will mainly be on the questions of *selection criteria* and *decision-making power*.

The question of which criterion is used as the foundation of selection is crucial. At present, the selection *criterion* is most of all the *condition* of the foetus or the embryo. The risk of having a child with a severe medical condition is normally the reason for foetal and embryo diagnosis. However, the *sex* of the foetus or embryo is also in focus. Sometimes sex selection is discussed in connection with genetic conditions if a hereditary disease is sex-linked, but it is also brought up as the sole criterion of selection. Lately, selection based on *tissue typing* has been a hot topic. This kind of selection is considered when a sick child needs a donor sibling.

Another important issue is *who* should decide – both in relation to diagnostics and selection? Who should make the decision regarding e.g. which tests should be offered to the future parents? Should it be the health care professionals, the future parents, or is it a matter for society? After the testing, who should decide when it comes to the question of selection?

## 4. Foetus selection

### 4.1. Prenatal diagnostics

In all Nordic countries, there is a *scheme of prenatal diagnostics*. However, these schemes vary, and they are governed by quite different perceptions regarding both values and purposes.

In Sweden, all pregnant women should be informed about the opportunities provided by prenatal diagnosis. Information should be more extensive if there is a specific risk to the health of the unborn child. This could be the case if there are genetic disorders in the family or if the age of the pregnant woman exceeds 35 years. It is then up to the pregnant woman and her doctor to decide about the testing. This – shared – decision is based on an assessment of the indication to be tested and the risk connected with the test. This scheme provides pregnant women with an option of having an invasive test if the risk connected with the test is acceptable from a medical point of view. In Denmark, a similar system has recently been introduced.<sup>3</sup>

The Swedish and the new Danish model are based on the supposition that the pregnant woman is perfectly capable of making a sound and ethically responsible decision – both regarding the test and the decision to be taken after the test in relation to abortion. This belief is most clearly expressed by the Swedish government in a statement from 1994, according to which the judgment regarding foetal diagnostics should be based on the philosophy that persons are expected to be able to make difficult decisions themselves.<sup>4</sup>

In Norway, prenatal diagnosis is only offered to pregnant women if there is a specific risk to the health of the unborn child due to e.g. genetic disorders or the age of the woman. Contrary to the Swedish and Danish system, the woman does not have a right to foetal diagnosis unless there is a medical indication. This is a different approach based on the assumption that society should define limits regarding the question of foetus selection. This point of view is e.g. articulated in a parliamentary position, according to which it is necessary to set

3. Sundhedsstyrelsen, “Retningslinier for fosterdiagnostik”, København 2004 and Sundhedsstyrelsen, “Fosterdiagnostik og risikovurdering – Rapport fra en arbejdsgruppe”, København 2003.

4. Regeringens proposition 1994/95:142 om fosterdiagnostik. The original text is as follows: “Enligt vår mening måste ställningstaganden till fosterdiagnostik ta sin utgångspunkt i en människosyn där människor förväntas klara av att fatta svåra beslut”).

up limits regarding the use of foetal diagnostics in order to avoid the development of practices that could lead to a different social perception of the equal worth of human beings.<sup>5</sup>

It follows that the regulatory approaches are quite different in Sweden and Norway. The Swedish position could be characterised as liberal, with a preference on individual autonomy, whereas the Norwegian approach is founded in the notion of social responsibility. With regard to Denmark, one could say that there is a movement from the social to the individualistic model. It would seem that the policy underpinning the regulation on prenatal diagnosis in Finland is in between the Swedish and the Norwegian approach.<sup>6</sup>

However, it is important to notice that although it seems there are differences in basic social values in the Nordic countries, the divergence is not necessarily that extensive. Advancement in diagnostic technologies has lately led to considerations in Sweden regarding social versus individual responsibility. The Swedish Committee on Genetic Integrity has recently published a white paper regarding genetic testing, in which it recommends that ongoing discussions should take place regarding the ethical questions related to the developments within research and treatment. In particular, the committee expresses its concern regarding the ethical implications connected to the test with the purpose of detecting particular talents or abilities.<sup>7</sup> This concern reflects support for more social responsibility in this area. It could also be mentioned that the individualistic approach also could be seen as an expression of a particular policy of society with regard to abortion of a foetus with disorders. By offering prenatal diagnosis society signals that selection of embryos is acceptable.

5. Part 5.7.1 in Stortingsmelding no. 14 (2001–2002) Evaluering av lov om medisinsk bruk av bioteknologi. It is expressed that “Departementet vil generelt understreke at fosterdiagnostikk er et viktig gode når det gjelder å bidra til å behandle alvorlige sykdommer hos fosteret eller forberede en vanskelig fødsel. Men det er avgjørende å sørge for rammer om virksomheten slik at det ikke får utvikle seg en praksis som innebærer at synet på menneskelig likeverd i samfunnet endres. Derfor er det nødvendig at praksis og regelverk jevnlig gjennomgås kritisk, slik det legges opp til i denne meldingen.”

6. Ilpo Helén describes the Finnish abortion policy as a combination of liberal legislation that acknowledges a woman’s personal choice and a controlling practice that attempts to keep the numbers of abortions at an acceptable level, Ilpo Helén, “Technics over life: risk, ethics and the existential condition in high-tech antenatal care”, *Economy and Society*, Vol. 33, No. 1, 2004, p. 28–51. However, the policy vis-à-vis elective abortion might differ from the policy on selective abortion.

7. SOU 2004:20, “Genetik, integritet og etik. Slutbetänkande av Komittén om genetisk integritet”, p. 278 ff.

Looking more specifically at the foetal conditions, which could justify prenatal diagnostics, it seems that none of the Nordic countries have issued formal legal regulations. However, there are informal guidelines normally emphasising the severity of the disorders, but with no clear definition of what constitutes a severe condition such as early death, death during childhood, impact on quality of life etc. In the Danish report on foetal diagnostics the question of severity is addressed and it is noted that due to technological developments, the perception of the severity of a specific disorder may change, because it becomes possible to treat disorders which previously were non-treatable.<sup>8</sup>

Norway, like the other Nordic countries, has no specification of severe conditions in formal legal regulation. There is, however, a system of authorisation allowing the Health Department to have some control in the area. Accordingly, health care institutions performing genetic tests – including prenatal diagnostics – should have an authorisation from the Health Department. The types of tests used as well as the methods should be approved by the Health Department. Before issuing an authorisation or approval of the tests, the Health Department is obliged to hear the opinion of the Biotechnology Advisory Board.<sup>9</sup>

Norway is the only country specifically addressing the question of *sex-selection* in relation to foetal diagnosis in formal law. According to section 4.5 of the Act on the medical use of biotechnology, information regarding the sex of the foetus must not be given to the parents before the end of the 12th week of pregnancy. However, if there is a risk of having a child with a severe hereditary sex-linked disorder, information may be given in the first trimester. The legal situation in Sweden is different. The general rules regarding the freedom of information provide the pregnant woman with a right to obtain information regarding the sex of the foetus. However, this information should not be given automatically but only on her request.<sup>10</sup>

8. Sundhedsstyrelsen, "Fosterdiagnostik og riskovurdering", København 2003, p. 84 ff.

9. Section 4.2 in the Act No. 100 of 5th December 2003 on the medical use of biotechnology.

10. SOU 2004:20, "Genetik, integritet och etik. Slutbetänkande av Kommittén om genetisk integritet", p. 274 f.

## 4.2. Abortion

The question regarding prenatal testing and information provided to the parents regarding the results of the test must be seen in connection with the *abortion* laws. The Nordic countries are often considered to be quite liberal regarding abortion. However, it is only in Norway, Denmark and Sweden, where abortion is available on request in the first part of the pregnancy. In Norway and Denmark, there is a right to abortion until the end of the 12th week of pregnancy. In Sweden, abortion is available on request until the end of the 18th week of pregnancy. In Finland and Iceland abortion is only permitted if certain conditions are fulfilled. The decision is normally taken by medical staff until the end of 12th week of pregnancy. Normally, abortion will be permitted, but there is no positive right to abortion.

Compared to the other Nordic countries, Sweden is unique as there is a right to abortion within the first 18 weeks of pregnancy. This gives the pregnant woman a right to decide whether a disorder detected in the first 18 weeks – or other conditions such as the sex of the child – should lead to an abortion. In Iceland, Norway, Denmark and Finland decisions regarding abortion after the expiration of the 12th week are taken by an independent board. This is also the case in Sweden after the 18th week. Currently, the result of prenatal diagnosis is normally not available before the expiration of the 14th–20th week depending on the test, which means that the board normally will consider and have the authority to decide whether the condition of the foetus is sufficiently severe to legitimise a late abortion.

Looking into the rules and regulations on the foetal conditions, which could justify an abortion, the abortion laws normally refer to severe disorders which could be related to genetic as well as non-genetic and physical as well as mental conditions.

Normally, there will also be an *upper limit* based on the viability of the foetus. It could be an exact limit – e.g. 24 weeks (Finland) – or a limit based on an individual judgement. In most countries, 20–22 weeks seems to be the normal upper limit. Some countries will still allow abortions after that time if the foetus has an extremely severe disorder.

### 4.3. Decision-making power

The first decision to be made regarding foetal diagnostics is *which test should be developed and used*. As the purpose of the testing is to establish a basis for selection, the tests should be seen in the context of the abortion rules. It would be unfounded to offer a test for a condition not being sufficiently severe to justify an abortion, unless the test is performed with a view to establishing the basis for treatment of the child. It seems that in most of the Nordic countries decisions regarding the development and use of tests are made within the medical profession. Decisions regarding the introduction of a new test will normally be based on a combination of availability, demand for a test and medical considerations regarding the quality of the test. However, as mentioned above, in Norway the government has a certain degree of control, as the Health Department authorises the types of genetic tests being used for diagnostic purposes.

The next decision to be taken is related to *which test should be offered to the individual pregnant woman*. In the previous section I have described the differences between the Swedish and the Norwegian system. In Sweden all kinds of tests are – in principle – available to all pregnant women, provided the test does not present an unjustified risk to the woman and the pregnancy. In Norway, the use of prenatal diagnosis is only available if there is a risk of having a child with a severe disorder. According to the Swedish position, the pregnant woman has the right to decide about the testing. The Norwegian position, on the contrary, only allows for testing when it is sufficiently justified from a social and medical point of view, thus giving the medical profession and society a share of the decision-making power. If a test is offered, it is of course up to the pregnant woman herself to agree or refuse to be tested.

Finally, after the testing, it might be necessary to *decide on an abortion*. No woman can be forced to have an abortion. Consequently, there is a negative right to self determination. However, although abortion is available on request in some countries, there is no absolute positive right to selective abortion either, as these abortions occur so late in pregnancy that abortion is no longer available on request. Sweden is an exception as there is a right to abortion until the end of the 18th week of pregnancy, which gives the pregnant woman the possibility to make a decision after having the results of the test. In the other

countries – and in Sweden after the expiration of the 18th week of pregnancy – the decision regarding abortion is normally made by an independent board which will look into whether the foetal condition could justify an abortion.

## 5. Embryo selection

### 5.1. Selection criteria

Embryo selection has been discussed extensively for some time, but has so far only led to the adoption of legislation in Norway and Denmark.

In Norway, prenatal genetic diagnosis (PGD) was explicitly addressed in the initial Act on medical use of biotechnology. According to section 4.2 of the Act, PGD was allowed with the purpose of diagnosing a severe hereditary and untreatable disease. This provision was changed when the Act was revised in 2003.<sup>11</sup> According to section 2.14 in the revised Act, PGD is only allowed with the purpose of diagnosing a serious sex-linked hereditary and untreatable disease. However, the revised Act has recently been amended as a result of a heated debate regarding a sick child who needed a baby brother or sister as a donor.<sup>12</sup> As a result of the debate, the rules were changed, not only permitting PGD with the purpose of having a donor child, but also allowing PGD in situations where there is a risk of a serious hereditary and untreatable disorder.<sup>13</sup> However, the use of PGD should in each case be authorised by a special board appointed by the Department of Health.

In Denmark, section 7.1 of the Act on artificial fertilisation permits PGD if there is a risk of having a child with a serious hereditary disorder. PGD with the purpose of detecting a chromosomal abnormality is also allowed, but only if the couple is in IVF-treatment, cf. section 7.2.<sup>14</sup> The Act has recently been amended with a new provision – section 73 – regarding selection of embryos based on tissue type.<sup>15</sup> According to this provision, the Minister of Health may authorise PGD in situations where a donor is needed for a sibling with a serious disease. Contrary to the Norwegian legislation, it is not required that the disease is hereditary.

11. Act no. 100 of 5th December 2003 on medical use of biotechnology.

12. This debate is addressed in Jan Helge Solbakk's contribution to this publication.

13. Act no. 45 of 25th June amending the Act on medical use of biotechnology.

14. Act no. 460 of 10th June 1997 on artificial fertilisation.

15. Act no. 240 of 5th April 2004 amending the Act on artificial fertilisation.

In Sweden, there are no formal legal regulations regarding the use of PGD. However, according to guidelines articulated by the government and the Parliament, PGD should only be used with the purpose of diagnosing a severe, progressively developing hereditary disease (or chromosomal disorder) which could lead to early death and where no treatment is available.<sup>16</sup> In its white paper, the Committee on Genetic Integrity proposes some amendments to the guidelines with the purpose – among others – of avoiding the use of PGD to choose characteristics. With respect to the use of PGD for tissue typing, the Committee concludes that more information is required before a final decision can be taken.<sup>17</sup>

In Iceland there is no legislation specifically addressing PGD. However, research on embryos is prohibited unless the intention is to diagnose a hereditary disease. Consequently, PGD would be allowed in this situation. There is no explicit legal position regarding selection based on the sex or the tissue type of the embryo.<sup>18</sup>

In Finland there is no Act on Artificial Reproduction. However, according to section 15 of the Medical Research Act, medical research on embryos and gametes for the purpose of developing procedures for modifying hereditary characteristics is prohibited, unless the research is for the purpose of curing or preventing a serious hereditary disease.

Looking into the regulation, it is possible to get an impression of the selection criteria. In relation to the *condition of the embryo*, the regulation normally refers to severe hereditary or chromosomal disorders. But similarly to foetus selection, there is no clear indication of which disorders are considered to be sufficiently severe to justify PGD. The question was addressed when the Danish Central Scientific Research Ethics Committee gave a decision regarding the first PGD research application. The Committee provided a list specifying the conditions which could be tested. However, this list has subsequently been withdrawn.

Selection based on the embryo's sex is explicitly addressed in the Norwegian and Danish legislation. According to the legislation, sex selection is only allowed if there is a risk of a sex-linked disease. The same position is expressed in the Swedish guidelines.

16. Regeringens proposition 1994/95: 142 om fosterdiagnostik and Socialutskottet 1994/95:SoU 18. This position is described in SOU 2004:20, "Genetik, integritet och etik. Slutbetänkande av Kommittén om genetisk integritet", p. 292 f.

17. SOU 2004:20, "Genetik, integritet och etik. Slutbetänkande av Kommittén om genetisk integritet", p. 301 ff.

18. Information obtained from the Icelandic Ministry of Health and Social Security.

Finally, selection based on tissue typing is only justified if a sibling is suffering from a serious – in Norway also hereditary – disease, which could not be treated by other means. It is also required that the donor child is not put at risk.

## 5.2. Decision-making power

In connection with embryo selection, various stakeholders have part of the power to make decisions. It is important to notice that IVF-treatment always involves embryo selection. The fertility doctors will choose the healthiest looking embryos for fertility treatment as a professional routine. This kind of selection is not addressed and has – to my knowledge – not given rise to major discussions.

Similarly to foetal diagnostics, the medical profession is involved in the decisions regarding the *development and introduction of tests*. The next decision addresses the question *which test should be offered to the couple*. In Denmark, PGD is only offered to a couple with a known and a considerable risk of having a child with a severe genetic disorder. The embryo must only be tested for this specific disorder and not for other abnormalities. The same situation seems to be the case in Norway. In Sweden, the Committee on Genetic Integrity also suggests that PGD should be used exclusively to prevent a child from inheriting a trait for the disease in question, whereas the use of PGD for screening purposes should be restricted to clearly defined research projects that are preceded by an ethical evaluation.<sup>19</sup>

In Denmark, however, the Act on artificial fertilisation also allows for PGD as a routine test in connection with infertility treatment. According to section 7.2 of the Act, PGD may take place in connection with IVF treatment where such an examination can demonstrate or exclude a serious chromosomal abnormality. In this situation, the embryo must not be tested for hereditary disorders but only for chromosomal abnormalities. All in all, it seems that society's involvement in decisions regarding PGD is more explicit than is the case in relation to foetal diagnostics. This also means that the medical profession and the future parents have less power to take part in making the decisions.

19. SOU 2004:20, "Genetik, integritet och etik. Slutbetänkande av Kommittén om genetisk integritet", p. 301 ff.

## 6. A Nordic dimension?

Looking at the legal situation in the Nordic countries there are both similarities and differences. Norway and Denmark seem to have the most comprehensive system of formal legal regulation. Finland is unique when it comes to the lack of regulation regarding artificial fertilisation. It is also remarkable that Norway is the only country to address foetal diagnosis in formal legislation.

At a general level, there seems to be a common perception about which foetal or embryo *condition* could justify selection. The regulation will point at *severe* disorders, however, without indicating specifically which disorders could be considered sufficiently severe. Remarkably, sex selection of foetuses is only specifically addressed in Norway, whereas sex selection of embryos is also regulated in Danish law. *Tissue* typing as a relative new phenomenon has only been addressed in Norway and Denmark – and with slightly different approaches.

When it comes to *decision-making*, it is possible to detect different attitudes. In Sweden and Denmark, the focus is on individual autonomy and right to self-determination. In Norway, the emphasis is more on social responsibility. Iceland and Finland seem to be in between. The importance of social responsibility in these two countries is reflected by the fact that there is no right to abortion on request. Nonetheless, in practice, the differences regarding abortion might not be that extensive. One could also regard the lack of regulation of artificial fertilisation in Finland as an expression of a liberal position. However, it is more reasonable to interpret this as a lack of ability to agree on legislation than as an expression of a liberal position.

Thus, the answer to the question of whether there is a Nordic dimension seems to be that in some areas we might talk about a common approach. Whether this approach is specifically Nordic, is another question. However, in other areas there are significant differences. All in all, this leads to a very provisional answer: perhaps there is a Nordic dimension. However, in order to have a more useful answer, we need to look closer not only at the legal regulation but also at the practice of the medical profession and of the abortion boards. We also have to look at legislation from the perspective of social and political science.

In my view, the most interesting challenge is how we as societies address the complexity in this area. We have to develop a normative framework, which could provide us with tools enabling us as a society to respond adequately to biotechnology. Whether these tools should be to empower the individual to make autonomous decisions in a complex environment or to reduce the complexity by defining limits, I will leave for further consideration and discussions.

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# 13 Cultural aspects on reproductive technology and genetic diagnosis

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## **Introduction**

In my paper, I will discuss some contextual factors or conditions at work in both scientific research and everyday life, especially related to medical or gene technology in general and to pre-implantation genetic diagnosis (PGD) and embryo selection in particular. I will reflect upon what it means that we as human beings are situated in a cultural as well as in a historical situation by which we are both constituted and constrained.<sup>1</sup> I will argue that some historical, cultural and individual prerequisites and perceptions that affect our actions and decisions sometimes remain unnoticed.

A starting point in my line of thinking is that everything and everyone is connected and dependent: dependent on relations with other humans and on linguistic systems of meaning. This position, and the struggle for the free autonomous self, has a long history, something that I will not go into in this paper. I will thus position myself in this line of thinking – with critical theory, French philosophers such as Derrida and Foucault, and in the tradition of many contemporary feminist writers.<sup>2</sup> The point I want to stress is that not only are we connected and dependent in order to survive and to create meaning, but we are also always physically located and constituted in a specific context.<sup>3</sup> It is this location in time and space that I will examine in relation to reproductive medicine on general and in relation to PGD in particular.

My discussion will mainly be based on my empirical research on attitudes to gene technology and experiences of childlessness, assist-

1. Warnke 1987, p. 169.

2. Warnke 1987, p. 167.

3. Weir 1996, p. 184.

ed conception and adoption, but I will try to relate this research to the current developments in PGD.<sup>4</sup> The division of contexts into three analytically separate spheres is a result from this research.

Firstly we have historical roots and the specific situation in relation to history that will provide modes of thinking and acting. Secondly we have the actual cultural or societal conditions and processes in force, and thirdly the concrete situation, including individual history and experiences, which together will form interpretations and grounds for decisions. To summarise: we have *the common historical (mental) forms and thoughts, the contemporary material and mental cultural phenomena, and individual experiences and expressions.*

In the following sections I will emphasise the historical and the contemporary aspects more profoundly and just touch upon the individual situation briefly. I would however like to stress the interdependence between these three levels or dimensions of reality. Contemporary phenomena are rooted in history and will influence individual experiences, which in turn will shape contemporary situations and history.

## **A historical perspective on form and thought**

Some of the general traits that stand out in relation to the historical development in western countries are related to the post modern, or more accurately in this context, the *late-modern society*. The term 'late-modern' is better suited when describing contemporary society, with the obvious link between the growing development of and interest in medical technology and the modern dream of progress and control, not least when it comes to genetic diagnosis applied to embryos.<sup>5</sup>

Historians speak of specific mentalities and typical traits for thoughts and experiences in an epoch. In science we speak of paradigms – common and unwritten rules, which include fundamental assumptions about the world as well as values.

One important trait is *reflexivity*, i.e. the individual's growing ability or will for reflection and choice, reinforced by the fact that institutions and other authorities are losing their influence.<sup>6</sup> This feeling of freedom of choice coincides with the declining influence from insti-

4. Westerlund, 2002.

6. Giddens 1991.

5. Franklin 1997, p. 213.

tutions and other normative authorities. As Anthony Giddens describes it “the reflexivity of modernity actually undermines the certainty of knowledge, even in the core domains of natural science.” Cherished and established scientific tenets are open to revision – or might have to be discarded altogether – in the light of new ideas or findings.<sup>7</sup> Not only authorities are questioned but also knowledge that previously was regarded as true is now found to be unreliable and left up to individual judgement. Doubt is present also in the field of natural science, a fact that could be noticeable for individuals caught up in choosing between different specialised technologies when needing treatment.<sup>8</sup>

Modern technologies – for instance genetic diagnosis in general as well as specific reproductive techniques – extend into peoples’ everyday lives and confront them with new conditions that could govern their lives. New choices and decisions must be made based on the new opportunities that the technologies offer. From my research on perceptions of genetics and gene technology, it is obvious that individuals feel real doubt about what knowledge is reliable and whom one can trust. Further findings show that when clinicians give slightly different or even contradictory information and suggestions for treatment, it creates serious frustration and doubt, which could keep the individuals from getting on with their lives.<sup>9</sup> The uncertainty in the PGD, regarding possible or permitted diagnosis, the IVF treatment, and potential risks for the child to be, places the PGD right into this situation of doubt and choice.

One other aspect or consequence of knowledge’s conditional character and of the low confidence in authority is the new dimension of risks. Human interplay with nature has also in earlier times entailed risks. What is new in contemporary society is, among other things, the number of technologies at work and the problems with calculating the risks.<sup>10</sup> This uncertainty and lack of scientific experience also applies to genetic diagnosis and several techniques for assisted conception.

Reflexivity; the ability to reflect and choose, is connected to the fact that more traditional ways of living and organising one’s life have lost their normative function. Moreover social life has become more differentiated and fragmented.<sup>11</sup> This development is described by some in terms of *individualisation*, *differentiation* and *fragmentation*.<sup>12</sup>

7. Giddens 1991, p. 21. Giddens’ emphasis.

8. Beck 1989, p. 10.

9. Westerlund, 2002

10. Beck 1989, p 22.

11. Giddens 1991, p. 82–85.

12. Pettersson 2000.

Differentiation of public sectors and life spheres, based on religious, ethnic or political convictions has brought about a fragmentation of norms and interpretations. Differentiation and fragmentation are, in this context, basically descriptive concepts trying to characterise two different kinds of pluralism, namely pluralism as a demarcation for interaction between individuals and subgroups, and pluralism as pointing towards many systems of meaning.

The shaping of a meaningful life is then more and more assigned to one's own efforts and choices. What used to be the work of destiny will be transformed to choice, and what was indisputably a choice, will sooner or later, necessarily become a duty.<sup>13</sup> In relation to reproductive technologies and PGD this means not only that the individual has to make her own decisions based on conditional knowledge, but also that there are no comprehensive systems of meaning to lean on. Values and norms become highly contextualised and deeply interwoven with actual circumstances in specific situations.<sup>14</sup> For instance one of my interviewees regarded most gene technology as unnatural and reprehensible, but when it came to injection of sperm cells into a human egg this was judged by other norms, norms that made it possible for him to make use of the technique in his own childlessness.<sup>15</sup>

Individualisation also creates special conditions for parenthood. In a society where individual choice and self-realisation are highly appreciated, reproduction and children could be viewed as a way for individuals to express themselves.<sup>16</sup> And needless to say, the motivating force for PGD, including IVF, is parents longing for children: healthy biological children. According to one Swedish researcher in the field:

The children become “sacralised”, not in terms of what they do for the nation or for their economic implications, but because of the opportunities they provide for the individual to express affection and to give.<sup>17</sup>

The traditional marriage does not accord with the contemporary individualisation trend. Self-realisation is constrained by family life and marital duties, and children restrict the freedom even more.<sup>18</sup> Today

13. Bauman 1997, p. 226.

14. Petterson 2000, p. 250.

15. Westerlund, 2002.

16. Wirtberg 1992, p. 20f. Lundin 1997, p. 48.

17. Wirtberg 1992, p. 21.

18. Beck 1989, p. 97, 116. Beck points out the radical opposition between the

way the market economy works and family life, in times when equality between the sexes is important: “Correspondingly, the ultimate market society is a *childless* society – unless the children grow up with mobile, single, fathers and mothers.” Beck’s emphasis.

children paradoxically become a threat to individual freedom, but simultaneously they stand out as the last remaining alternative to loneliness. Children invade everyday life with irresistible needs and thereby circumscribe the freedom of the parents. At the same time individuality and social mobility in society are strengthening the need for a close, unselfish and non-negotiable relationship. After a series of temporary relations the child becomes the last remaining life-long and non-exchangeable relation. The emotional relationship to a child, characterised by unselfish love and non-reciprocal giving, is exceptional and in some respects dubious in contemporary society. And maybe individualisation is precisely what makes this relationship of unconditional love so much longed-for.<sup>19</sup> Consequently, this cultural situation contributes to the experience of children being important for the meaning of one's existence.

The rapid progress within reproductive medicine, now also including PGD and pre-implantation genetic screening (PGS), is following this line of thinking. It has almost become a (human) right to have a child, a healthy biological child.

Inherent in my starting position though, i.e. the interdependence between all human beings, described as relationality, is a criticism of the freedom of choice that is presumed in the trend towards individualisation and in the stressing of reflexivity. Not that I deny that this is how people partly experience the world, but is human choice really that free and autonomous? Instead of an increased freedom one could, with the sociologist Ulrich Beck, speak of new restrictions to individual freedom.

The place of *traditional* ties and social forms (social class, nuclear family) is taken by *secondary* agencies and institutions, which stamp the biography of the individual and make that person dependent upon fashions, social policy, economic cycles and markets, contrary to the image of individual control which establishes itself in consciousness.<sup>20</sup>

The individual is more and more released from traditional commitments and supporting relations, but is trading them against other kinds of relationships and institutions. This change of determining factors, or more openly described, dialogue-partners could also imply that these new factors are less conscious and manifest. Different cul-

19. Beck 1989, p. 118. Wirtberg 1992, p. 21.

20. Beck 1989, p. 131. Beck's emphasis.

tural factors and interpretations shape the individual and are simultaneously used to create personal life and identity. All this takes place in an embodied reality, in an actual situation. And in the concrete situation different interests will both co-operate and compete on an individual as well as a cultural level.<sup>21</sup>

### Cultural references and dialogue partners

Natural science is transmitted in different ways to the public. When scientific authority has lost its given priority, the person mediating science is gaining an increasingly important role. When trust in science itself is shaken, other factors will affect the way science influences perceptions and knowledge. Trust and confidence in institutions, organisations and specific persons then become important for the mediation of scientific knowledge.<sup>22</sup>

Perceptions of genetics and medical technology are deeply affected by the *media* in a broad sense.<sup>23</sup> Newspapers, scientific journals, radio and television are important mediators of benefits, risks and ethical problems.<sup>24</sup>

When research and scientific findings are put forward in the press, the information has been adapted to everyday language and into pictures of threats or cures.

(W)hat may be termed public understanding of the new genetics are not passive reflections of professional, scientific understandings; rather, they are active constructs, the products of multiply-mediated historical and cultural (including mass media) influences, which may be expected to diverge significantly from those professional understandings of science with which they coexist.<sup>25</sup>

Public perceptions including knowledge, about genetics and PGD, will in this way form a cultural understanding, which also is significant for clinical practice and scientific research.<sup>26</sup>

21. Frykman 1992.

22. Beck 1989, p. 169.

23. Heijs and Midden 1997, p. 160.

Reiss and Straughan 1996, p. 237.

24. Ideland 2002. Olofsson 2002.

25. Durant, Hansen and Bauer 1996, p. 236.

26. Durant, Hansen and Bauer 1996, p. 236. The authors are stressing the importance of studying and of taking into account public knowledge and attitudes to biotechnology, among other things because those attitudes will affect the future developments within the field.

One effective method for mediation of science is the use of pictures and metaphors. These kinds of representations are full of meaning and will affect people's perceptions and attitudes.<sup>27</sup> For instance genes are given personal traits, are regarded as acting subjects, called female or male, could be sick or healthy, and could even influence the way in which a person acts. An obvious trend is that the pictures used in the media often are either positive or negative.<sup>28</sup> The possible diagnoses and cures of diseases stand in sharp contrast to the risks for genetic discrimination and eugenics.<sup>29</sup> Moreover, in the media, as well as in people's minds, the focus is on applications of genetics and not on the long-term developments.

Recent reports in the Swedish media about PGD have concerned cases where donors are created to older siblings suffering from leukaemia. One article was entitled: "Five chosen children born as donors", another "Reconsider the prohibition against donor children".<sup>30</sup> Both articles referred to cases in the US where PGD has been used to create donor children for sick siblings. Swedish medical experts commented upon it and expressed their doubts about the method, mainly because there already exist quite good methods to cure leukaemia (at least in 80% of the cases). Their line of reasoning was primarily focused on risks and benefits, leading to the conclusion that it was more acceptable to create a sibling as donor in cases with hereditary blood diseases.

This example shows, among other things, that the media also functions as a global mediator. As one sociologist has phrased it: "Mass-media do not only reflect occurring values and systems of norms, but has also a 'main-streaming' and formative influence".<sup>31</sup> One should be aware of that debate and that praxis of a specific technique or application often has an accustomising effect.<sup>32</sup>

Also *fiction* and art – movies, cartoons, short stories and novels – make use of biological developments. Fiction is sometimes a way to deliver criticism and to express suspicion.<sup>33</sup> But fiction not only shapes peoples' perceptions, it also expresses anxiety or other moods already present in society.<sup>34</sup>

27. Ideland 2002. Ideland 2000, p. 23. Ideland 1997, p. 14.

28. Reiss and Straughan 1996, p. 238. "This technique produces an exaggerated impression of both the potential risks and the benefits of genetic engineering."

29. Durant, Hansen and Bauer 1996, p. 239.

30. Svenska Dagbladet, Inrikes, "Fem utvalda barn födda som donator", 2004-05-09. Dagens Nyheter, "Ompröva förbud mot donatorbarn", 2004-05.

31. Pettersson 2000, s. 201.

32. Hansson, Herta.

33. Ideland 2002, p. 149.

34. Åkesson 1997, p. 91.

I do not suggest that people uncritically adapt to pictures and attitudes in the media, but these pictures constitute important references when dealing with genetics and reproductive medicine. There are findings that suggest that the impact of the media increases when it comes to areas where people lack personal experience, as is often the case with genetics and different biotechnologies.<sup>35</sup> This is the case with PGD, where, at least in Sweden, there has been very little information or discussion.

When discussing any biotechnology related to assisted conception, *medical practice and ideology* becomes important. This applies to PGD and embryo selection which is a medical practice that is affected by and is affecting the perceptions and attitudes in this field of science. The processes and the use of new technology are providing frames of reference, and when one is in great need, for instance of PGD or some other genetic diagnosis or method of assisted fertilisation, science also becomes an authority.<sup>36</sup>

Reproduction technology combined with genetic diagnosis is becoming a powerful method that, when it is established, could be hard to reject for a couple longing for a healthy child. Reproduction technologies as such are sometimes put forward as one of the best examples of the modern dream of hope, progress and a better future.<sup>37</sup> Children, together with science, are also two of the most powerful symbols one could find for future opportunities. In my opinion, one ought to pay special attention to what has been described as the “*technological imperative*” in the field of reproductive medicine. I am referring to the notion that all that is technically possible to do, should be done.<sup>38</sup> I am trying to say that all that one technically can do should be done. Both medical practitioners and individuals could consequently feel almost obliged to use the techniques that are available. The use of in-vitro fertilisation is one obvious technique governed by

35. Olofsson 2002, p. 16.

36. Franklin 1997, p. 190, 199.

37. Franklin 1997, p. 166. Beck 1989, p. 206. “In the sub-politics of medicine, (-), the possibilities for thoughtless and unplanned exceeding of limits lie in the logic of ‘progress’. Even *in vitro* fertilization was first tested in animal experiments. One can very well argue over whether that should be permitted. But certainly an essential barrier was

crossed in applying this technique to people. This risk, which is after all not a risk for medicine, but for the next generation of people, for all of us, could and can be taken purely *immanently* in the circle of medical practice, and under the conditions and needs of a (global) competition for reputation which prevails there.”

38. Lundin and Åkesson 2000, p. 12. von Wright 1986, p. 138.

the technological imperative, but similar tendencies are found also within other medical technologies, for instance foetal diagnosis.<sup>39</sup> Once the techniques are there, they are hard to resist.

Furthermore, within established techniques, as for instance IVF, praxis is established. The overproduction of ova in the procedure has paved the way for the use of these ova in stem-cell research. In PGD this overproduction is even bigger, though the quality of the ova often is poorer. Praxis will in this way carry wanted or unwanted consequences for further technological experiments, consequences that perhaps should not be easily accepted as grounds for new research.

Different *organisations for disabled persons* are also important contributors to the cultural debate about PGD and embryo selection. In Sweden this debate has taken two directions. On the one hand the National Organisation for Cystic Fibrosis (Riksförbundet för Cystisk Fibros) has expressed their acceptance of some forms of PGD, i.e. PGD in order to detect serious, progressive, hereditary diseases that will lead to a premature death. On the other hand, the National Organisation for Disabled (Handikappförbundets Riksorganisation) has rejected every technique trying to diagnose disabilities, stating that PGD and other methods for detecting any defect in the foetus violate human rights. Whichever view one takes, diagnosis and selection of embryos does affect the way we perceive impairment.

But there are, however, other factors to consider. One important factor is the *market*. Consequently, there is always the risk that if new technologies are explored on the free market, PGD could for instance be offered as a matter of routine in private IVF-clinics. The closely related technique, Pre-implantation Genetic Screening (PGS), is already used more and more frequently. Science and technology have proved interesting in a special way for politicians and private companies due to their applicability. Comparatively, new alliances have appeared between economists and scientists, where the results are judged not only by scientific criteria, but also by social and technological applicability.<sup>40</sup> Strong economic and scientific interest in a particular medical technology could also impair an open and critical debate.<sup>41</sup>

40. Uddenberg, Bråkenhielm and Westerlund 2000, p. 27.

41. Munthe 1996, p. 76.

39. Franklin 1997, p. 170.

In such a perspective, the importance of *regulations and laws*, ethical codes, and elaborated praxis in order to control the use of medical technologies becomes obvious. There is, however, rapid development of new technologies and their applications. The slow process of producing new regulations and the lack of public debate are in fact a problem.<sup>42</sup>

Political decisions affecting both regulations and the market are, in most cases, preceded by official reports and ethical discussions. One important official Council in Sweden is the Swedish National Council on Medical Ethics (Statens medicinsk-etiska råd, SMER). At the beginning of 2004, they delivered an official letter on PGD. Their conclusion was that PGD should be allowed in a slightly more extended way than it is in Sweden today, though not as a matter of routine. The Council states that:

- A PGD should be permitted for couples
  - that carry a specific, serious mono-genetic or chromosomal hereditary disease
  - that present a high risk of getting a child with genetic disease or lesion.
- B The aim of the PGD must only be that the child should not inherit a hereditary disposition for disease or other lesion.
- A PGD should not be used with the aim of choosing personal characteristics.<sup>43</sup>

The point I want to make is not primarily to point out the actual content of the statement, but that this kind of official document constitutes yet another framework for interpretation of the technique.

Finally, I would like to point out the obvious link to history often discussed in relation to all gene technology, namely *eugenics*. Throughout history eugenic endeavour has been combined with official policy and social reform, which has justified sterilisation and extermination on the basis of religion, ethnicity, sex or social background. One obvious difference in contemporary western society is that we nowadays place the responsibility for choices on the individual, saying that it must be up to the couple or the individual it concerns to decide. Previously in history eugenics often was a means for social planning.<sup>44</sup>

42. Bioteknikkommittén 2000, p. 299. Assistant professor Elisabeth Rynning here points out the scanty legal regulations and lack of supplementary directions, referring to the use of gene technology on human beings.

43. Statens medicinsk-etiska råd, 2004. My translation, English version soon available at [www.smer.se](http://www.smer.se)

44. Tydén 2002.

The discussion about PGD and embryo selection cannot ignore the abuse of eugenics in a historical context. In the light of history we can say that eugenics from 1920 onwards is built on what we today look upon as prejudices about ethnicity and class. Eugenics has throughout history walked hand and hand with contemporary science.<sup>45</sup> Where do we have our blind spots, which will stand out in the light of history?

### **Fundamental dependence, abstraction and reflection**

I have tried to set out some of the cultural and historical factors in western society that interplay and affect perceptions and decisions. In brief: individualisation and reflexivity, fragmentation and the declining trust in authority, the sacralisation of the child, media and fiction, medical praxis and ideology, the market, interest groups, political decisions, regulations and laws, and the fear of eugenics. With Ulrich Beck's words:

These different partial arenas of cultural and social sub-politics – media publicity, judiciary, privacy, citizens' initiative groups and the new social movements – add up to forms of a new culture, some extra-institutional, some institutionally protected.<sup>46</sup>

This partly new culture does not only interplay with individual interpretations, but also affects political as well as technological developments.<sup>47</sup> To a greater or lesser extent, these factors on the cultural arena also are contributing to what one could call cultural normality, by which I mean a notion of what is, in a sometimes unreflected or unconscious way, regarded as normal life – of different phases in life including children and family life.

Some of these factors do remain partly invisible because of the nature of these elements. The individual is more or less independent in relation to cultural processes, subject to personal factors and experiences. Concrete circumstances will make a difference. The relation between the individual and culture could sometimes be described in terms of individual adaptation. But on other occasions, this relation could also be depicted as individual strategies to shape society.<sup>48</sup> When an individual or a couple are in crisis or at least in great need of help,

45. Tydén 2002, p. 24.

46. Beck 1989, p. 198.

47. Beck 1989, p. 198.

48. Frykman 1992, s. 39-40.

for instance seeking medical assistance in order to get a child (with or without PGD), they are probably more dependent than at times when life is fairly stable. To make an independent choice, meaning to choose something that breaks with the normal, established or acceptable mode of behaviour, in that situation takes a lot of strength and consciousness. I would argue that in situations where the individual is in an exposed position and therefore is reminded of the fragility of life itself, he or she is more dependent on cultural normality and societal forces. When exposed to one's own existential vulnerability, one also recognises the dependence on other persons and on things which are beyond personal control.<sup>49</sup>

In this perspective, it seems almost ironic to include criteria demanding that couples seeking PGD should express a free will in relation to social circumstances, in order to get access to the treatment. An independent ethical consultation group in Sweden puts this criterion of independent choice forward, when estimating a couple's need for PGD.<sup>50</sup>

Ethical reflections and decisions cannot be left to individuals seeking treatment, nor could they be made solely in medical practice. In order to create room for various interpretations and make conscious ethical decisions, it is important that we reflect over what otherwise could remain a form of cultural normality or a matter of course. Abstraction and reflection over those cultural patterns that affect interpretations and choices related to PGD and embryo selection are therefore crucial.<sup>51</sup> Only then is it possible to criticise or change the current situation and in a more conscious way delimit future developments and applications.

49. Westerlund 2000.

50. Statens medicinsk-etiska råd, 2004, p. 12.

51. Weir 1996, p. 185–190. Westerlund,

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# 14 Preimplantation Genetic Diagnosis for Elective Sex Selection: Individual Needs in Developing Countries; Financial, Social, Cultural and Religious Aspects

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Any interference with or alteration of the determination of sex is absolutely beyond human power, a statement said by *John Beard, University of Jena in 1902*. Long before that, mankind tried different methods to determine the sex of the newborn which were mythical. The ancient Greeks believed that the male determining sperms come from the right testicle; a man can produce a son while lying on his right side (1). In the Jewish tradition, the gender of the offspring is believed to be influenced by the sequence of orgasm: “A male child is likely to be conceived if the woman emits her semen first, whereas if the man emits his semen first it is more likely that the child will be a female” (2). In medieval times the suggested formula became even more bizarre: to have a son, alchemists recommended drinking the blood of a lion and then having intercourse under a full moon (3). The Chinese calendar method to conceive the desired gender relates the age of the wife to the month of conception. Ancient Egyptians believed that women of dark complexion were destined to have boys. In the eighteenth century in France, it was recommended that men who wish to have a son should tie off their left testicle during intercourse. The old advice to wear boots to bed was recommended to husbands keen to have a boy, or that mothers who desire to have a daughter should eat sweets (sour food for a son) (1).

Challenging the psychological, ethical implications and ignoring rules and laws, aggressive criminal acts were practised in some cultures to get rid of females e.g. infanticide has been practised by Chi-

nese, Indians and ancient Arabs (4, 5, 6). Sex selective abortion has been made possible through the introduction of prenatal diagnostic techniques. The introduction of ultrasonography, in particular to save babies and assure their well being, made it possible for some to diagnose the gender of the foetus and subsequently to terminate the pregnancy with the unwanted gender. Estimates indicate that in Asia several million female foetuses were aborted in the last two decades of the twentieth century (7).

By the end of the twentieth century, that statement by *John Beard* turned out to be *NOT TRUE*. Nowadays there are scientific and sound methods for sex determination such as:

A Sperm sorting techniques (Pre-conceptual).

The basis of this method is to separate X from Y bearing sperms using either gradient or flow cytometry. The latter depends on the difference of DNA content as the Y chromosome in humans contains 2.8% less DNA than the X chromosome. The outcome of these methods is variable, inconsistent, and the sorting efficiency is not absolute, either for the X- or for the Y-bearing sperms in the treated sample, therefore the application of these techniques for the purpose of pre-conceptual sex selection is questionable (8, 9, 10, 11, 12).

B Pre-Implantation: Preimplantation Genetic Diagnosis (PGD).

This technique involves taking one or two cells from the embryo(s) obtained through in vitro fertilisation (IVF) procedure for chromosomal analysis using fluorescent in situ hybridisation (FISH) before they are transferred to the uterus (13). This technique is well established, and shows a high degree of safety and accuracy. In our series (14), 354 PGD transfer cycles using FISH technique resulted in 92 (26%) clinical pregnancies, and the birth of 68 children. All were of the desired gender, normal and healthy, except for one male baby affected by Beckwith – Wiedemann Syndrome.

The PGD program for sex selection is a complex, stressful and costly one. It requires IVF which may be associated with potential problems and disappointments at each and every step such as a) ovarian hyperstimulation syndrome (OHSS), a well known, and potentially life threatening iatrogenic complication of superovulation, b) poor response,

c) fertilisation failure, d) embryo development arrest, and e) damage to the embryos during the biopsy procedure. Obviously it is impossible to guarantee that the desired gender embryo(s) will be obtained, or even available for transfer. In our series, embryos of both genders were diagnosed in 349 (74.5%) cycles, while in 56 (12%) cycles only male embryos were diagnosed, and in 63 (13.5%) cycles, only female embryos were diagnosed.

In our experience embryo transfer was cancelled in 141 out of 459 initiated cycles (28.5%). The reason for the cancellation was either due to the lack of the desired gender embryo(s) in 89 (63.1%) cycles or to the presence of aneuploid embryo(s) *only* in 52 (36.9%) cycles.

### **Sex selection: Religious considerations**

In several countries the application of assisted reproduction techniques including PGD for sex selection is strongly influenced by religious doctrines. A frequently asked question by couples asking for pre-conceptual or preimplantation gender selection is whether these techniques are permissible from a religious point of view? Judaism, Christianity, and Islam have expressed different views in this regard (15).

In *Judaism*, the use of either pre-conceptual or preimplantation methods can be justified and may be of certain practical importance, since the presence of at least one son is a pre-requisite in order to fulfil the criteria of procreation. For *Christianity* on the other hand, and as viewed by the Catholic Church, the concept of sex selection is totally forbidden even for medical purposes. However, in *Islamic* religion, although the attitude towards sex selection is guarded, the concept of sex selection is not prohibited by the Holy book. However a place is left for judgment on an individual basis, with the premise that there is no harm to the family or society.

### **Social aspects of sex selection**

The desire for sex selection reflects different individual and social needs. In that context it is important to differentiate between family balance and gender bias. Family balance applies to the desire of some couples to have a family with both sexes, whereas gender bias implies

a preference of one gender over the other. In our experience gender bias has never been an issue, since couples requesting sex selection usually have on average three children of the same gender, have lost one child and wish to have a balanced family without having to keep trying to achieve their goal, but can still maintain a reasonable family size. The use of inaccurate methods may result in health hazards mainly to the wife, larger family size, and a financial burden to the family and society. By giving the couple a choice for sex selection using a reliable and accurate method like PGD, family harmony is maintained and sufficient attention is given to children without any risk of neglect. Furthermore, family stability is protected, multiple marriages are avoided, and finally the ethical principles of autonomy, beneficence and non-maleficence are assured.

### **Sex selections and international organisations:**

In 1997, The International Federation of Gynecology and Obstetrics (FIGO) offered a somewhat lenient conclusion. It rejected sex-selection abortion, and reached the conclusion that “pre-conceptional sex selection can be justified on social grounds in certain cases for the objective of *allowing children of the two sexes to enjoy the love and the care of parents* (16).

The Ethics Committee of the American Society for Reproductive Medicine (ASRM) in 1999 criticised the use of PGD exclusively for the purpose of sex control, and claimed that it is “*morally inappropriate*”. The Ethics Committee of the ASRM concluded that “PGD for sex selection for *non-medical* reasons should be discouraged because it poses a risk of unwarranted gender bias, social harm, and results in diversion of medical resources from genuine medical needs.” *Significantly*, the report noted that the ethical objection would apply *equally* to other sperm-sorting techniques. Although the Committee did not favour its legal prohibition, it claims that the social risks of sex selection for non-medical reasons outweigh the social benefits. In 2001, the ASRM reviewed the concept of *preconception* gender selection for non-medical reasons, and concluded that it is permissible to use the technology of sperm sorting for sex control but not yet the technology of PGD for the same purpose, and raised concerns about both gender bias and the *moral status* of the embryo. The Committee concluded that “the use

of preconception methods of gender selection for creating gender variety in a family would *not* necessarily be *unethical* when certain other conditions are met, including establishment of safety and efficacy of the preconception methods that at present are still experimental” (17). However, the issue is still controversial and it is currently under revision again by the ASRM Ethical Committee.

The ESHRE Task Force on Ethics and Law in 2001, expressed certain concerns related to the technique of PGD: “We are aware of the *risks of abuse* for non-medical reasons.” Furthermore the Task Force in its statement in 2003 has *not* been able to reach a *unanimous* decision regarding the application of PGD for gender selection for non-medical reasons. Two positions can be distinguished: those opposed to every application of sexing for non-medical reasons and those who accept sex selection for family balancing (18).

The Human Fertilisation and Embryology Authority in the UK (HFEA) in 2003 stated, regarding the issue of sex selection, “We found this a difficult issue. It is clear that most people are against sex selection for social reasons. The HFEA has to balance the potential benefit of any technique against the potential harm. We are not persuaded that the likely benefits of permitting sex selection for social reasons are strong enough to outweigh the possible harm that might be done.” Furthermore the HFEA added that “The HFEA cannot stop people from going abroad for sex selection.”

## Conclusion

In developing countries, particularly in an Islamic context where there is a high premium placed on couples having at least one male offspring, the availability of PGD for non-medical reasons does have a positive effect. It maintains family and marital harmony, reduces the long term financial burden of keeping on trying, limits family size and maintains the ethical principles of autonomy, beneficence and non-maleficence, provided it is undertaken within strict guidelines that should be developed for each particular cultural context.

Of course there should be rules and regulations. There should be justice. There should be broad minded people to make the judgements and there should be no generalisation, looking into what is fair in each individual case.

Taking all these considerations into account, the Ethical Committee at The Farah Institute adopted the following guidelines in considering sex selection using PGD for non-medical reasons:

- a) The presence of three children or more of the same gender and the desire to have the opposite sex.
- b) The presence of a mentally or physically handicapped child of a certain gender with the desire to have a healthy child of the same gender.
- c) The loss of a child of a certain gender and the desire to have another child of the same gender.
- d) Maternal age >35 years, with one or more children of the same gender, and the desire to have a child of the opposite sex.
- e) Late marriage with a special need to have a certain gender order.

The availability of a relatively reliable, and accurate method for gender selection such as PGD has not only raised hopes and expectations, but also serious moral, legal, ethical, social and religious concerns.

The medical profession will be confronted with the implications of such a practice if left unregulated. Therefore, gender selection services should be limited to specialised, licensed, highly qualified Centres, subject to *strict* monitoring by health authorities. This will ensure high scientific standards, high quality professional care, and will enable detailed research.

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# 15 Feminist Views on Sex Selection

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In this paper, I will examine the subject of sex selection in the context of Anglo-American feminist discourse on reproductive technologies. There is a wealth of feminist discussion in the English-speaking world, particularly in the United States, about reproductive technology, and sex selection has been viewed as part of this topic. The most vocal feminism against sex selection has been radical feminism. Radical feminism is an influential strand of feminism, which claims that patriarchy is the defining characteristic of modern society and that all forms of oppression are extensions of male supremacy. Liberal feminists, on the other hand, take as their position the standard liberal emphasis on individual autonomy. Since the liberal argument is both familiar and general, I will present it but give more space to the more specific and less well-known radical feminist argument.

In his article on the abortion debate, philosopher Michael Boylan describes the premise for a pro-choice position in the following way: “The general station of women in this society, as in most societies in history, has been as a repressed and enslaved group. (...) Despite all our laws and aspirations as a society, women are treated differently from men. This difference is an added hurdle that women must overcome but that men do not face.

“To make the point more clearly, women are the oppressed gender. For men to say to women that they must abide by laws enacted by men that constrict their reproductive freedom (so that they might not be as free as men) is an act of political enslavement. (...) In this way, freedom of choice is essential (...)

“This freedom of choice is a cornerstone in the edifice that stands against gender enslavement. The struggle of oppressed women demands that they not be subjected to the will of men on something so essential to their biological nature as their reproductive equality.”<sup>1</sup>

1. Boylan 2000, 292–293.

Even though Boylan's description is somewhat of a caricature, it is nonetheless useful in setting the stage for a feminist discussion of sex selection. It contains the basic elements of both the feminist case *for* and the feminist case *against* sex selection.

### Feminists for Sex Selection

Boylan's description of the context for a pro-choice position in the abortion debate was cited in order to illustrate the interconnectedness of the various issues on the feminist agenda. The last part of Boylan's description, "(t)his freedom of choice is a cornerstone in the edifice that stands against gender enslavement," also makes the case for liberal feminists' argument for allowing sex selection. 'Choice' emerged in the late 1960s and early 1970s when the women's movement was part of a general push by liberationist groups internationally. A woman's right to choose was linked, initially, to the fight for access to safe abortion.<sup>2</sup> From there, it has been broadened to include other reproductive arrangements and technologies under the term 'reproductive choice.'

Liberal feminists endorse choice as a force of empowerment in a domain that, by most radical feminist accounts, has been lost to patriarchy. "This liberal conception of choice," says Sharyn Roach Anleu, "implies that actors freely make decisions to maximise their self-interest."<sup>3</sup> Indeed, if the distinction is between a liberal view of women as free agents actively pursuing their own goals and a radical feminist view of women as subjugated by male domination, it is easy to see how a feminist might want to hold on to the first option – even when presented with the hard case of sex selection. Thus, although a liberal feminist may find sex selection morally reprehensible, she might also consider policies to prevent its practice unacceptable.<sup>4</sup> She might reason that such policies would only serve to undermine the limited degree of reproductive freedom that women have already achieved. Such policies would also, from a liberal point of view, involve an unacceptable governmental intrusion into people's private lives. In addition, as Dorothy Wertz and John Fletcher point out, "sex choice may

2. Rowland 1992, 283.

3. Roach Anleu 1997, 99.

4. Susan Easton, for example, has said that "(t)he right to make mistakes and to

select the wrong choice might be seen as the cornerstone of liberal thought."

Cited in Lublin 1998, 95.

seem to be a logical extension of parent's rights to control the number, timing, spacing, and quality of their offspring."<sup>5</sup> Mary Anne Warren echoes this argument when she claims that freedom of choice "(...) includes not only the right to choose abortion, but also the right to decide whether and when to become pregnant in the first place. It includes the right of women of all ages, married or single, lesbian or heterosexual, to equal access to both the older reproductive technologies, such as contraception and abortion, and the newer ones, such as artificial insemination and in vitro fertilization."<sup>6</sup>

Notwithstanding this, sex selection remains an issue that tests the limits of reproductive choice. In their discussion of choice in the context of sex selection, Helen Bequaert Holmes and Betty Hoskins express the frustration of many feminists: "This question poses a real dilemma to the feminist. If we should advocate restrictions of research into sex choice technologies, or if we should advocate regulations against the use of such technologies, we then can be understood as suggesting to policy makers that governments ought to regulate human reproduction. Hard-won reproductive freedoms would then be jeopardized. Thus, while standing in strong opposition to these technologies, we cannot urge laws against them."<sup>7</sup>

For radical feminists, it is the notion of choice itself which has become the primary target of criticism. They argue that, under patriarchy, genuine choice is necessarily a fiction. Janice Raymond, in particular, launches a forceful attack against the liberal notion of choice: "New reproductive arrangements are presented as a woman's private choice. But they are publicly sanctioned violence against women. The absoluteness of this privatised perspective, especially as emphasised by the medical profession and the media, who present women as having unconditioned free will, functions as a smoke screen for medical experimentation and, ultimately, for the violation of women's bodies. Choice so dominates the discourse that it is almost impossible to recognise the injury that is done to women."<sup>8</sup> Gena Corea suggests that a woman's preference for a son "may not be a 'preference' at all, but rather something that is maintained by force and ideology."<sup>9</sup> Finally, Betty Hoskins and Helen Bequaert Holmes claim that 'choice' in the

5. Wertz & Fletcher 1992, 240.

6. Warren 1985, 183. – See also Homes & Hoskins: "If we think family-planning is a good idea, why not sex-planning? Is not this reproductive freedom?" Holmes & Hoskins 1987, 21.

7. Holmes & Hoskins 1987, 24.

8. Raymond 1993, ix.

9. Corea 1985, 191.

context of sex selection is not only fictional but also dangerous in that it benefits the patriarchy: “Under the guise of choice we may indeed exacerbate our own oppression.”<sup>10</sup>

The radical feminist critique against the concept of choice has been, in its turn, criticised by feminists sympathetic to liberal thought. According to Sharyn Roach Anleu, “(t)he portrayal of women who participate in conceptive technology programmes as acting contrary to their own interests suggests they experience false consciousness.”<sup>11</sup> Roach Anleu considers the charge of false consciousness as denigrating women’s ability to make autonomous decisions. She offers what she considers a more realistic account of the notion of choice: “Reproductive choices (...) are *constrained, but not completely determined*, by various intersecting inequalities which structure opportunities, the medico-legal environment and the prevailing normative system.”<sup>12</sup>

Another liberal feminist argument departs from the notion of *contract*. According to this argument, contract law should be applied to ‘reproductive collaboration,’ i.e. arrangements such as surrogate motherhood and gamete donation: “Free from government regulation, the general rules of contract law – the meeting of the minds regarding an exchange of binding promises – are applicable. Like any other free compact, these agreements are sacred, and third-party objections are deemed impotent.”<sup>13</sup> Canadian philosopher Ingrid Makus takes this line of thinking a step further when she describes parenthood as a contract. According to this *contractual model of parenthood*, the parents-to-be expect to benefit from having a child. Without the expected benefits, rational people might stop reproducing.<sup>14</sup> If one applies this argument to sex selection, couples and individuals may freely and legitimately use sex selection, if they consider its use to maximise their self-interest.

To some, this position may sound cold and calculative. For example, Glenn McGee characterises the overt control and planning of reproduction as *parenthood of oppressive control*. He argues that “(p)arents who choose traits as calculative consumers may come to devalue the essential connections of relatedness and sameness in the family relationship.”<sup>15</sup> The U.S. President’s Commission for the Study of Ethical

10. Holmes & Hoskins 1987, 25.

11. Roach Anleu 1997, 121.

12. *Ibid.*, 99. (Emphasis added)

13. Susan Easton, cited in Lublin 1998, 95.

14. Makus 1996, 127.

15. McGee 2000, 130.

Problems in Medicine and Biomedical and Behavioral Research states that becoming a parent requires a willingness to accept the child a woman gives birth to: “A parental concern with the sex of the foetus seems incompatible with the attitude of virtually unconditional acceptance that developmental psychologists have found to be essential to successful parenting.”<sup>16</sup>

### **Feminists against sex selection**

A house full of daughters is like a cellar  
full of sour beer<sup>17</sup>

The first part of Michael Boylan’s description quoted in the beginning of this article lays out the starting point for the radical feminist position against sex selection – that “the general station of women (...) has been as a repressed and enslaved group” which is, according to radical feminists, a direct result of patriarchy. By patriarchy they mean an all-pervasive system of male domination. In her classic text on radical feminism, Mary Daly states that “patriarchy appears to be ‘everywhere.’ Even outer space and the future have been colonised.”<sup>18</sup> It is of no surprise, therefore, that in 1984 a group of radical feminists created FINRRAGE, the Feminist International Network of Resistance to Reproductive and Genetic Engineering<sup>19</sup>, claiming that reproductive technology is yet another extension of patriarchy. To begin with, as far as FINRRAGE feminists are concerned, technology itself is permeated with the patriarchal sins of hierarchism, the exploitation of nature, objectification, the profit motive and others. And since reproduction, according to radical feminism, is the epicentre of male supremacy, reproductive technology as the conglomerate of the two enclaves of patriarchy is the ultimate evil. It is the latest stage in “the gradual attempt by man to extricate the process of birth from women and call it his own.”<sup>20</sup> Robyn Rowland, an Australian poet and one of the founders of FINRRAGE, writes that reproductive technology is the instrument that enables men not only “to control which women have children,

16. U.S. President’s Commission 1983, 57.

17. A German proverb, cited in Corea 1985, 190.

18. Daly 1978, 1.

19. For more about FINRRAGE, see Lublin 1998.

20. Cited in Rich 1976, 102.

when, how and how many,”<sup>21</sup> but also to “alienate women from their own reproductive processes.”<sup>22</sup> Sex selection is the first and, perhaps, the worst form of patriarchal control over reproduction through genetics since, ultimately, sex selection enables patriarchy to reproduce itself.

Feminist aversion towards sex selection is not limited to the feminists affiliated with FINRRAGE. A great variety of feminists dislike sex selection for a weighty reason: in the majority of cases it *favours males over females*. Almost every major study reveals a preference for boys, from the writings of Aristotle to the present, and around the globe, from the developing nations such as India, Morocco, and Bangladesh to China and Korea, to the United States and parts of Europe.<sup>23</sup> The message of sex selection is that being female is of less value than being male or, as Marielouise Janssen-Jurreit puts it, “Women are the unwanted sex.”<sup>24</sup> Even in Western societies, where the preference for males is less pronounced, there is an uneasiness among feminists towards sex selection. Dion Farquhar, for instance, defines sex selection as “a political achievement of institutionalised misogyny.”<sup>25</sup> According to Tabitha Powledge, sex selection is “one of the most stupendously sexist acts in which it is possible to engage.”<sup>26</sup>

In much the same way that even the most benevolent forms of human genetics are capable of bringing forth the memory of Nazi atrocities, sex selection evokes images of some of the most brutal manifestations of male domination: the European witch hunt between the 15th and 17th centuries, the practice of *suttee* or widow-sacrifice within the Hindu culture in India, female infanticide which still takes place in parts of Asia, and genital mutilation in many African nations, as well as connotations of rape and domestic violence, the universal

21. Rowland 1992, 5.

22. *Ibid.*, 12.

23. A survey from 2003 shows that if couples in the United States could have only one child, 38% would prefer a boy, 28% would prefer a girl, while 27% have no preference one way or the other. (Newsweek, January 26, 2004, 49) – On the other hand, according to a survey conducted in Germany in 2003, allowing sex selection for social reasons would have no or only minimal effect on the sex ratio. The results of this survey show that 58% of the respondents said they did not care about the sex of their

children, 30% said they wanted an equal number of boys and girls, 4% said they'd like more boys than girls and 3% said they'd like more girls than boys. When the respondents were presented with a hypothetical situation where they could take a blue pill for a boy and a pink pill for a girl, 9 out of 10 said they would not be interested. (European Society for Human Reproduction and Embryology, 24.9.2003, [www.eurekalert.org](http://www.eurekalert.org))

24. Janssen-Jurreit 1982, 264.

25. Farquhar 1996, 172.

26. Cited in Holmes & Hoskins 1987, 23–24.

insignia of male power over females. Janice Raymond, a prominent FINRRAGE feminist, talks about 'previctimisation' in the context of sex selection. Previctimisation, according to Raymond, refers to "the oppression and obliteration of the female before she is born."<sup>27</sup> The historical and contemporary precedents of sex selection are many: the abortion of female fetuses; female infanticide; and the selective neglect, abuse, and abandonment of female children.

The imagery of male domination over women is buried deep in the collective consciousness – so deep, in fact, that even the mainstream culture has developed a sensitivity to sex selection. In the United States, for example, the President's Commission for the Study of Ethical Problems in Medicine and Biomedical and Behavioral Research has come to a conclusion that, "in some cases, the prospective parents' desire to undertake the procedure (of sex selection) is an expression of sex prejudice. Such attitudes are an affront to the notion of human equality and are especially inappropriate in a society struggling to rid itself of a heritage of such prejudices. (...) Surveys of parents and prospective parents (...) indicate (...) a preference for sons (especially as the first-born child). If it became an accepted practice, the selection of sons in preference to daughters would be yet another means of assigning greater social value to one sex over the other and of perpetuating the historical discrimination against women."<sup>28</sup>

According to the Commission, sex selection is inherently *sexist*. Sex selection is inherently sexist, according to most feminists, because it is "invariably motivated by sexist beliefs;"<sup>29</sup> because it is "founded on and reaffirms sexist notions of the values of females and males;"<sup>30</sup> and because it would "increase sexism and sex role stereotyping, and could undo the hard-won advances of the women's movement."<sup>31</sup> Betty Hoskins and Helen Bequaert Holmes ask poignantly: "What would be more sexist than to *create* a person to fit a sex role ideology?"<sup>32</sup>

Even preference for girls is an expression of sexism since it emphasises "patriarchal values of rank-ordering and judgementalism,"<sup>33</sup>

27. Cited in Farquhar 1996, 116.

28. U.S. President's Commission 1983, 57. – Notice, however, that the Commission did not recommend that sex selection be banned: "The Commission recognizes, however, that a legal prohibition would probably be ineffective and, worse, offensive to important social values (because vigorous enforcement

of any such statute might depend on coercive state inquiries into private motivations)." U.S. President's Commission 1983, 58.

29. Warren 1985, 84.

30. Rowland 1992, 91.

31. Wertz & Fletcher 1992, 249.

32. Hoskins & Holmes 1984, 248.

33. Holmes & Hoskins 1987, 24.

according to Holmes and Hoskins. Furthermore, American law professor Dena Davis has looked into the motives of women who want girls. She has found that they speak of Barbies and ballet and matching mother-daughter outfits and other such things that are supposed to come with girls.<sup>34</sup> This is, undoubtedly, a case of creating a person to fit a sex role ideology.

The charge of sexism has also been levelled against so-called *family balancing*, which for many represents a morally neutral or harmless form of sex selection.<sup>35</sup> Thus John Robertson, an ethicist and lawyer at the University of Texas, suggests that sex selection be allowed for family balancing or *gender variety* as he calls it.<sup>36</sup> Dorothy Wertz and John Fletcher initially claim that “prima facie there is no reason to condemn the desire to balance sex in families.”<sup>37</sup> On closer look, however, they come to the conclusion that family balancing is also morally condemnable: “Why desire to balance a family unless you already hold stereotypes about sex?”<sup>38</sup>

## The Sex Ratio Argument

The most obvious consequence of sex selection is its impact on the sex ratio. The biological sex ratio at birth is 105 boys to every 100 girls. However, in the adult population women outnumber men because women, on the average, live longer.<sup>39</sup> This is, as behavioural scientist Valerie Grant points out, “true for all human populations in all countries.”<sup>40</sup> Thus, any deviation from the standard biological sex ratio indicates selective interference of some sort.<sup>41</sup>

34. Davis 2001, 98-101.

35. For example Roger Gosden argues that “‘(f)amily balancing’ is the more acceptable face of sex selection in the West.” He predicts that “we will see greater acceptance of family balancing,” and doubts “that it will ever be used or abused as much as is feared.” Gosden 1999, 170 and 178.

36. See Kolata 2001.

37. Wertz & Fletcher 1992, 244.

38. Ibid.

39. Ullman and Fidell explain this in more detail: “(T)here are more boys conceived and born than girls, but, owing to higher infant mortality among boys, the gender ratio is about even by the end of the first year of life and stays even through the first two decades. Then, owing to the greater male accident and, eventually, illness rate, the ratio favors women increasingly into middle and late years. Women over 65 far outnumber men.” Ullman & Fidell 1989, 183.

40. Grant 1998, 4.

Given the almost universal preference for male offspring, it is likely that the ability to select the sex of the infant would result in more males being born and, ultimately, in an imbalanced sex ratio. Robyn Rowland comments on this: “Women are the most exploited, manipulated, oppressed and brutalised group in the world, yet we have the numbers. What would our status be as a vastly outnumbered group?”<sup>42</sup>

Couldn’t get better, according to British psychology professor Richard Lynn: “Even if sex selection does develop on a significant scale and leads to an excess of males, this could well be desirable. In such a society, males would have to compete more energetically for females, and in this competition males with higher status would tend to succeed. Conversely, women would have greater choice of men and would tend to select those with higher status, as women normally do. The males with higher status who succeeded in obtaining females and who were selected by females would tend to be the more intelligent and with stronger moral character, so the effect would be eugenic and desirable.”<sup>43</sup>

American philosopher Mary Anne Warren makes a similar claim: “A relative scarcity of women might increase their value in both the marriage and labour markets, thereby enabling a strong feminist movement successfully to demand more equitable laws and social arrangements.”<sup>44</sup>

The *argument on scarcity value* has, nevertheless, been forcefully countered in the context of sex ratio – including by Mary Anne Warren herself: “But where women do not already possess substantial legal and political rights, or where the women’s movement is weak, disorganised or nonexistent, higher sex ratios would be less likely to work to their advantage. Under these conditions, a shortage of women might lead instead to a tightening of patriarchal restrictions, as many men come to believe that maintaining control over the behaviour and reproductive lives of women is more important than ever.”<sup>45</sup>

41. According to the United Nation’s most recent statistics, the sex ratio is in India 94 women to every 100 men; in Bangladesh 95 to 100; in Sri Lanka 93 to 100; and in China 95 to 100, to name a few examples. In comparison, the sex ratio is in Finland 105 women to every 100 men; in Germany 105 to 100; in

Japan 105 to 100; and in the United States 104 to 100. (United States, Statistics Division 2000, [www.un.org](http://www.un.org).)

42. Rowland 1987, 83.

43. Lynn 2001, 266–267.

44. Warren 1985, 21.

45. *Ibid.*

In fact, the impact of sex selection could be as dramatic as that suggested by John Postgate: "All sorts of taboos would be expected and it is probable that a form of *pardah* would become necessary. Women's right to work, even to travel alone freely, would probably be forgotten transiently. Polyandry might well become accepted in some societies; some might treat their women as queen ants, others as rewards for the most outstanding (or most determined) males."<sup>46</sup> In a similar fashion, Robyn Rowland predicts that women will be valued merely for the purposes of sex and reproduction. For Rowland, sex selection will "reinforce stereotypical definitions of what it is to be male and female in a patriarchal world."<sup>47</sup>

Furthermore, it has been hypothesised that an imbalance in the sex ratio would lead to a rise in *male aggression and violence*. These predictions have been based on the observation that men are more apt than women to behave violently. Amitai Etzioni, for example, argues that "a significant and cumulative male surplus will (...) produce a society with some of the rougher features of a frontier town."<sup>48</sup> In fact, it would not be long before society's values changed and females would be more welcome since they, according to Etzioni, "read more books, commit fewer crimes, go to more plays, are more religious, and do more about the moral education of the young."<sup>49</sup>

However, if it is true that the surplus of men only works to male benefit, then the *argument of self-correction* falls short. Lynn offers one nonetheless: "Even if a significantly greater number of males were to be born, this would probably be self-correcting, as girls would acquire scarcity value and come to be desired more than boys. The preferences of couples would then be expected to switch in favour of selecting girls."<sup>50</sup>

46. Cited in Corea 1985, 201.

47. Rowland 1987, 91. – Ullman and Fidell point out that women "choosing not to have children or those unable to bear children might be ostracized by society." Furthermore, according to Ullman and Fidell, "women would be denied opportunities of career and education in favor of maximal child-bearing." And lastly, also men might

suffer: "What would happen if (...) a man had to compete not just for the girl of his dreams but for any girl at all? What would happen if lots of men had to look forward to a life largely bereft of female companionship?" Ullman & Fidell 1989, 184.

48. Cited in Kumar 1987, 175.

49. Cited in Grant 1998, 192.

50. Lynn 2001, 267.

Of course, the existing examples of societies that have a surplus of men show no signs of self-correction. In fact, the situation may be getting worse in some places. Females in Nepal and Bangladesh, for instance, have higher mortality rates than males at all ages and indications are that the gap is widening.<sup>51</sup> Dharma Kumar, an economic historian from India, a nation notoriously short of women, advises against allowing sex selection: "(...) since most people prefer boys to girls, if they are allowed to choose the sex of their child, an unbalanced sex ratio will result, so people must not be allowed to choose. The loss in individual freedom of choice and (short run) happiness of a few is outweighed by the unhappiness of an unbalanced society."<sup>52</sup>

### The Male Firstborns Argument

First comes love, then comes marriage,  
Then comes [name] with a baby carriage.  
I wish you love, I wish you joy,  
I wish you first a baby boy.  
And when his hair begins to curl,  
I wish you then a baby girl.<sup>53</sup>

The most frequently desired family unit in Western cultures is said to be a boy first and then a girl. The Congressional Office of Technology Assessment stated in its 1988 report that "it has been demonstrated that, if it were possible to choose the sex of their children, many individuals and couples would prefer that their firstborn be male. It has also been demonstrated that firstborn children benefit from their early period of exclusive parental attention. If firstborn boys became the norm, it might further compromise equality of opportunity between men and women."<sup>54</sup>

51. Mathema 1998, 586.

52. Kumar 1987, 180.

53. From an American autograph book, cited in Steinbacher & Holmes 1987, 52.

54. U.S. Congress, Office of Technology Assessment 1988, 83.

So-called *birth order* research correlates birth order with such aspects of life as temperament and behaviour. Feminists, too, have explored sex selection from the perspective of birth order research.<sup>55</sup> Based on this research, they have come to the conclusion that the preference for male firstborns is of as much concern to feminists as the preference for all-male or predominantly male families. If sex selection technology were to be widely available in the West, we would end up having nations of older brothers and younger sisters.<sup>56</sup> Since birth order research indicates that firstborn children have certain advantages over children who are born later, these advantages would be concentrated among males. There is evidence that firstborn children tend to enjoy significant advantages in personal, social, and intellectual development. For example, birth order research has consistently linked firstborn children and academic achievement so that firstborns are overrepresented in academic and professional eminence. In addition, since children themselves perceive that firstborns are bigger, stronger and smarter than their younger siblings, firstborns tend to develop dominant, assertive personalities and end up in leadership positions as adults. Later-born children, on the other hand, tend to be trusting, accepting and other-centred. They are more likely to seek help, they are more talkative, and they have a greater need for affiliation than firstborns.

Since some of the characteristics assigned in birth order research to firstborns and later-borns correlate remarkably with the traditional sex roles assigned to males and females, Robyn Rowland laments that "(m)edical technology would therefore be building the traditional sex role stereotypes into a biological determinism. Males would be more stereotypically masculine; and (second-born) females more stereotypically feminine."<sup>57</sup> This would further complicate efforts to effectuate gender equality in society.

Even if birth order is inherently insignificant, there is still room for concern that girls will suffer from the knowledge that they were selected to be born only after the preferred sons. The second-class status of women would be confirmed *de facto*. "The ramifications to women of knowing that they were 'wanted' but second, can hardly be beneficial,"<sup>58</sup> say Jodie Ullman and Linda Fidell.

55. See, for instance, Corea 1985, Rowland 1992, Holmes & Hoskins 1987, Warren 1985, Ullman & Fidell 1989.

56. Corea 1985, 204.

57. Rowland 1992, 89.

58. Ullman & Fidell 1989, 186.

## Conclusion

I have described above the various feminist arguments on sex selection. The two broad lines of thought, radical feminism and liberal feminism, are both burdened with contradictions and inconsistencies. Liberal feminism presumes an autonomous female agency, furnished with an unproblematic atomic individuality. This is a presumption that second-wave feminism has, with no small amount of success, demonstrated to be both erroneous and undesirable in its disregard for the essential human condition of inter-connectedness. Radical feminists, on the other hand, take their criticism against freedom of choice to the other extreme. The radical feminist portrait of all other women as “duped ventriloquists of the patriarchy”<sup>59</sup> is not only presumptuous but also detached from reality. In my opinion, a more moderate approach to the notion of choice is in order. Dion Farquhar hits the target in her discussion of freedom of choice: “We are all subject to pressure in many areas of our lives and that does not make us incapable of making choices or the decisions that we take any less worthy of respect.”<sup>60</sup>

In addition, radical feminist opposition to technology in general and reproductive technology in particular does not, as far as I am concerned, even come close to qualifying as a sound feminist strategy. Its defeatism serves only to strengthen male domination of technology and to alienate women from useful and potentially empowering applications of technological innovation. By the way: how does women’s use of computers fortify male supremacy? Must we denounce technology forever?

A few critical remarks aside, one cannot help but appreciate the enormous contribution Anglo-American feminists have made to bring about a thoughtful and ongoing debate on reproductive technologies in general and on sex selection technology in particular. Ideally, a society should not make any significant public policy decisions until *after* such a debate has taken place. Thus, whether one is for or against sex selection, the feminist discussion on the issue has, in its part, enabled an informed decision-making.

59. Farquhar 1996, 109.

60. *Ibid.*

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