



Pre-implantation Genetic Diagnosis

A Discussion Paper

**Synod Bioethics Committee
Uniting Church (Queensland Synod)**

Could the proliferation of techniques that increasingly enable us not just to have children, but to choose characteristics unrelated to their health, exacerbate our tendency to think of children as objects of our making? Could these techniques lead us to think of ourselves as mechanisms that are valued for our individual parts or traits rather than as individuals who are valued for being unique wholes? ... Put positively, what can we do to increase the chances that these techniques are used in ways that further the happiness of children, families—and ultimately the well-being of our society as a whole?

Parens & Knowles, 'Reprogenetics and public policy', S4

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Introduction and background

This paper explores the issue of pre-implantation genetic diagnosis (PGD). It is hoped that the information provided will promote further discussion from which shared understandings will emerge. Opportunity to provide feedback is given at the end of the paper.

The Bioethics Committee was asked to review the Queensland Synod's current position on a range of assisted reproduction services, including preimplantation genetic diagnosis. The initial request came from fertility professionals at the Wesley Hospital.

Prenatal diagnostic tests such as amniocentesis, chorionic villus sampling, and foetal cell sorting can be used in pregnancies achieved with assisted reproductive techniques. A technique called **pre-implantation genetic diagnosis** detects genetic and chromosomal abnormalities before a pregnancy starts. The couple can select a very early embryo—termed a "pre-implantation embryo" because it would not normally have yet arrived at the uterus for implantation—that is free of a certain detectable genetic condition.

R. Lewis, *Human Genetics*, p. 388

Patients choosing PGD undergo in-vitro fertilisation (IVF) treatment. Sperm and ova are joined in a laboratory dish. On day three of embryo development, one or two cells are removed from the embryo. Genetic probes are placed into the cell nucleus, and a genetic analysis is carried out. This nuclear material is characteristic of the genetic material that would ultimately make up the new individual. (Lewis 2001; Allan 2001)

In Australia, under National Health and Medical Council guidelines, an embryo may not be cultured in vitro for more than fourteen days. After this period, a process of individuation takes place.

Before fourteen days from the time of fertilisation the embryo, or pre-embryo as it was scientifically known, was a cluster of first two, then four, then sixteen cells, undifferentiated. An undifferentiated cell can develop into any of the types of cells that go to make up the human body and some would not become part of the embryo at all, but would form the placenta. After fourteen days, there begins to appear the first traces of what will become the central nervous system of the embryo, the primitive streaks....From this time the cells develop into their particular types, and the embryo develops fast into a recognisable foetus ... There are therefore good scientific reasons for distinguishing between an embryo before fourteen days, when it can hardly be referred to as a human individual, and an embryo after this stage.

M. Warnock, *Making Babies*, p. 35

According to current guidelines, there is no requirement that all embryos be implanted. 'Embryos may be allowed to succumb by withdrawal of support' (NHMRC Guidelines, 7.4). For this reason, however, clinics are required to limit the number of embryos produced. They 'should take account of the success rates of fertilisation typically achieved in the clinic and, on that basis, seek to avoid the likelihood of production of embryos in excess of the needs of the couple. Techniques and procedures which create embryos surplus to the needs of the infertility treatment should be discouraged' (NHMRC Guidelines, 6.5).

PGD can alleviate potential suffering for patients who are susceptible to inheritable conditions or other factors that may lead to an increased risk of chromosomal abnormalities. As 'chromosomal abnormalities make up 80-85% of the major causes of miscarriage and severe chromosomal abnormalities encountered in foetal development' (Allan 2001), pre-implantation genetic diagnosis allows parents to diagnose conditions before pregnancy has been initiated, thus avoiding the need to later terminate a pregnancy (Killer 2000).

PGD has extended the range of personal and social choices into areas hitherto left to chance. There is some concern, in the community and amongst many professionals themselves, that the technology can be inappropriately used to focus not on serious genetic conditions or disease but on trivial matters such as sex or appearance and, therefore, lead to the commodification of reproduction. Other ethical issues raised include concerns that PGD implies selective abortion and that the selection of embryos based on disability traits impacts on disability rights.

Those supporting the use of PGD point out that some of these issues are not unique to PGD itself but reflect wider moral concerns over which there are differences of opinion informed by various religious traditions and moral frameworks. PGD itself, wisely used, it is argued, can alleviate the necessity of facing these genuinely difficult moral choices at a later date. Nevertheless, PGD is a difficult, intrusive and expensive procedure and in an environment of finite resources any benefits to individuals and the community must be carefully weighed.

Approaching the ethical issues

The Synod Bioethics Committee's previous discussion paper on gamete donation introduced a framework for approaching applied ethical issues

which sought to be responsive to the mutual needs and interests of stakeholders. Clinical decisions do not just impact on an individual or couple but also on their offspring and extended family. Rather than seeing ethical dilemmas as the preserve of isolated individuals, we appreciate that these individuals are embedded in ever widening circles of concern, from the petri dish to the wider community.

Medical ethics and bioethics have usually focused on four key principles: autonomy, non-maleficence, beneficence and justice. *Autonomy* focuses on respect for persons and asks, is an individual free to choose for themselves? *Non-maleficence* focuses on the harm principle and asks, is this likely to harm others? *Beneficence* focuses on whether a practice or choice will enhance the well-being of others. Will it do them good? *Justice* focuses on issues of fairness. Will the benefits and risks be distributed equitably, or to those who are most in need, or to those who deserve it?

Principles of medical ethics

Respect for Autonomy

Does this decision or course of action respect a person's capacity to make informed decisions about their own life?

Non-maleficence

Will this decision or course of action cause physical, psychological or social harm?

Beneficence

Will this decision or action promote the wellbeing of individuals or the community?

Justice

Is this decision fair? Does it treat people equally, according to their needs and abilities, whatever their wealth, gender, ethnicity or beliefs?

These core principles of bioethics have, up to a point, served us well; however, they need to be placed in the context of both the individual and *collective* life stories which shape an ethical situation. The church itself has a collective story, a tradition, which shapes its response. The foundation values of Uniting HealthCare, for example, require us to always consider issues of autonomy, justice, non-maleficence and beneficence in relation to the Church's core commitment to valuing the 'whole person' and 'community'.

Healthcare of the whole person in community

In recent decades, the health profession has declared that healthcare should address the needs of the whole person. The World Health Organisation in 1958 made its now well-known statement that, 'Health is physical, emotional and social well-being, and not simply the absence of disease or infirmity.'

The Christian understanding the human person is of an indivisible unity of body, mind and spirit. That understanding goes further to seeing each person not just in terms of their individual existence, but in terms of the rich context of relationships in which they live. Of six 'foundational values' articulated by Uniting HealthCare, the first two are 'the whole person' and 'community'.

Healthcare, according to such an understanding and value base, should seek the harmonious functioning of a unified person within a community of persons. It cannot therefore view an issue like IVF as simply the treatment of the physical limitation of infertility in isolation from consideration of the ongoing consequences for a resultant child, the parents, and indeed for a range of other people whose lives may be affected by this activity.

Ian Peers, Synod Bioethics Committee

The Uniting Church attitude to bioethical issues has also been informed by the traditions which have shaped it. According to UC theologian and bioethicist Andrew Dutney (2001, 137), compared to the traditions of medical ethics in the liberal society, Christian ethics in the Uniting Church and the traditions which have formed it are 'post-liberal'.

Post-liberal theologies have given more emphasis to the way personhood is relationally constituted. That is, the 'image of God' in the human person is located not so much in the exercise of autonomy (being 'like' God in authority) as it is in building relationships and being-in-relationship (being 'like' God in mutuality and love) ...

The second feature of post-liberal theologies is related to this: the recognition of the importance of *community*. 'Individualism' and 'libertarianism' have become pejoratives, especially where their ready acceptance by liberalism has been seen to rebound on the weaker members of society. Instead 'solidarity' has become a leitmotif in the various types of post-liberal theological ethics.

A. Dutney, *Playing God: Ethics and Faith*, p. 138

Other new approaches to applied ethics also resonate with this post-liberal approach. Peter Isaacs and David Massey (1994), for example, argue that applied ethics requires 'creating and sustaining relationships which mutually recognise the needs, interests and aspirations of all participants as ends in themselves'. They offer the following framework for exploring ethical issues.

An applied ethics framework

1. *Explore meanings.* (Hermeneutical dimension) First we need to ask questions which will help us to understand the frameworks of all participants, individual and institutional. What are their assumptions, insights and limitations? From the point of view of the various people involved, what is going on here? Not just from my point of view? What meanings does this have for the participants from their point of view.
2. *Appreciate particulars, including constraints on choices.* (Appreciative dimension) The second set of questions we should ask acknowledges the richness, complexity and particularity of others. Do I understand the factors which enable or constrain them; that is, their relative power or powerlessness? Is engagement with others being promoted, or are solutions being advocated from a distance without a fuller, deeper understanding of the situation? Are relationships, practices, individuals, institutions and communities being morally enriched? We ask these questions because not everyone is in a position to choose freely from all the options.
3. *Explore ethical frameworks.* (Appraisive dimension) Only after opening up the context by exploring these two sets of questions can we begin to bring back in the ethical frameworks from our philosophical and religious traditions. Then we can ask what values, principles, and virtues should inform our response? What would be the caring thing to do? Again, we should seek to understand which moral codes other participants bring to the situation.
4. *Do something about it.* (Transformative dimension) We should not stop our inquiry with an intellectual appraisal. We need to ask ourselves a final set of questions. What can we do about this? What action is possible? What strategies for change are appropriate? What strategies are participants already using to promote their values? What possibilities are there for informing, educating, mobilising, mediating or, if necessary, resisting?

Based on Peter Isaacs & David Massey, 1994

The Committee has again employed this framework to define an ethical stance toward PGD which takes into account the concerns of various stakeholders, not the least because PGD impacts in various, sometimes conflicting, ways on a number of stakeholders. For example, the Uniting Church has a long-standing commitment to providing support for the needs and rights of persons with disabilities and shares their concerns about the possible impacts of new reproductive technologies on their rights. At the same time, the Uniting Church's Reformed heritage supports compassionate medical intervention in ways that differ markedly from the assumptions of other traditions; most particularly, the Roman

Catholic tradition, whose moral theological assumptions start from radically different premises.

Current situation

Women who are 35 years of age or older, women who have had a number of previous miscarriages, or those with a known genetic abnormality in their family tree and are more likely to have a foetus that suffers from a chromosomal abnormality, can be offered embryo biopsy and preimplantation genetic diagnosis. A result is obtained on the day of biopsy and an unaffected embryo can be transferred to the patient's uterus on the following day (Allan 2001).

The Wesley IVF unit considers PGD to be only appropriate to a highly restricted number of patients: those women (i) of advanced maternal age, (ii) or who have a history of recurrent miscarriage during pregnancy, or (iii) a family history of genetic disease. This policy, combined with the complexity and difficulty of the procedure, means that there is currently little demand. In some instances, embryo biopsy is being abandoned and replaced by implantation of pre-embryos at Day 5 blastocyst stage, as the majority of pre-embryos containing chromosomal abnormalities fail to survive to this stage. In a sense, the pre-embryos are 'diagnosed' by natural processes. However, ethical concerns will remain for the small number of people who will undergo, or consider undergoing, the PGD procedure.

In 1989, the first children were born using PGD procedures. Pre-implantation embryos were selected after being screened to ensure they would be girls. This was so that X-linked conditions their mother carried could be avoided. In 1992, the first child was born using PGD to avoid a specific inherited disease. The parents used the technology to avoid having a second child with cystic fibrosis. (Lewis 2001, 382-389).

The particular chromosomes currently being targeted at the Wesley IVF Unit are the sex chromosomes in the female XX and male XY and the autosomes 13 [Patau syndrome], 16, 18 [Edward syndrome], 21 [Down syndrome], and 22. Abnormalities in the number of chromosomes in the embryo comprise 80-85% of the major causes of miscarriage and severe chromosomal abnormalities encountered in foetal development. In other words, these chromosome abnormalities or aneuploidy would in most cases either result in the embryo not implanting, a miscarriage during the pregnancy or in the event that the foetus survived to delivery, most foetus's would die shortly after birth. [refer Attachment 1.]

(Allan 2001)

Assisted reproduction practices in all states are underpinned by a national system of self-regulation and accreditation by the Reproductive Technology Accreditation Committee (RTAC) of the Fertility Society of Australia. Accreditation is partly determined on compliance with the National Health and Medical Research Council (NHMRC) guidelines. These *guidelines*, issued in 1996, do not make any specific reference to pre-implantation genetic diagnosis. In early 2003, new draft guidelines were issued for public consultation. Four new guidelines (8.1-8.4) addressed pre-implantation genetic diagnosis.

- 8.1 Pre-implantation genetic diagnosis (PGD) should be used only to obtain information about a serious genetic condition or disease (including serious chromosome abnormalities not associated with a known condition or disease).
- 8.2 The seriousness of a condition should be a matter for discussion between the people seeking testing and the clinical team. Information to be provided to, and considered by, those seeking testing should include:
 - 8.2.1 the risks of the procedure itself;
 - 8.2.2 genetic and clinical information about the specific condition ;
 - 8.2.3 the likely impact on those affected and their families;
 - 8.2.4 information about treatment and social support available; and
 - 8.2.5 the testimony of families and individuals about the full range of experiences of living with the condition.
- 8.3 In any particular situation the people seeking testing should be encouraged to consider the following factors when deciding the appropriateness of PGD:
 - 8.3.1 their previous reproductive experience
 - 8.3.2 the likely effect of the condition, disease or abnormality, including the degree of suffering associated with the condition or impact on development of the embryo;
 - 8.3.3 the likely availability of effective therapy or management now and in the future;
 - 8.3.4 the likely speed of degeneration in progressive disorders;
 - 8.3.5 the likely extent of any intellectual impairment;
 - 8.3.4 the extent of social support available; and
 - 8.3.7 the family circumstances of the people seeking testing.
- 8.4 Clinics should ensure that those seeking testing should have access to both clinical geneticists and genetic counsellors.

National Health and Medical Research Council, 'Ethical guidelines for reproductive technology in clinical practice and research: Draft for public consultation', February 2003

There are no specific laws covering pre-implantation genetic diagnosis. In 2003, the Infertility Treatment Authority in Victoria introduced a 'Policy in relation to the use of Preimplantation Genetic Diagnosis for Genetic Testing'. In Western Australia, a draft 'Code of Ethical Practice for the Provision of Genetic Services in Western Australia' is under discussion.

Emerging themes and issues

As a practice, PGD intersects with a range of ethical concerns; for example, its relation to other forms of prenatal diagnosis, such as amniocentesis, chorionic villus sampling, and foetal cell sorting (discussed in a previous Synod Bioethics Committee statement), disability rights, IVF, selective abortion, reproductive liberty, medical ethics and ethics in genetic counselling. This discussion paper focuses on the following themes:

- Are there risks associated with PGD? Are these risks acceptable?
- Can PGD provide information on genetic characteristics relevant to the pursuit of a shared good such as achieving a viable pregnancy resulting in the birth of a healthy child?
- Does PGD encourage selective parenthood and reduce children to the status of commodities?
- Does PGD involve selective abortion?
- Does PGD encourage choices to be made on the basis of a single characteristic, such as a disability and, therefore, as a practice reinforces wider social discrimination against persons with a disability?

Risks and Responsibilities

Assessing whether PGD is a responsible practice involves assessing both tangible harms and non-tangible harms; the former concern issues of safety, and the latter involve more contested notions of well-being, both personal and social (Parens and Knowles 2003, S6).

Because PGD requires the use of in-vitro fertilisation (IVF) procedures, there are risks associated with the use of superovulation drugs (the drugs which cause the patient to release more than one 'ripe' oocyte at a time) (Lewis 2001, 386). Severe ovarian hyperstimulation syndrome is rare but life-threatening; there is also a potential increase in the risk of ovarian cancer. Surgical risks include possible 'puncture of the fallopian

tubes, infection and bleeding'. Traditional assisted-reproductive techniques also put gestating women at risk of preeclampsia, diabetes mellitus, bleeding and anaemia. There is also the general risk of infection which accompanies tissue transplantation (Parens & Knowles 2003, S6).

These clinical safety concerns are usually well-known to those conducting the procedures, if not always to those undergoing them. Parens and Knowles (2003) argue that in reproductive medicine reliable data on risks often lags behind practice. 'Without good data, it is unlikely that meaningful informed consent can balance the desire to have a child.'

In reproductive medicine ... the line between clinical innovation and human experimentation is fuzzy: 'patients' in reproductive medicine sometimes can be subjected to the high levels of uncertainty and risk commonly associated with being a research subject

Parens & Knowles, 2003, p. S6

Complex issues of individual and social well-being are less likely to be addressed in clinical and public policy. The risk of commodification of children, reproduction of social inequalities, and discrimination against people with disabilities will be addressed below. However, the most recurrent risk to well-being in IVF programs is the relative unlikelihood of a successful outcome.

The risks that a couple must weigh up are those always associated with IVF. Because it is a relatively unsuccessful procedure they risk the disappointment of there being no further pregnancy—even after the demanding regime of treatments. In addition, the arduous and intrusive nature of IVF treatment places a great strain on patients and their marriages. Before accepting pre-implantation genetic diagnosis as the solution to their dilemma they would have to be confident that IVF would be tolerable for them.

Andrew Dutney, *Playing God: ethics and faith*, p. 16

There are psychological risks associated with the termination of pregnancy whether it occurs by medical intervention or natural processes. As well as the grief and loss which result from termination, there may sometimes be feelings of guilt over a decision to terminate a pregnancy. PGD can be seen as a responsible practice addressing these risks because conditions which may lead to a termination are diagnosed before pregnancy is initiated. Termination can thus be avoided. There will still be grief and loss but, arguably, less so. Because the diagnosis is carried out on a pre-embryo prior to implantation, the decision not to proceed with implantation is of a morally different order than making that decision with respect to a foetus. One study (Lavery, et al. 2002)

suggests that PGD, though itself stressful, is acceptable to patients and seen by them as a valuable alternative to other forms of prenatal diagnoses. According to another study (Cameron & Williamson, 2003), couples at one in four risk of having a child with a serious inherited disease will often choose IVF followed by PGD rather than abortion following chorionic villus sampling at 10-12 weeks.

In Australia, the draft NHMRC guidelines (2003) reflect a current consensus that the techniques should be 'used only to obtain information about a serious genetic condition or disease'. However, what constitutes a serious disease, or indeed a disease, is not always clear. Selecting against colour blindness or tone deafness may seem trivial, but what about blindness or deafness? Recently, there have been close examinations of the way in which notions of disability have been socially constructed (Clapton, 2003) and the impact this may have on prenatal screening (Edwards, 2003).

The research of Dorothy C. Wertz and colleagues suggests that even genetics professionals have very different ideas of what is and what is not 'serious'. In one of Wertz's surveys, cleft lip/palate, neurofibromatosis, hereditary deafness, insulin-dependent diabetes, Huntington disease, cystic fibrosis, sickle cell anaemia, Down syndrome, and manic depression were deemed serious by some professionals and not serious by others.

Parens & Asch, 2000, p. 9

Many individuals with these conditions lead otherwise fruitful lives. Disappointingly, however, some studies confirm that there is a widespread attitude among prospective parents that all impairments or incapacities are undesirable (Roberts, Stough & Parrish 2002; Erikson 2003).

If this is the case, there are serious repercussions for the positioning of autonomy in ethical decision-making in clinical settings. The principle that parents ought to be free to make reproductive choices themselves involves a risk that their preferences may be based on ignorance or prejudice. Some have even argued that the principle of autonomy might permit some parents to select in favour of particular disabilities; for example, deaf parents might select an embryo which exhibited the genetic potentiality for deafness. The child would then more fully share in the culture of the parents.

While current attitudes to disability and PGD may be determinate of its public acceptability, it does not determine its rightness. These views may

be held, but ought they to be held? Perhaps, this highlights a significant difference between a majority opinion and a shared understanding. The former is a matter of maths; the latter a matter of morality. It does highlight, however, that risk and harm are not the same thing, and the moral life is not about avoiding all risks; rather, it is about negotiating responsibility in risk-laden situations.

Many people with disabilities, while we understand quite well the burdens of disability, are not willing to make the judgment that lives like ours are not worth living. Every life has its burdens, some of them far worse than disability.

Wendell, 1996, p 154

Seeking to maximise the health and well-being of our children is seen as an important virtue. The goal of physicians to achieve the best outcome and quality of life for patients is shared by patients and the general community. Actions by individuals or organisations which compromise the health and development of their children are viewed as irresponsible. We expect parents to act in responsible ways which prevent their children, wherever possible, from acquiring a disability. We expect organisations not to compromise the health and safety of children. We punish them if they do. Arguably, the choices which arise from PGD are on this continuum of responsibility--not simply so, but complexly so, nonetheless.

Commodification and selective parenthood

In modern societies, when it comes to fertility the basic imperative is that it should be controlled and the organising myth is that it *can* be controlled. It is normal to use contraception ... Similarly, it is normal to postpone pregnancy in a long-term relationship ... In due course the couple will probably decide that is 'the right time' to 'start a family'. But this does not mean that they cease to control their fertility. Just the opposite, the normal thing to do is to plan the pregnancy

Dutney, 2001, p. 150

Arguably, many well-being concerns are facets of the same fundamental worry that, in a consumer culture such as ours, using technology to produce 'better' children will drive us toward making the fundamental mistake of treating children—and the rest of us—as commodities rather than as persons.

E. Parens & K. Knowles, 2003, p. 57

While new reproductive technologies induce a public panic about 'designer babies' selective parenthood is, in fact, the norm in our society. Most people decide when they will have children, how many they will have and whether they will use artificial or natural means of contraception to

delay child-bearing. Having created a family they make decisions about whether to have more children; that decision may even be influenced by a desire to have a boy or a girl. Where pregnancy may involve significant risk to either the mother or a future child, or risks of transmitting inheritable conditions, parents may decide not to have children. At the individual level, these desires are not seen as eugenic. Selective parenthood is something very common, and it is perverse to consider those undergoing fertility treatments as being particularly obsessed with controlling their fertility while others are not .

Eugenics is the control of individual reproduction to achieve societal goals (Lewis 2001). It is usually associated with notions of improving the human race through the selection of desirable characteristics and the eradication of undesirable characteristics, which are often associated with race or disability.

The parameters of this socially acceptable selective parenthood are breached, however, if parents have the fantasy that they can create perfection for their children. Unwillingness to accept any significant departure from parental dreams that a child's characteristics might occasion undermines core values important to parenthood. Parenthood, for example, is not a mere extension of individual autonomy but a significant curtailment of it. Hospitality towards and care for the other defines responsible parenthood. Excessive self-regard undermines it. An acceptance of the other which is conditional on perfection would appear to undermine the unconditional love required to parent effectively in a less than perfect world.

Well-being concerns are, in part, about the fact that rerogenetic technologies are being used, not by persons who aim to shape themselves, but rather by parents who aim to shape their children The worry is that in using these means we will lose sight of the fact that children are wholes who cannot be reduced to the sum of their traits if we are to adequately understand what they are.

E. Parens & K. Knowles, 2003, p. S7

There is a further concern that selection might be combined with other techniques as a means of not only physical but also social enhancement.

If we approved general use of rerogenetic enhancements, we might then begin to use rerogenetic means to solve complex social problems, and in so doing undermine our common commitments to equality and diversity, prospective parents might use the technology to increase the chances that their children will better live up to dominant ideals, which at least in some cases will be unjust.

E. Parens & K. Knowles, 2003, p. S7

Insofar as these enhancements might reflect relative social advantages, or even to correct disadvantages, in the name of individual freedom, prospective parents may paradoxically open the whole realm of reproduction to social control. King (1999) asks whether that control will be through regulation or market forces.

If we presume that access to such "enhancement" is unequal, then there is reason to worry that parents who already purchase social advantages will be able ... to purchase genetic capacities to use those advantages—thereby potentially increasing the gap between the have and have nots.

Parens & Knowles, 2003, S7

Given the current costs and risks associated with PGD, using the procedure to select for enhanced social characteristics would be a profligate waste of professional knowledge and skills.

I would deplore any tendency for people to become so much obsessed with their right to have child, and to have it in the way that they want, even with the characteristics they would prefer, that they forget the old sense of astonishment and gratitude that come with the birth of a child. ... gratitude is something you do not feel when all you have got is what is owed.

Mary Warnock, *Making Babies*, p. 113-114

Disability rights and selective abortion

The routine use of PGD and other forms of prenatal testing has been trenchantly opposed by disability rights activists. They argue that what is most objectionable about prenatal testing is not abortion per se. 'People with disabilities can be found taking positions on both sides of the issue, for the same reasons as other people' (Kaplan 1999, 131). It is using disability as the sole basis for deciding to prevent a birth that is of concern; individual worth is being determined according to a single trait.

Ending an otherwise desired pregnancy after learning of a diagnosis of spina bifida or cystic fibrosis says that this one fact trumps everything else one could discover about the child to be ... a health report card becomes a precursor to membership in the family, making the family rather like [a] 'club'...

Asch, 2000, p. 239

As with discrimination more generally, with prenatal diagnosis a single trait stands in for the whole, the trait obliterates the whole. With both discrimination and prenatal diagnosis, nobody finds out about the rest. The tests send the message that there's no need to find out about the rest.

Asch, in Parens & Asch, 2000, p 13

In most cases of pre-implantation genetic diagnosis or prenatal diagnosis, the woman or couple desires to be pregnant at this time; the termination of the process only occurs because of something learned about *this child*. We cannot avoid the fact that the primary choice offered by PGD appears to be the choice to avoid having a child with a genetic condition (Gillott 2001).

It is doubtful that PGD will ever become a widespread procedure; nevertheless, if costs come down and techniques improve, it will find a place within the existing routines of IVF and its impact on persons with disability must be assessed. PGD will add to the tendency to see disability as primarily a medical rather than a social problem. Will prospects of medical 'cures' wind back social gains achieved after decades of struggle?

People with just the disabilities that can now be diagnosed have struggled against an inhospitable, often unwelcoming, discriminatory, and cruel society to fashion lives of richness, of social relationships, of economic productivity. For people with disabilities to work each day against the societally imposed hardships can be exhausting; learning that the world one lives in considers it to be better to 'solve problems of disability by prenatal detection and abortion, rather than by expending those resources on improving society so that everyone—including those people who have disabilities—could participate more easily, is demoralising. It invalidates the effort to lead a life in an inhospitable world.

Asch, 2000, p. 240

Disability activists have challenged the notion that disability inherently involves suffering and argue that as a trait disability is an inadequate predictor of quality of life. Disadvantages of disability which arise from social conditions and attitudes must be clearly distinguished from those that arise from the condition itself. The presence of a disability can be consistent with living 'the good life'.

Knowledge, power and choice

One criticism of both pre-implantation genetic diagnosis (PGD) and prenatal genetics diagnosis (amniocentesis, chorionic villus sampling, and foetal cell sorting) is that they not only provide information but also imply only one set of options that ought to follow from that knowledge. If genetic diagnosis reveals the presence of an abnormality, then prevention of birth is often the main option to be considered. Of course, this is not the only option. PGD may be used to indicate the need for early

treatment of a diagnosed condition or 'to prevent family disruption through pre-natal preparation by family members' (Kaplan 1999, 130).

If the prevention of birth option pre-dominates, however, some women might prefer not to be tested rather than be faced with such a choice. There is no data on this in relation to PGD. However, Nancy Press (2000), researched pregnant women's use of, attitudes toward, and understandings about non-invasive forms of prenatal screening. She reported that these procedures often become routine or, in some cases, mandated. Testing came to be seen as 'a standard part of prenatal care ... imbued with the same meanings and perceived purposes as the rest of routine prenatal care.' The purpose of the screening—to find cases of untreatable birth defects in order to allow women and couples the opportunity to terminate a pregnancy—'appeared to be obscured from view'. Women felt encouraged by the medical culture to find out as much as possible about their babies, but there was little corresponding information about what would be done in the light of that knowledge. Culturally, she argues, it is very hard to separate knowing from doing. 'Knowing is a kind of doing and knowing will inevitably lead to doing' (Press 2000, 219-220).

A lack of standardization in information provided, or procedures used, in prenatal screening and genetic counselling gives individual doctors and counsellors substantial control over what information is given to women. In this study the majority of women referred by their physicians for genetic counselling indicated they would choose to terminate a pregnancy that tested positive for a disability, but the type of disability, made *no difference* in the decision they believed they would make. This statement was qualified by their belief that the information they received from the genetic counsellors regarding future quality-of-life issues, either positive or negative, was inadequate. A variety of studies indicate a termination rate of between 92% to 95% for the most commonly tested chromosomal abnormalities.

Roberts, Stough, & Parrish, 2002

From an ethical point of view it is important that procedures do not become so routinised that they subvert our ability to choose.

Responding in faith

In responding to PGD, Uniting Church members will find themselves balancing a number a deeply held values and commitments. The UC approach to bioethical issues is influenced by the traditions which have shaped it. These Reformed traditions frame bioethical issues in ways

which are fundamentally different from the Roman Catholic view which, in the public arena, is sometimes mistakenly viewed as *the* Christian view.

This divergence becomes particularly clear when comparing Uniting Church and Catholic positions on abortion. For example, examining the various UC synods' statements on abortion, theologian Andrew Dutney (1998; 2001) demonstrates a clear contrast between the UC position and the Roman Catholic position which condemns abortion regardless of circumstances.

While it is an overstatement to call it 'pro-choice', the consistency of Uniting Church teaching and its apparent resonance with the church's membership might justify calling it a 'tradition'....

- Abortion is always a matter for lament
- There are circumstances in which a decision to terminate a pregnancy is a morally responsible decision
- There is a legitimate difference of opinion among Christians
- The decision is the woman's to make
- The woman must be provided with adequate and appropriate counsel and pastoral support.

Dutney, 'Uniting Church teaching on abortion', p. 75

The Uniting Church emphasises the value of persons in relationships and community. On the one hand, it upholds the ultimacy of individual choice rather than an institutional voice which prescribes one set of actions. On the other hand, the UC approach expresses solidarity with the vulnerable.

The Uniting Church tradition does not see persons with a disability as a burden on society and seeks to foster shared responsibility to build the kind of society in which disabilities do not become a handicap. Persons with a disability are valued for themselves, not for what they can teach us, or because they enrich *our* lives and turn us in to better people. However, this acceptance of, and advocacy of the rights of, persons with disabilities, ought not prevent us from recognising that a particular form of disability itself is not desirable, and that it can occasion significant grief and loss. Responsible parents and professionals will always want to act in ways which prevent children and adults from acquiring disabilities. These types of decisions, in their context, are qualitatively different to the types of decisions, act and omissions which would later discriminate against persons with a disability.

All parents suffer when their child is found to have a disability. The initial grief and bereavement becomes less acute. ... Much as they love their children they often find little that is positive about their circumstances.

B. Carmichael, 'The human genome project - threat or promise?', p. 506-7

The decision of an individual or couple not to have children so as not to pass on an inherited condition ought to be respected. In the UC tradition, the decision of someone in similar circumstances to proceed with a pregnancy is also respected. To demand that individuals with such medical histories do not proceed with pregnancies would be a form of eugenics.

UC theological ethics recognises the reality of a fallen natural order which can be the occasion for the operation of grace and forgiveness. There are no abstract rules that can be prescribed at this point. Decisions must be based on caring for real people in real situations. This care must be pastoral as well as medical. Ultimately, however, those decisions must be made by the couple themselves. There will be circumstances in which, for some people, PGD offers a choice which will genuinely relieve unnecessary suffering. Parens and Asche (2000) have pointed out that for such decisions to be truly informed significant changes to medical and counselling practices may be required.

If we want to live in a society willing to include people with disabilities as well as accepting of parental decisions to avoid the birth of disabled children, we must radically change how we offer prenatal diagnosis and selective abortion.... Professional literature should speak about the 'possibility' or 'likelihood' of having children with Down syndrome or spina bifida, rather than insisting upon using the word 'risk' in discussions with prospective parents. Let the parents themselves decide whether the possibility of having a child with one or another disabling condition is a risk to their hopes for family life. Similarly, spina bifida and other non-lethal disabilities should not still be described as 'devastating defects' in professional literature or in materials given to parents contemplating offers of prenatal testing....

I recognize that prospective parents have their own limits and differences (call them disabilities?). If parents can make their own choices about selective abortion after receiving information that helps them imagine a worthwhile life for their child and family, I support parents in the decisions they make.

Adrienne Asch, 2000, p. 252-254

Pre-implantation genetic diagnosis as a responsible social practice

The significant risks and responsibilities that go with PGD must be communicated clearly to couples. The fact that PGD is carried out on pre-embryos before implantation means that the differences between it and other forms of prenatal testing may be logically, experientially and morally significant. Attempting to frame PGD as a responsible social practice, however, must start by acknowledging its potential to be diverted to irresponsible ends. We deal with this potential slippery slope by putting up fences which establish clear boundaries between responsible and irresponsible practice.

The commitment to persons and community which lies at the core of UnitingCare values encourages individuals to make the best decisions possible in their particular context with due reference to, and recognition of, the impact of their actions on other persons (including a future child's wellbeing) and the community.

In recent Uniting Church thinking ... it is not the judgement of 'experts' but that of those who are directly affected by the decision which is given weight. This reflects our appropriation of a general trend in ecumenical social ethics which has given special emphasis to hearing people's stories.

Dutney 1998, 77

Both patients and professionals are persons in the community and are required to act responsibly. Nevertheless, the disparity between the relative power of the professional and the vulnerability of the patient must be carefully attended to. Not only the Uniting Church's Reformed heritage and its recent thinking, but also good professional practice, place the ultimate burden of decision-making on the patient. However, there are grounds and limits framing the professional-client relationship, which constrain both professional power and patient autonomy. Professionals and clients ought to be pursuing a shared good. In the case of IVF practices this shared good is a particular health goal: *a viable pregnancy resulting in the birth of a healthy child.*

In IVF, the pursuit of this good is undertaken under conditions which are personally, professionally, socially, psychologically, economically and, for many, spiritually challenging. IVF procedures themselves have relatively low success rates compared with unassisted pregnancies. While it is an

area in which successes are widely trumpeted, there is a long shadow of failure falling over the majority of participants.

To increase the chance of success in IVF, a patient is super-ovulated to increase the number of eggs available in each cycle. To further increase the chance of successful implantation and the wellbeing of the mother, the number of pre-embryos created *in vitro* is now usually restricted to three. PGD allows these pre-embryos to be assessed for the presence of chromosomal abnormalities that might result in implantation failure, the termination of a pregnancy, or early infant demise. Pre-embryos with the most likelihood of resulting in a pregnancy ought to be selected for implantation.

Although overall pregnancy rates in IVF are not improved with PGD, the selection of pre-embryos without chromosomal abnormalities for implantation results in relatively good pregnancy rates with a low incidence of miscarriage for patients from the high risk categories (*Fertility & Sterility*, 2003, 0-308).

In the natural process of gestation not all pre-embryos will be successful. Already, confidence in PGD as a clear guide to decision-making is so low that implantation of pre-embryos at the five day stage is considered a preferred course. In most cases, those pre-embryos with abnormalities will simply not implant. This in effect lets the natural process take the place of active decision-making; however, the psychological affects of loss may remain. Arguably, there seems no significant moral advantage in thus avoiding selecting a pre-embryo. Preferably, selection and the avoidance of selection ought to be based on characteristics relevant to achieving the shared good; that is, achieving *a viable pregnancy resulting in the birth of a healthy child*.

Let us say a woman is undergoing IVF treatment because of her age, a history of recurrent miscarriage, or a family history of genetic disease. (These are three risk categories which result in a high incidence of chromosomal abnormalities) Three pre-embryos have been created. In order to reduce the potential risk to mother and child, only one embryo is to be implanted.

The pre-embryos are genetically tested and one is found to have a chromosomal abnormality. A decision to choose to implant a pre-embryo with a chromosomal abnormality, either singly or together with a 'normal'

pre-embryo reduces the chances of successful implantation and full-term pregnancy, and thus, arguably, should be avoided in the IVF context. Using potential viability as a criterion for selecting which pre-embryo to implant would be personally and professionally responsible.

The fact that these chromosomal abnormalities may also mark the presence of a disability does lead to a kind of double effect. However, so long as the intention is to select for a viable pregnancy, and not to select against a disability *per se*, this is acceptable and not discriminatory. Selection is based on a relevant characteristic known at the time of the decision.

double effect *noun* the good and bad effect of an action, compared according to a principle which seeks to justify the action if the bad effect, though foreseen, is outweighed by the good effect.

PGD allows us to select on the basis of such contextually relevant criteria. It is not in itself a eugenic procedure; though it may easily be perverted to be so. This would happen if PGD were to be used to control individual reproduction to achieve a social goal; for example, to make selections based on existing or proposed systems of advantage and disadvantage. The values of the Uniting Church emphatically do not support the use of medicine to eradicate persons with disability. The church also supports parents who choose to accept the risks and responsibilities of choosing to raise a child with a disability.

Given the difficulty of achieving a viable pregnancy, current clinical practice is not to knowingly implant a pre-embryo with a chromosomal abnormality. There may be exceptional circumstances in which the only possibility for creating a family is to implant a pre-embryo with an abnormality. The decision is for the parents to make, after prudently assessing their ability to bear both the personal, physical and psychological risks, and the responsibilities, entailed in such a decision. According to the values of the Uniting Church, parents ought to be free to choose to implant a pre-embryo with a chromosomal abnormality if they are willing and able to accept the responsibilities that flow from that decision. In the absence of any exceptional circumstances, however, the current practice of not knowingly implanting pre-embryos with abnormalities appears to be sound.

The conscious selection of pre-embryos with an abnormality over those without any abnormalities, however, must be viewed as imprudent. Under

these circumstances to select in favour of disability would be an inappropriate pursuit of a social end which subverts the attainment of a more contextually relevant shared good--*a viable pregnancy resulting in the birth of a healthy child.*

Unlike other traditions, the Uniting Church has no desire to stipulate or control individual reproduction. It accepts that parents, taking into consideration their circumstances and the support of friends, relations and the community, ought to make informed reproductive decisions themselves.

If PGD itself creates these difficult questions would it be simply better not to use it? Leaving it to chance, however, by exercising options such as random selection of embryos for implantation, or by creating only a single pre-embryo would seem to be just avoiding responsibility. In light of the substantial risks of possible failure, assisting people to achieve just any conception—without consideration as to the viability of that pregnancy—would appear to be irresponsible. There are times when our desires may outrun the known risks and uncertainties and, from an ethical point of view, ought not to be acted upon.

Recommendations

Within the ethical frameworks of the UC it is acceptable that PGD be offered under a careful and restricted set of circumstances.

As a socially responsible practice PGD ought to be:

- defined by the shared good of achieving a viable pregnancy resulting in the birth of a healthy child
- restricted to those patients for whom PGD increases the likelihood of a successful pregnancy.
- involve selection of a pre-embryo on the basis of its relative likelihood to achieve a viable pregnancy resulting in the birth of a healthy child.
- Involve selection on the basis of only those other characteristics which may be significant and relevant to the circumstances of the particular health needs of the patient.

- Before PGD is offered patients ought to receive significant information on medical, psychological and social aspects of any disability relevant to their circumstances.

The decision not to use these techniques is also to be respected. The Church remains open to acting and promoting the rights of persons with a disability.

ATTACHMENT 1.

ABNORMAL CHROMOSOME NUMBER

Polyploidy an entire extra set

Aneuploidy cells missing a single chromosome or having an extra one

A human karyotype is abnormal if the number of chromosomes is not 46, or if individual chromosomes have extra, missing, or rearranged genetic material.

Abnormal chromosomes are the most frequent cause of spontaneous abortion [miscarriage].

AUTOSOMAL ANEUPLOIDS

Autosomes are chromosomes not normally involved in determining sex.

Most autosomal aneuploids are very rarely seen in live births, due to the lethality of such a large imbalance of genetic material. Following are brief descriptions of the most common autosomal aneuploids seen among liveborns:

Trisomy 21 - Down Syndrome - the most common autosomal aneuploids among liveborns.

Person is usually short and has straight, sparse hair and a tongue protruding through thick lips. The hands have an abnormal pattern of creases, the joints are loose, and reflexes and muscle tone are poor. Development milestones are delayed. Intelligence varies greatly. Physical problems can include: heart and kidney defects, and hearing and visual loss, a suppressed immune system.

Trisomy 18 - Edward Syndrome

Only 1 in 6,000-10,000 newborns. Associated abnormalities - heart defects, a displaced liver, growth retardation and oddly clenched fists, overlapping placement of fingers, a narrow and flat skull, abnormally shaped and low-set ears, a small mouth and face, unusual or absent

fingerprints, short large toes with fused second and third toes, and 'rocker-bottom' feet. Developmental skills stalled at the six-month level.

Trisomy 13 - Patau Syndrome

Affects 1 in 2000 female births. Sexual development delayed - wide set nipples, slight webbing at back of neck, short stature, coarse facial features and a low hairline at the back of the head. At sexual maturity, sparse body hair develops, but the girls do not ovulate or menstruate, and have underdeveloped breasts. Intelligence is normal and can lead fairly normal lives with hormone supplements.

Trisomy 22 Mosaicism

Clinical features may include: microcephaly, abnormal ears, webbed neck, cardiac abnormalities, long fingers, kidney problems (missing, extra or underdeveloped), growth retardation, shortened limbs, mental delay, hemidystrophy, drooping eyelids, elbow malformations, abnormal or missing finger/toe nails, absent ovaries/fallopian tubes, underdeveloped testes or ovaries, and more.....

Trisomy 16 Mosaicism

Trisomy 16 usually miscarries. Adverse outcomes usually involve Trisomy 16 Mosaicism.

Problems: Low birth weight, lesser but significant risk for fetal malformations (many of which are repairable and may not be a long term problem), maternal hypertension, pre-term delivery, and fetal or neonatal death. Fetal malformations : heart defects, hypospadias, vessel cord, clinodactyly and pulmonary hypoplasia.

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