# Chapter 4 A DISCUSSION OF ETHICAL ISSUES

# PART A: PREIMPLANTATION GENETIC DIAGNOSIS – PROVIDING NEW ETHICAL CHALLENGES?

## 1 INTRODUCTION

The aim of this section is to identify a number of concerns about PGD and to discuss new ethical challenges framed by those concerns in the context of current and foreseeable applications in the area of pre-birth genetics.

Between 1981 and 2000, a total of 1112 genes responsible for mutations leading to monogenic diseases were discovered.[1] Among the most serious disorders caused by single gene defects are cystic fibrosis, Duchenne muscular dystrophy, Huntington's disease, the thalassaemias, sickle cell disease, haemophilia and some uncommon hereditary cancers.[2] While tests have been developed to identify both carriers and sufferers of these genetic conditions, these advances have not yet resulted in cures for the disorders in question. Instead, one of the most significant uses of these tests has been in the area of reproduction, where they are used to enable parents to discover information about the genetic makeup of their future child and to make reproductive decisions accordingly.[3]

Genetic testing undertaken to enhance choices about future offspring can be undertaken either *during* pregnancy, when a woman undergoes testing to discover if the fetus she is carrying is at risk of a genetic disease (prenatal testing) or (more infrequently) *prior* to pregnancy when embryos are tested during IVF to determine their genetic status (preimplantation genetic diagnosis or PGD). Most testing conducted in the context of reproduction has been undertaken to test for the presence of genetic factors that are likely to directly affect the health of the child-to-be in predictable ways.

While prenatal genetic testing is now a routine part of prenatal care in most countries, PGD is far less common. This is because it is an expensive and highly invasive procedure. While annually hundreds of thousands of couples undergo prenatal testing to date, current predications are that only a few hundred babies have been born as a result of PGD.[4] Another significant clinical difference is that while prenatal testing is commonly undertaken to test for around 1,500 monogenic diseases and chromosomal abnormalities,[5] PGD can presently only test for a small number of chromosomal abnormalities and 30 or so monogenic diseases at the 1-2 cell stage.[6]

These clinical differences are not, however, reflected in the way the two technologies are regulated. While PGD has provoked specific regulatory responses in the countries that allow it, prenatal testing has attracted no such targeted regulation and operates within the confines of existing legislation around abortion. As a result, while countries that allow PGD have placed tight restrictions upon its use, allowing it only to be used to avoid the birth of children who are at significant risk of a serious genetic disease (although what is considered 'serious' can differ between countries), decisions around prenatal testing and selective abortion are still largely private decisions made between a woman and her doctor, within the confines of abortion legislation in the jurisdiction concerned.

## 2 IMPACT ON PRENATAL LIFE

In what ways is the new technique of PGD preferable to prenatal testing? Although PGD is clinically more involved, it is considered by some to be preferable, since it allows genetic testing to be undertaken at a very early stage of fetal development, and thereby avoids a woman having to undergo a termination of pregnancy if the fetus is found to have an unwanted genetic condition. This, however, raises a complex moral question: is destroying an embryo less morally problematic than terminating a pregnancy?

How one considers the distinction between prenatal testing and PGD will be influenced by what value is attributed to prenatal life. This will depend on our views about when the early human embryo becomes a being which can bear rights and to whom we owe obligations. Differing moral arguments have been proposed to assist our deliberations in the determination of what moral status we should attribute to prenatal life. Some (holding the 'conservative' position) attribute moral status to prenatal life at, or soon after, the moment of conception. Others hold the view that moral status is tied to personhood. The 'gradualist' view falls somewhere between these two positions and asserts there is no final answer to the question of when the fertilised egg becomes a person with valid moral status.

The stage at which genetic testing takes place is generally, but not always, considered morally significant. The gradualist view (that we owe more duties to a fetus nearer the time of birth than we do to an early embryo) entails that fetal testing is morally more problematic than PGD since it may ultimately involve the killing of human life at a relatively late stage of its development.[7] The 'conservative' view (where prenatal life is valued from the moment of conception) entails that prenatal testing and PGD are equally morally wrong, since they both involve the destruction of a human life.[8] This strict moral view entails that it is just as morally wrong to destroy an embryo as it is to terminate a pregnancy once established.

While it may initially seem in terms of the potential impact on prenatal life that the limits for prenatal testing should be tighter than for PGD (since prenatal testing during pregnancy potentially leads to the destruction of prenatal life at a later stage of development), the question is complicated by two significant issues. First, tightening the grounds for abortion following the results of genetic testing would involve altering the present scope of abortion laws and be seen as an unacceptable restriction on a woman's access to abortion. Second, unlike prenatal testing, PGD can only occur if embryos have already been created for the purposes of IVF. To many, it is the creation of prenatal life for the purposes of genetic analysis (not merely its destruction) that singles out PGD as being more morally problematic than prenatal testing.

**PGD, the creation of life, and impact on offspring**

Preimplantation genetic diagnosis cannot take place unless embryos are available for genetic analysis. The process therefore necessarily involves the creation and selection of some embryos in preference to others. Embryos that are not selected will be destroyed, stored, or used for research purposes. The fact that preimplantation genetic diagnosis relies on the creation, selection, rejection, and possible destruction of embryos is a significant reason why preimplantation genetic diagnosis is subject to such intense scrutiny. Since PGD can *only* take place if embryos are created specifically for genetic analysis, it is morally wrong to create embryos for testing only for non-health related conditions or 'trivial' characteristics. In terms of safety, current indications are that the removal of cells from the early embryo during the process of preimplantation genetic diagnosis for analysis has no long-term effects on the 'child-to-be', although recent reports have called for ongoing studies to confirm that this is indeed the case. This suggests a second reason why it seems right to exercise some degree of caution in relation to how PGD should be used, and restrict it to cases where parents seek to avoid the birth of offspring with serious genetic disease.

## 3 PGD AND THE CREATION OF EMBRYOS

The fact that PGD can only occur if embryos have been created for the purposes of IVF leads some to challenge PGD on the basis that it is unacceptable as it involves the instrumentalisation of early human life. This objection is superimposed on the objection held by some against the creation of embryos that will not be implanted, which is standard in IVF practice. PGD cannot take place unless embryos are available for genetic analysis. The process therefore necessarily involves the creation and selection of some embryos in preference to others. Embryos that are not selected will be destroyed, stored, or used for research purposes. The fact that PGD relies on the creation, and the possible selection, rejection, and destruction of embryos is a significant reason why PGD is subject to such intense scrutiny, despite the fact that it seems prima facie less morally worrying, since it involves the genetic analysis of prenatal life at a much earlier stage of development than prenatal testing.

While it is tempting to polarise the debate around the acceptability of these technologies as hinging upon whether one adheres to the 'right to life' view or the 'no interest' view of prenatal life, this dichotomy does not encapsulate the complexity of the arguments surrounding what duties we owe to prenatal life. John Robertson has explained the situation in the following way:

> *PGD is ethically controversial because it involves the screening and likely destruction of embryos, and the selection of offspring on the basis of expected traits. While persons holding right to life views will probably object to PGD for any reason, those who view the early embryo as too rudimentary in development to have rights or interests see no principled objection to all PGD. They may disagree, however, over whether particular reasons for PGD show sufficient respect for embryos and potential offspring to justify intentional creation and selection of embryos.*[9]

This highlights one of the most difficult problems with PGD, namely the fact that even those who think that early embryos have limited or no rights, appear to contradict this view when they do not think it is acceptable to create embryos for reasons that are seen as 'trivial' or unimportant. It is this act of creation (rather than the act of genetic analysis, selection, and possible destruction) which even some of those who hold the 'no interest' view feel 'debases the inherent dignity of all human life'.[10]

## 4 IMPACT ON THE CHILD-TO-BE AND THE CHANGING NATURE OF REPRODUCTION

A significant point of difference between prenatal testing and PGD is that the process of PGD is still surrounded by questions of how it will affect the child resulting from the process. The two main concerns surrounding the 'child-to-be' relate to issues of safety and the potential for the child to suffer damaging psychological consequences arising from learning that they were 'chosen' on the basis of observable genetic preferences.

In terms of safety, current indications are that the removal of cells from the early embryo during the process of PGD for analysis has no long-term effects on the 'child-to-be', although recent reports have called for ongoing studies to confirm that this is indeed the case.[11] This might suggest that until we can be certain that no harm is done to the 'child-to-be' through the use of the technique, it seems right to exercise some degree of caution in relation to how PGD should be used. This approach, however, raises a number of ethical questions. What degree of caution should be adopted? How do we determine the level of protection accorded to the embryo (or future child) in considering the limits of reproductive technologies? What types of harm would it be necessary to establish before the state may assume a legitimate role in regulating reproduction and what evidence will be acceptable to establish these harms?

In its recent review of the UK's regulation of reproduction, the House of Commons Science and Technology Committee adopted the approach that '[r]eproductive and research freedoms must be balanced against the interests of society but alleged harms to society, too, should be based on evidence'.[12] In a pluralistic society it is unlikely that consensus will ever be achieved in relation to these issues. While views on all sides should be respected, there must be some method of navigating a path between them. This itself raises a central question which underpins the whole regulatory framework of reproductive medicine, namely how far is the state justified in intervening to limit the reproductive lives of its citizens? What position we take will most likely be influenced by whether we begin by accepting the presumption that the state has a role in regulating reproduction, or whether we take the reverse position, namely the presumption that the state should not intervene in private reproductive decisions *unless* evidence of harm is available, for example, the Ethics Committee of the American Society of Reproductive Medicine has suggested that 'serious reasons … must be provided if a limitation on reproductive freedom is to be justified.'[13]

More difficult issues arise when we move away from questions of immediate safety and turn to consider how genetic technologies may impact on the emotional and psychological stability of the child born from these techniques. It is important to bear in mind that while prenatal testing involves the decision to either keep or abort a child which the parents find 'undesirable', in PGD 'a whole range of embryos are scrutinised and tested' and the choice is between the 'best in the class'.[14] This has raised concerns that some limits need to be placed upon what the President's Council on Bioethics calls the 'parental desire for quality control'.[15] The question is: will this unprecedented power in the hands of the parents necessarily be used for the good of the child? Should parents be willing to gamble the safety of their children for the chance to make them 'better than well?' What risks to their health and safety are worth taking in pursuit of improvement or perfection?

While both prenatal testing and PGD are predicated on the assumption that it is acceptable for parents to avoid the birth of certain kinds of children based on their 'genetic endowment', in the case of prenatal testing the process has been described as more of a 'weeding-out' of those kinds of children who are not wanted rather than a 'selecting-in' process which pertains to PGD.[16] The President's Council on Bioethics has warned that using genetic technologies such as prenatal testing and PGD to select one child over another may raise significant concerns about how these technologies may ultimately change the nature of parenthood, our views about children, and society in general.[17]

Fears are sometimes voiced that new genetic technologies will change the nature and meaning of reproduction. Rather than childbearing being an act of love where parents accept their children for who they are, no matter what their genetic endowment, genetic diagnosis of the embryo or fetus is seen to alter the essential act of procreation. Procreation has traditionally been seen to be an act of acceptance of the children which fate bestows rather than a relationship where parents view children as products that can be shaped and engineered to meet their desires and wants.[18] This view is encapsulated in the following quote:

> *[Children] are, in an important sense, "given" to us. Though they are our children, they are not our property. Though they are our flesh and blood, and deeply kin, they are also independent "strangers" who arrive suddenly out of the darkness and whom we must struggle to get to know. Though we may seek to have them for our own self-fulfilment, they exist also and especially for their own sakes. Though we seek to educate them, they are not like our other projects, determined strictly according to our plans and serving only our desires.*[19]

This dichotomy which contrasts natural reproduction (in which children are categorised as a 'blessing') with assisted reproduction (in which children are labelled more as products of their parents' desires) seems in some ways to be too simplistic to describe the complexities of reproduction in the 21st century. One point often made against this stark categorisation is that there are many ways in which parents may shape their children, both before and after birth. An essential part of parenting is moulding our children to meet the demands of the family, prepare them for adulthood, and give them the skills to interact meaningfully in society. Different societies impose differing responsibilities on the family, all based, until now, on the natural process of reproduction. Genetic technology that allows us to choose the characteristics of our offspring provides new challenges to this fragile balance. While a certain degree of 'moulding' of offspring is not only tolerated, but expected, in some contexts, the degree of 'manipulation' (when conducted at the genetic level) is seen to elevate the scope for parental influence to an unacceptable level.

Cultural differences also play a significant role in the way children are regarded and cared for.[20] The principle of reproductive autonomy provides that parents have the right to choose *when* to have children, but this is not universally understood to bestow the wider right of the power to choose *what kind* of a child to have. Reproductive cloning, for example, is almost universally condemned on the basis not only of safety, but because it would open the door for parents to choose conclusively the genetic endowment of their children. PGD is also seen to be morally problematic because it too allows parents much control over the selection of one embryo in favour of another.

It may reasonably be argued that a real reason why we should be cautious about accepting an unrestrained principle of reproductive autonomy to use PGD to choose characteristics in our offspring is the fact that if left unchecked, it may bring about subtle but important changes in the relationship between parent and child. Some have argued that this subtle change has already taken place and that some degree of judging the 'fitness' of prospective children is currently already undertaken when we use prenatal testing to select against serious genetic conditions that will affect the health of the child.[21] This current level of interference is justified, however, by arguing that current uses are aimed at producing a 'healthy or disease-free baby', whereas if we allow parents to select for desired traits '[s]uch an enlarged degree of parental control over the genetic endowments of their children cannot fail to alter the parent-child relationship'.[22]

There remains a significant level of disagreement about how arguments such as these should be dealt with. While the welfare of the child is an important guiding ethical principle when considering acts which create human life, there is no clear formula for how this principle should be applied. How do we determine what is best for a child born as a result of assisted reproduction?[23] If children born from assisted reproductive procedures do feel a degree of uneasiness about the acts which created them, or parental expectations on them are heightened as a result of their selection at an embryonic stage of development, is this reason enough to propose a restriction on parental freedom to use reproductive technology in this way?

While these concerns have been raised in the literature, there is no general agreement as to how they should be addressed. These highly complex problems surrounding our obligations to future persons have been termed 'genesis' problems by some philosophers, meaning those problems relating to decisions regarding the existence, number, and identity of future people. This category of problem is unique in philosophy because our traditional ethical analysis and moral intuitions both lead us to paradoxical solutions (or else break down altogether) when applied to questions about the creation of human life.[24] The question of whether we can harm future people by bringing them into existence is one of those problems that has received a great deal of the philosophical attention.[25] For now, it suffices to say that the welfare of the child principle introduces new complexities to these genesis problems, rather than offering a water-tight solution.[26]

## 5 SOCIAL IMPACT OF GENETIC CHOICES

The public is increasingly concerned about the prospect of genetic technology being used by parents to choose their offspring.[27] The term 'designer babies' is used prominently in the media to refer to these acts of selection. In truth, rather than designing their children, parents using genetic analysis are selecting or rejecting an embryo or fetus, based on its pre-existing genetic makeup. It is this process of selection and rejection that is not encapsulated with the controversial term 'designer babies' and which is, in some ways, more worrying than the term 'designer' would indicate.

Public opinion surveys indicate that there is some level of concern in society that genetic developments will one day give parents too much power to 'choose' their offspring. One view that has emerged is that while it is generally felt to be appropriate to use genetic technology to test for 'severe conditions', certain uses of genetic testing are inappropriate. Most concerns focus on those technologies which aim to avoid the birth of children with certain characteristics or to make 'perfect' people.[28] Clear areas where some members of the public feel that testing should not be undertaken are in relation to tests for 'sex, physical characteristics such as eye colour or 'looks', skills, and non-health related attributes in general'.[29]

These views raise special ethical concerns. While consultation can inform on a spectrum of beliefs, it is still unclear to what extent the ethical concerns expressed by some groups in society should be accepted as a reason for restraining the freedom of others to use technology in ways they desire. How important are the views of the public in formulating policy? How, if at all, should these concerns expressed by some groups in society be translated into law? There are no clear answers to these questions. Two prominent, but conflicting, views seem to emerge. In terms of the 'majoritarian' approach, the group which is successful at achieving the 'balance of power' forces its values on others, although there is still reasonable disagreement with those values in society.[30] While this may seem to express a description of democracy, McCarthy continues that a better approach in a pluralistic society is 'to have a society in which value disputes are resolved in a way in which no one can reasonably reject.'[31]

### The social impact of genetic choices

Some members of the public fear that the new genetic technologies will have eugenic implications. The terms eugenics has had multiple meanings over time, but is generally taken to mean 'well born', a literal interpretation of the term which was first coined by Sir Francis Galton in 1883. The new genetic technologies may have potential eugenic uses, but this does not mean they are morally questionable *per se*. Genetic choices today about offspring are not imposed through a State imposed blueprint or enforced sterilisation of the 'unfit' (indicia of past applications of eugenics), but they may raise new moral concerns. Ongoing research needs to be undertaken into the long-term effects of using genetic data to make reproductive choices. Continued surveillance should be undertaken as to what impact these technologies will have on those who are already living with the conditions for which testing is offered. Attitudes towards people with disabilities in society should be carefully monitored, and mechanisms established to ensure testing (aimed at avoiding the birth of children with some genetic disorders) does not result in a change in attitude towards those in society who are living with these conditions. Publicly funded programmes aimed at reducing the incidence of genetic disease should be offered *in tandem* with public education programmes about disability. These programmes should work towards the elimination of prejudice in society against disabled persons, promote a better awareness of life with disability, and establish better relations between the disabled and society, than at present.

To what extent ethical concerns raised by new genetic technologies are incorporated into the law is a political decision that law and policy makers must make, with reference to the ethical values of the society in which they operate. A thorough analysis of this ethical problem is outside the scope of this part of the report. However, subsequent parts deal with matters which touch on the central question of how ethical disagreement should be dealt with at a policy level.

## 6 EUGENICS

Among the fears associated with the potential new uses of technology is the concern that genetic testing may lead to a new form of eugenics. Eugenics, a term which has developed multiple meanings over the years, is generally taken to mean 'well born', a literal interpretation of the term which was first coined by Sir Francis Galton in 1883. Eugenics was defined by Galton as 'the science of improving stock, not only by judicious mating, but by whatever tends to give the more suitable races or strains of blood, a better chance of prevailing over the less suitable'.[32]

The application of eugenics ideology into practice has a chequered history. Eugenics, as practised in Nazi Germany, is perhaps the best known application, and one which raises the spectre of such horrific abuses of fundamental human rights that it is clear why those who see the benefit in current genetic technology seek to distance what can be achieved today through genetics from these past abuses. Nazi eugenics involved the sterilisation of significant numbers of people considered 'unfit' to reproduce and the killing of disabled children and adults. The history of the Nazi euthanasia programme is complex but what is evident today is that many people still link eugenics as practised in the past with current clinical applications of genetics.[33]

Some members of the public, for example, when asked the question what springs to mind when they hear 'genetics', spontaneously associated genetics with 'trying to create a super race' and 'Hitler'.[34] Consultation directed specifically at PGD reveals eugenics as an area of concern for some members of the public. Surveys conducted in the United States reveal some respondents strongly feel that restrictions should be placed on the freedom of parents to use genetics in the context of reproduction, with around half of some groups in some cases indicating eugenics as their 'top concern when asked about the possible harmful effects of reproductive testing'.[35]

Why should the link be made between current clinical applications of genetics and eugenics? Some people, particularly many disabled people, fear that the 'medical surveillance of reproduction' made possible by new genetic technologies will continue the eugenic practices of the early 20th century.[36] The term 'consumer eugenics' has been coined to refer to this new form of eugenics.[37] There are, however, clear differences between how genetics is used now, and past uses and abuses of genetics. As Julian Savulescu argues '[w]hat was wrong with the Nazi eugenic programme was that the State imposed a blueprint of perfection on couples seeking to have children by forcing sterilisation of the 'unfit' and removed their reproductive freedom'. This separation of state control from individual desire was tacitly accepted in the UK by the House of Commons Science and Technology Committee in its report *Human Reproductive Technologies and the Law* (2005). It stated that in its opinion '[i]f ensuring that your child is less likely to face a debilitating disease in the course of their life can be termed eugenics, we have no problem with its use. State programmes that impose a genetic blueprint are another matter. They should be outlawed as part of any regulation of assisted reproduction. Use of the word eugenics must not be used as an emotive term of abuse to obscure rational debate'.[38]

It may be the case that most fears of eugenics are unfounded, based as they are on an unrealistic expectation of what can be achieved through genetic technology. In the view of the Human Genetics Commission in the UK, '[t]he anxiety that PGD lies at the top of a slippery slope leading to the possibility of a wide range of potential enhancements, such as intelligence or beauty, is misplaced'.[39] Enhancements which some people fear may give rise to a 'designer baby' (such as beauty, intelligence, personality) will involve a large number of genes which interact in complex ways with each other and the environment.[40] Given that there is a limited number of embryos for implantation, it is highly unlikely that it would be possible to select for one combination of gene variants over the other. In the view of the Human Genetics Commission, '[t]he hope of making a designer baby is fanciful'.[41] In any event, there is an ethical distinction to be drawn between state-enforced selection and the individual choices of a small number of intending parents.

## 7 PERSPECTIVES OF PEOPLE WITH DISABILITIES

One of the most forceful critiques of the use of genetics comes from people with disabilities. The disability rights critique of genetics is founded on a view of disability that sees it as not purely a medical construct, but also a political and social one.[42] It argues that while the medical profession sees genetics as a major contribution to human health and a way of avoiding suffering connected with impairment genetics when used to allow parents to avoid the birth of children with disabilities, some forms of disability are unfairly singled out as undesirable and therefore appropriate for testing.

Some disability rights advocates argue that prenatal testing followed by selective abortion expresses a 'hurtful attitude about and send[s] a hurtful message to people who live with those same traits'.[43] According to Adrienne Asch, 'with prenatal diagnosis, a single trait stands in for the whole, the trait obliterates the whole…The tests send the message that there's no need to find out about the rest.'[44] This argument is referred to in the writings as the 'expressivist argument'. The personal impact of these decisions to avoid the birth of children with disabilities is one that is acutely felt by many in the disability community. One writer explains the personal impact of this feeling of being non-valued by society in the following way:

> *The message at the heart of widespread selective abortion on the basis of prenatal diagnosis is the greatest insult; some of us are "too flawed" in our very DNA to exist; we are unworthy of being born…*[45]

These views lead some disability rights activists to be cautious about how we should use information about genetic links to disease and disability gained from the Human Genome Project. Some fear it 'will enable doctors to conduct a 'search and destroy' mission against the disabled people on behalf of society'.[46] Others warn that if a couple refuses testing for some conditions, and subsequently has a child with the condition, this news will no longer be 'considered a tragic surprise or shock', but an 'example of wilful and deliberate ignorance'.[47] The disability rights critique of genetics challenges the assumption that there is a correct response (i.e. abortion) when a woman finds that she is carrying a fetus that has a genetic condition. Advocates such as Marsha Saxton argue that '…the current promotion and application of prenatal screening has a potent message that negatively affects people with disabilities, influences women in decision-making about their pregnancies, and reinforces the general public's stereotyped attitudes about people with disabilities'.[48]

For disabled women, reproductive rights encompass not just the right to contraception and abortion, but broader themes such as the right to bear and raise children.[49] In their exploration of what reproductive rights means for disabled women, Kallianes and Rubenfeld argue that whereas 'normal' women are expected to marry and have children, a double standard exists for disabled women who are seen as '‘defective' and undesirable as sexual partners or mothers.[50] They assert that disabled women have been subjected to a process under which they are discouraged from childbearing, forced to undergo abortions or sterilisations, and have lost control of their children.[51] Kallianes and Rubenfeld argue that disabled women view reproductive rights as 'more than the right to choose *not* to have a child; the concept also encompasses the right to be recognised as sexual, to bear children – even a disabled child – to be seen as 'fit' to mother and to refuse the use of genetic technologies.'[52]

Embodied in many articles on the subject of disabled women's rights to reproduction are the personal experiences of disabled women. These writings are rich with the experiences of women and the pressures they experienced (from doctors, their parents and spouses) not to have children.[53] One of the most vivid narratives is provided by Deborah Kent, who describes the 'chasm' she discovered between herself and her husband and parents regarding her blindness when she contemplated having children.[54] She contrasts her views of blindness as a 'neutral characteristic' with those of her husband and parents, who viewed blindness as fundamentally undesirable. The fear that her husband felt at the prospect of having a child who was blind (a fear not shared by Kent) was only alleviated after a specialist reassured him that her blindness was caused by an autosomal recessive condition and was therefore unlikely to be passed on to their children. Her story is a poignant reminder of how the concerns surrounding genetic testing are heightened in the case of women with disabilities and how important it is to ensure that this group of women are supported in the choices they make. It also emphasises how views held by practitioners can alter a woman's (and a couple's) experience of genetic testing and how ultimately subjective the notion of risk remains.[55]

A second claim emerging from the disability rights critique has more general application. Whereas the first claim relates primarily to how prenatal testing and PGD will alter our attitudes towards those with disabilities, the second claim advanced by the disability rights critique argues that these technologies will have significant impact on society in general. *Disabled People International* argues that this devaluing of the disabled and the 'discriminatory attitudes spawned by the new genetics' has implications for *everyone*, not just the disabled.[56] In a forceful statement, *Disabled People International* contends that 'the genetic goal of prevention and impairment by the prevention of lives judged not to be 'normal' is a threat to human diversity. It is a potential Nagasaki for everyone, not just disabled people'.[57] The causal link between the present threat to the disability community and the potential threat to society in general is explained by *Disabled People International* as follows:

> *The value of life must not be reduced to a matter of genetic inheritance. If it is allowed to happen no potential child will be safe from arbitrary selection. No parents will escape the moral burden of making impossible choices and no one will be safe from genetic discrimination.*[58] *(emphasis added)*

This assertion is related to the 'parental attitude' argument (outlined above) which alleges that prenatal testing to select against some traits indicates a 'problematic conception of and attitude toward parenthood'.[59] This argument is, in part, rooted in the acceptance of the assertion that 'the part stands in for the whole'.[60] As Parens and Asch explain:

> *Those who connect acceptance of disability to what is desirable in any parent-child relationship will worry that our attitudes toward parenthood and ultimately toward each other are changing as a result of technologies like prenatal diagnosis.*[61]

This concern has also been picked up by the President's Council on Bioethics in its report *Reproduction and Responsibility*. In considering the impact of new biotechnologies such as PGD, the Council states that:

> *The new technologies, even when used only to screen out and eliminate the sick or 'deficient', may change parents' attitudes toward their children, introducing both the desire to control and the tacit expectation of certain qualities.*[62]

In this way, the disability rights 'parental attitude' argument is linked to the wider bioethical concern around the changing nature of the parent/child relationship. Arguments like these that focus on the wider implications of genetic testing are receiving greater attention in the bioethics discourse. Others have argued along similar lines, alleging not only that we are all at risk of discrimination, but that 'society needs people with impairments', just as it needs people from different races and backgrounds.[63] The British Council of Disabled People states that '[t]he new genetics not only poses a danger for disabled people. We are just the first in the firing line'.[64] Shakespeare argues in a similar vein, asserting that '[w]hile genetics threatens to reduce the number of disabled people, in practice it expands the disability category, and de-stabilizes the identity of non-disabled people'.[65] Shakespeare explains that the term 'disabled people' is used by those within the disability movement to refer to people who 'face discrimination and prejudice, not people with illness or impairment'.[66] Used in this manner, the term is wide enough to include within its scope people who have a genetic susceptibility or who are diagnosed with late-onset conditions.[67] Shakespeare argues that the Human Genome Project teaches us that there is no perfect human genome and that the notion that a perfect genetic makeup exists was a 'Platonic fallacy'.[68] This 'wider social impact' argument (or the challenge that 'we are all disabled now')[69] introduces new armoury into the disability rights critique. By appealing to the potential effect these technologies will have on society as a whole, these writers signal how present uses of genetic technology will affect all of our lives, and should concern the able-bodied and the disabled alike.

Whereas the challenge that genetic technology will have implications on society is not new, the strength of these new challenges is that they are not rooted in some idealised view of human nature or the 'unnaturalness' of 'playing God', arguments that have been roundly criticised in the bioethics literature. Instead, they are based on the claim that all of us will lose something which we hold precious, namely the benefit we receive from living in a society which values diversity, not just of religion, race, gender, or wealth, but of physical (and mental) attributes. These benefits include not only what we directly gain from the contribution to society made by disabled persons but the value we gain indirectly from living in a society that accepts and values diversity.

## 8 CONCLUSION

Conflicting views have emerged in relation to how far social responsibility and the fear of altering the fabric of society should be taken into account in policy setting. The principle of reproductive autonomy is an important guiding principle, but as this section has outlined, ethical questions continue around how far the principle extends, and to what extent the state should have a role in regulating reproduction. While the principle of reproductive autonomy unequivocally applies to require the state to respect an individual's right to control his or her own body, and their choice of whether (or not) to have a child, questions continue as to how the principle operates in the context of the complex reproductive decisions that typify those arising from the merger of genetic technology and assisted reproduction.[70]

Independent reproductive decisions may have wider social consequences and affect those outside the immediate family. This section has outlined a number of arguments that may seem to 'tip-the-scales' in favour of limiting reproductive autonomy in some circumstances. Before we enter the path of restricting freedom to use these new technologies for reasons of 'social responsibility', we should recall that historical analysis tells of more abuses of human rights and freedoms from limiting reproductive freedom than from supporting it.[71]

The tension between reproductive autonomy and the state's role in regulating reproduction will remain an ongoing area of examination for this project. It is a complex area that deserves continued surveillance. Despite ethical disagreement in relation to the extent to which reproductive autonomy should be restricted by state regulation of genetics, we need to affirm the importance of the principle in ethical discussions. As the Human Genetics Commission in the UK has said:

> *Perhaps the best formulation is that whilst autonomous decision making should be supported and encouraged, it is legitimate to limit this autonomy where its exercise unreasonably impacts on the autonomy of others, or threatens others with significant harm. This may well be easier to state, than to apply in practice, but it is nonetheless worth stating.*[72]

## ACKNOWLEDGMENTS

This section of the report is written by Dana Wensley, PhD Candidate (King's College, London), MA (Distinction) (London), LLB (Hons) (Auckland). Dana would like to thank the researchers on this project for their support and many stimulating discussions, and particularly Professor Don Evans for valuable comments and feedback.

# PART B: PLAYING GOD AND THE GENETIC MANIPULATION OF OFFSPRING

## 1 INTRODUCTION

> *If you play God, play God at tennis.*
> *A strict code of conduct is expected.*
> *Clear lines must be drawn in the sand.*
> *The ball will be either in or out...*[73]

Assisted reproductive technologies are often objected to on the basis that we assume the role of God (or for those with fewer religious inclinations, the role of nature) when we tinker with reproduction and early human life.[74] In the case of PGD, it is argued that to screen embryos with genetic tests and only implant those embryos with 'satisfactory' genetic make-ups is to be guilty of hubris – the overweening pride involved in assuming the powers of God. The foundation for religious based objections to 'playing God' can be found in the creation stories of various religions, for example, the Judaeo-Christian story in Genesis, states that God 'formed man of the dust of the ground, and breathed into his nostrils the breath of life' thus making man 'a living soul' (Genesis 2:7).

## 2 CONSERVATIVE INTERPRETATIONS

According to conservative religious interpretations of creation stories, because God is the creator of life, only He has the right to create life. Children are not human artefacts but are gifts from God. Not only is God the creator of life, but He is also the governor of what we will be like (i.e. what our genetic make-up will be). While each human being shares certain common characteristics and features, each is 'unique by the design of the Creator'[75] and not a mere biological artefact or accidental form of life.

The special, purposeful, and direct creation of every human being in the image of God is central to numerous religious worldviews.[76] This requires us to carefully consider how technologies such as PGD define our relationship with God. Because of God's role in the creation and expression of human life, conservative believers argue that tinkering with creation through science comprises a 'morally culpable or hubristic transgression into the prerogatives of the deity'.[77] When we 'play God' through such tinkering, we fail to honour the parameters of human life.

What implication do these conservative interpretations of the creation of life have for PGD? A strictly conservative interpretation leads to the conclusion that interference in creation through PGD is an unwarranted and unauthorised interference with God's gift of creation and should be prohibited. But more than that, its implication is that any form of assisted reproduction is intrinsically wrong. However, many religious people do not take this view. Consider, for example, the following. In 1987 the Catholic Church issued a statement indicating that not all pre-birth technology is to be opposed. In accordance with respect for the dignity of the human person (which, of relevance here, includes respect for the human being who is treated as a person from the moment of conception), science and technology may be welcomed where they are at the service of the human person:

> *Applied biology and medicine work together for the integral good of human life when they come to the aid of a person stricken by illness and infirmity and when they respect his or her dignity as a creature of God.*[78]

On this approach, interventions on the human embryo that respect its life and integrity and that are directed towards the healing, health and survival of the embryo are acceptable in Catholic tradition. This would include the genetic testing of embryos where the information obtained in the test will be used for the benefit of the tested embryo. As Pope John Paul II said:

> *A strictly therapeutic intervention whose explicit objective is the healing of various maladies such as those stemming from chromosomal defects will, in principle, be considered desirable, provided it is directed to the true promotion of the personal well-being of the individual without doing harm to his integrity or worsening his conditions of life. Such an intervention would indeed fall within the logic of the Christian moral tradition.*[79]*However, PGD to enable parents to select genetically healthy embryos (and correspondingly select against genetically unhealthy embryos) is not acceptable to the Catholic Church. As noted in its statement, 'no biologist or doctor can reasonably claim, by virtue of his scientific competence, to be able to decide on people's origin and destiny'.*[80]

Accordingly, traditional Catholic interpretations are facilitative in so far as they do not close the door to pre-birth technology, but restrictive in that their interpretation of human roles in creation would be prohibitive of PGD. To engage in PGD would amount to an attempt to usurp the role of God and arbitrarily set oneself up as 'the master of the destiny of others inasmuch as [one] arbitrarily chooses whom [one] will allow to live and whom [one] will send to death'.[81] We should be guided by the principle that God loves each of us regardless of our genetic make-up and we should do likewise.[82] As Ramsey says:

> *[God] is not a rationalist whose care is a function of indicators of our personhood, or of our achievement within those capacities. He makes his rain to fall upon the just and the unjust alike, and his sun to rise on the abnormal as well as the normal. Indeed, he has special care for the weak and the vulnerable among us earth people. He cares according to need, not capacity or merit.*[83]

The principle that God loves us unconditionally and we should similarly love one another is enshrined in the Bible in 1 John 4:11 which states ’Beloved, if God so loved us, we ought also to love one another.' This conservative position may seem harsh and unduly restrictive in the modern world. Arguments that close the door on biotechnologies aimed at improving health and alleviating suffering 'tacitly bless' a status quo that is filled with human misery (of which some is genetically caused).[84] Accordingly, conservative Christian views as well as those enshrined in other faiths may have limited application in our more modern pluralistic society.

**Conservative Approaches**

According to conservative religious interpretations of creation stories, because God is the creator of life, only He has the right to create life and determine what its form will be. A strictly conservative interpretation leads to the conclusion that interference in creation through PGD is an unwarranted and unauthorised interference with God's gift of creation and should be prohibited. These arguments that close the door on biotechnologies aimed at improving health and alleviating suffering may seem harsh and unduly restrictive in the modern world.

## 3 FACILITATIVE INTERPRETATIONS

An alternative interpretation of creation stories suggests that humans may have a role to play in creating a better world, and indeed, selecting children who will be born with a better genetic endowment. While the conservative interpretation of Genesis (discussed above) sees creation as a completed act and humans being powerless to change our environment once created by God, alternative interpretations see creation as a 'transformative process'. Under this latter view humans can be 'co-creators' of the world in which we live.

This view does not foreclose us being seen as participants in the act of creating with God, and indeed working in partnership with God – a view associated with Jewish and Islamic traditions.[85] The 'partnership' model provides that God has given humans a positive commandment to master the world. On this view, 'to `work' nature is to improve it to meet human needs, and this activity is both right and obligatory 'as long as we preserve nature'.[86] As such, it is permissible to intervene in nature for human well-being, including intervening with embryonic development to improve human health. The co-creator model provides that as co-creators, humans acquire and implement knowledge to improve humanity and have an important creative role in the shaping of God's world.

If we accept the 'co-creator' model, the real issue lies not in whether we allow such technologies as PGD to proceed, but whether we use the technologies for good or evil – the moral valence of such technologies lies on how we use them to fulfil God's creative design. The question then is: how do we know whether PGD is 'good' and should be utilised to realise God's creative design? Hughson argues that the view our role in artificial reproduction as creation in cooperation with God (with an awareness of divine direction to guide our work) avoids dominating and exploitative applications of reproductive biotechnologies that might otherwise occur. Protestant theologian, Verhey, has noted that 'human creativity is given with the creation. Human beings are created and called to exercise dominion in the world – and I see no reason to suppose that such creativity and control does not extend to genetics.'[87]

But what does this mean for reproductive biotechnologies and PGD? Peters' theory that correlates God as creator with future interests in improving the world, and humans as the created co-creator orients us to working to make our future better. We should look forward to the new, and our ethical guide for utilising the new should be discerned from the divine purpose in creating a better and more just world. We should work towards creating a future that is better than the past or present. It is on this basis that Peters argues the door to germ-line intervention (and, by extension for the purposes of this paper, also PGD) should be kept open until such time as it becomes 'convincingly clear that negative repercussions resulting from the technological means requires us to then close the door'.[88] To seek a better future, Peters argues, is to 'play human' as God intends us to. And, in 'playing human' there is no theological reason to leave human nature unchanged.[89]

While this view may have implications for the way we sense God in ourselves, it does not necessarily have to have these implications. As noted by Cohen in the context of cloning, a co-creator view of reproductive technologies may actually increase our awe of God, where:

> *Instead of viewing God as a distant Creator who formed our world long ago, perhaps we will see God as the Power of Creation and recognise that we too possess a share of that power. If asked: are we 'playing God' by engaging in cloning, we might reply: 'Yes, for God is in us too'.*[90]

In summary, the view that we are co-creators with God and that there is a role for us to assist creation through assisted reproductive technologies and PGD is not necessarily contrary to numerous religious traditions, including the Christian religion. Children created both of traditional/natural means and those of artificial means will be equally pleasing in God's eyes.[91] Furthermore, even in the course of IVF, God remains de facto creator – it is not accurate to say that the reproductive specialist creates the resulting child because all he or she does is create conditions under which fertilisation and implantation can take place.[92]

More has been written of the relationship between a creative God and genetic technologies in the Christian tradition than in other religious systems. Some further reactions to PGD from this tradition therefore call for consideration, for example, a basis on which it may be argued that PGD is not necessarily inconsistent with Christian tradition draws on the tradition of God as healer.

God is compassionate and God is healer. His cause is life, not death, and human flourishing and health, not disease. God gave His son Jesus the power to heal as a sign that Jesus was doing God's work and that he was sent by God.[93] As stewards of God's world, we should act as God would act in the care and treatment of the ill. Placing ourselves in the role of God the healer means that we must intend life and its flourishing, and not death or human suffering. Accordingly, where possible we should seek to alleviate suffering. The World Council of Churches noted when the pain of another person can be relieved or avoided, it is usually counted as good to do so, and failing to do so may be regarded as a moral wrong.[94] As such, just as God gave His son Jesus the power to heal, God has given us the power to develop new biotechnologies to enable us to eliminate significant suffering in His world. Using that power to heal and alleviate suffering in a manner consistent with God's purpose may be seen as part of God's divine plan. As noted by Verhey:

> *There are some things which we already know how to do (and so can hardly be said to trespass the boundaries of human ignorance and powerlessness), but which we surely ought never to do. And there are some things (including some things in genetics) which we cannot yet do, but which we must make an effort to learn to do if… we are called to 'follow' one who heals the sick and feeds the hungry.*[95]

What does ‘playing God’ in this Christian perspective mean for PGD? On this view one does not have to be accepting of suffering to be God-fearing, as our compassionate God heals and seeks to alleviate suffering. Instead of accepting illness as a direct chastisement by God to be met with resignation and repentance, we should pursue biomedical possibilities in ways that imitate God’s healing of human suffering. Verhey notes that ‘[g]enetic therapy, like other therapeutic interventions which aim at health, may be celebrated’. However, PGD does not involve therapeutic interventions, but rather the testing and discarding of affected embryos. As pointed out by Verhey, genetic diagnosis without therapeutic options is sometimes deeply ambiguous. Discussing prenatal diagnosis and the quandary of abortion, Verhey notes that there are some genetic conditions which justify abortion, such as Tay-Sachs disease and Trisomy 18, because those diseases are inconsistent with life and ‘subjectively indistinguishable from torture’. However, abortion for Down’s syndrome or sex selection would amount to irresponsible use prebirth diagnosis. The idea that some conditions are so severe as to warrant intervention, but not other conditions, is commonly advocated. However, the difficulty with Verhey’s analysis is that beyond the following statement he fails to provide a detailed justification for his conclusion:

> *When the slogan about ‘preventing birth defects’ is taken to justify preventing the birth of ‘defectives’, those who do not measure up to the standards or match the preferences of parents, then there are reasons to worry a little… ‘Playing God’ the way God plays God – or, if you will, the way God plays ‘parent’ – would sustain care for the weak and the helpless, and for the little ones who do not measure up …*
>
> *[T]o use this knowledge and technology responsibly it must be aimed at ‘health’, not genetic enhancement. The distinction between intervening for health and intervening for genetic enhancement may be a slippery one, but casting ourselves playfully in the role of God the healer will encourage us to make such a distinction and to abide by it. Eugenics is not the way to ‘play God’ the way God plays God.*[96]

This view gives us some useful guidance on the appropriate and acceptable limits on our use of this technology. Utilising PGD for therapeutic purposes (i.e. to alleviate suffering) may be consistent with God’s will that we ‘follow’ his lead in healing the sick. We should imitate God’s care for creation, and ‘[h]umans are called to pursue biomedical possibilities in ways that imitate God’s healing of human suffering, which are hence not purely instrumental, and are oriented by a concern for the poor and powerless’.[97] However, the line would be drawn at PGD for non-therapeutic purposes as that would not be uses consistent with God’s creative design and care for creation.

### Facilitative Interpretations of Creation

Another interpretation of creation stories suggests that humans may have a role to play in creating a better world, and indeed, selecting children who will be born with a 'better' genetic endowment. For example, while the conservative interpretation of Genesis sees creation as a completed act, and humans being powerless to change our environment once created by God, the alternative interpretations see creation as a 'transformative process'. Under this later view humans can be 'co-creaters' of the world in which we live. Here, the real issue lies not in whether we allow such technologies as PGD to proceed, but whether we use the technologies for good or evil. The argument then turns on whether and how we know that PGD is 'good' and should be utilised to realise God's creative design.

## 4 SECULAR VERSIONS OF THE 'PLAYING GOD' ARGUMENT

The age of technology brings with it new knowledge and accordingly new ways of organising nature. The secular use of the term 'playing God' is concerned with objections about interference with nature and the natural order. Drawing on the emotive term 'playing God' as a poetic way of referring to the natural order, some observers argue that assisted reproductive biotechnologies are unnatural, and an unwarranted intrusion into the natural process of procreation. The warning not to 'play God' promotes a sense of reserve about the aims of science and its uses. The concerns tend to focus on the negative consequences of PGD, rather than on any intrinsic basis of PGD use.

Beyond concerns that it is unnatural to intrude into the natural process of procreation, there are concerns that doing so may have negative repercussions for the human race that are beyond our control. Thus, for example, despite our best intentions to reduce human suffering and enhance the quality of life through the use of genetic technologies, tinkering with genes may disturb biodiversity '[d]ue to our inability to see the whole range of interconnected factors, we may inadvertently disturb some sort of existing balance in nature and this disturbance could rebound deleteriously'.[98] Anxieties are expressed that scientific zeal will outpace human wisdom.

The questions raised in this context are: what right do we have to modify the future? What right do we have to predetermine future persons, and what wisdom do we have to exercise it?[99] Arguments that PGD will inevitably lead us down a slippery slope to genetic enhancement and the human control of evolution are often invoked to strengthen the natural order objection.

**Secular Perspectives**

It is the interference with nature and the natural order that is objected to in the secular use of the term 'playing God'. Drawing on the emotive term 'playing God' as a poetic way of referring to the natural order, observers argue that assisted reproductive biotechnologies are unnatural, and an unwarranted intrusion into the natural process of procreation. The warning not to 'play God' promotes a sense of reserve about the aims of science and its uses. It is through a focus on the negative consequences of PGD, rather than any intrinsic basis, that PGD is regarded as morally wrong on this approach. Arguments that PGD will inevitably lead us down a slippery slope to genetic enhancement and the human control of evolution are often invoked to strengthen the natural order objection.

## 4.1 UNWARRANTED INTERFERENCE WITH THE NATURAL ORDER

As with the Christian versions of the 'Playing God' arguments, there are variations in perspectives about whether or on what basis PGD constitutes an unwarranted interference with the natural order. Conservative-based observers argue that genetic interventions represent an unwarranted human meddling in a biological order that is delicate and self-sustaining. As noted by Grey, biological processes and products have evolved over billion-year geological time scales and have thereby proved their robustness.[100] Natural life-forms come with the quality assurance of exceptionally prolonged testing under the most searching conditions. 'Nature knows best' and that is evidenced, for example, through natural selection and immunity to disease – who are we to assume power to interfere with natural structures developed over such significant time periods? Those who propose radical alterations in the gene pool through human reproductive technologies do not know for certain whether the benefits of those technologies will outweigh what are as yet unknown risks. By the time any negative consequences of such 'tinkering' become known, it may be too late and our children will already have been harmed, and 'the institutions at issue irretrievably altered'.[101] McGee argues that '[t]he 'only certainty' of this endeavour is 'the impoverishment of the genetic stock.'[102] Concerns such as this have been expressed against scientific progress and development, yet there may in fact be no risks or the level of any risk may be deemed acceptable by society.

Another basis for the argument that PGD is an unwarranted interference in the natural order rests on the effects that selecting against embryos with certain genotypes will have on biodiversity. The basis for this objection is that changes in genetic diversity (variation at the level of individual genes) will necessarily result in a loss of biodiversity.[103] Biodiversity is important because it allows the population to survive particular environmental challenges. In the context of health, genetic diversity is believed to confer the capacity to resist damage and disease,[104] for example, sufferers of sickle-cell anaemia (a painful, debilitating, and life-shortening rare genetic blood disorder, principally found in black populations in Africa or in populations of African descent in other parts of the world) seem to have a higher resistance to malaria. Sickle-cell anaemia is thought potentially to be a compensating genetic advantage.

Because of the role of biodiversity in naturally regulating the environment in which we live, it is argued that 'it is in our best interests to monitor and preserve that diversity.'[105] In the case of genetic diseases such as sickle cell anaemia, the concern is that if we screen out embryos with the disease, we risk losing what may prove to be a valuable genetic resource (resistance to malaria in the case of sickle-cell anemia).[106] To appreciate biodiversity requires us to take care to ensure we do not reduce biodiversity through tinkering with the gene pool. The counterargument is that genetic engineering of a kind has been practised by selective breeding in animals (including humans), horticulture and agriculture for thousands of years.[107] With selective breeding we have, throughout history, interfered with biodiversity. Furthermore, from a population genetics perspective, impacts on biodiversity through PGD will be negligible. As noted by Harris, '[e]ven deleting one or two, or even ten or twenty defective genes in one individual or altering the same number of base pairs is not going to make a significant contribution to either genetic diversity or human diversity or lack of diversity.'[108]

Observers who believe PGD represents an unwarranted interference in the natural order often invoke concerns about the slippery slope and eugenics to support their argument. Concerns about eugenics and the slippery slope are not new in discussions about assisted reproductive biotechnologies. The concerns highlighted in the PGD context is that if we allow PGD to proceed, the doors to racial purity, increased economic efficiency, better performance standards and enhancement in the quality of life will be opened. This will lead to societal inequalities and an overemphasis on increased efficiency, where the "good' is defined as engineering life to improve performance.'[109] Cries of 'holocaust' abound, as do concerns that with each additional diagnostic test we move further down a slippery slope to trading away our humanity.

The essence of the concern is not that there may be very beneficial and worthwhile uses of the technology but that a line will never be able to be drawn between positive and negative selection, or between PGD for therapeutic or healing purposes and PGD for social purposes aimed at enhancement. Once we separate the biological and personal dimensions of procreation, it is argued, there are no limits to the possibilities for recombination; that designer babies are not merely the subject of science fiction but the 'logical outcome of making reproduction a union of intentions rather than of bodies'.[110]

Bagaric, in responding to the slippery slope argument to eugenics, noted that there is 'strong evidence that the values and beliefs which created the culture in which misguided eugenic practices led to large-scale abuses of fundamental human interests have largely disappeared from the human psyche.'[111] Society has come a long way since the atrocities of the holocaust. The current international environment is one of a strong level of disapprobation towards racism and elitism, and a genuine commitment to human rights and the equal moral worth of all individuals. As such, Bagaric argues that 'eugenics is no different to many discoveries, such as splitting the atom - it can be used for good or bad'.[112] What we need to concentrate on is not prohibiting eugenics but paying attention to the moral and legal environment in which it is practised. Echoing some Christian observers, the question is not whether we should 'play God' but whether we will 'play God' responsibly. An awareness of the concern that new reproductive biotechnologies such as PGD could 'deepen the temptations of science toward an inappropriate domination of nature'[113] can help us recognise the need to 'play God' carefully to mitigate against the risk of that feared outcome. Restrictive secular 'playing God' arguments are somewhat unconvincing. However, it is important to note that underlying these objections is a sense of intuitive discomfort with using PGD technology to manipulate who we allow to be born. This objection perhaps provides an indication more for education than prohibition or heavy restriction.

## 4.2 DESIRABLE INTERFERENCE WITH THE NATURAL ORDER

At the other end of the spectrum, some observers argue that although PGD may amount to interference in the natural order, such interference is not unwarranted but desirable. It can be argued that nature does not know best, and observers question why we should wait several billion years for evolution to take its course when it is within our power to make rapid and radical desirable changes through genetic technology.[114] It is argued that the natural order and natural processes have no dignity of their own, 'their value is reduced to their utility to humanity – and nature does not serve humanity 'naturally''.[115] Verhey notes:

> *Nature threatens to rule and to ruin humanity. Against the powers of nature, knowledge promises the power to relieve humanity's miseries and 'to endow the human family with new mercies' … The fault that runs through our world and through our lives must finally be located in nature. Nature may be - and must be - mastered.*[116]

On this view, the reality of the limited effects on biodiversity and the significant benefits that can be attained through the utilisation of this technology provide that any risk of interference in the natural order is worth taking. In fact, it is desirable and for some, morally obligatory, that we engage in PGD to improve our gene pool. As is to be expected, there is also a 'middle path' approach to the secular 'playing God' objection. The 'middle path' approach recognises the concerns expressed by conservative observers but holds that these concerns are not a sufficient reason to curb the use of technology. As Clark says, the 'middle path' approach promotes 'careful biotechnological stewardship'[117] and would have us 'move forward with caution into genomic research and with insights from valued traditions as to the proper purposes and uses of new knowledge'.[118] On this view there is no deep moral objection to our 'playing God' so long as we 'play God' carefully. We must shape the ends we seek by channelling the use of biotechnology in humane, not monstrous, directions.[119]

In many instances in medicine, we already 'play God' and the further question is not whether we should 'play God' but what sorts of local 'Gods' we will or should become.[120]

# 5 CONCLUSION

So how do we make sense of the 'playing God' objection when considering the permissibility and limits of PGD? We can ask ourselves whether there is an all-encompassing interpretation of the phrase that is useful to guide decision-making about the use of human powers in the context of PGD. The answer seems to be no. The President's Commission (United States) attempted to make sense of the phrase by stating that the phrase does not have 'a specific religious meaning' but rather that at its heart, the phrase was 'an expression of a sense of awe [in response to extraordinary human powers] and concern [about the possible consequences of these vast new powers]'.[121] As noted by Verhey, in this respect the Commission simply 'translated the warnings against 'playing God' into a concern about the consequences of exercising great human powers'. In doing so, the Commission reduced the phrase to secular terms, making God superfluous. The conclusion that the phrase 'playing God' would have nothing to do with God at all is difficult to fathom, and is unlikely to sit comfortably with those who advocate this objection by drawing inspiration from religious texts.

'Playing God' means different things to different people and it is not possible to adopt an interpretation of the phrase that would encompass varying applications of the term and from which principles for guiding action can be drawn. We can only go so far to say that the phrase is a useful way to describe generic concerns about overstepping human boundaries, whether those concerns are based on religious or secular beliefs. The debate in this area reveals perspectives about the appropriate limits of human action.[122] 'Playing God' objections require us to consider very carefully the implications and limits of what we are doing and to reflect closely our policies on PGD. Indeed, this is a view recognised by several observers. Ryan argues that while no interpretations of the phrase 'playing God' tend to be persuasive, warnings not to 'play God' have an important parenetic function, 'occasioning needed reflection on the meaning of creatureliness, finitude and responsible co-creation in the context of new forms of reproduction.'[123] She states that 'playing God' objections are persistent and rhetorically powerful because of the immense importance of the questions they raise and that '[t]aken seriously, they challenge us to articulate the right relationship between divine authority and human responsibility in reproduction; they force us to discern the meaning of creatureliness and co-creativity under new circumstances.'[124] In other words:

> *[W]e can disagree on the conditions under which medicine ceases serving and begins violating those parameters or breaching those obligations. Still, the warning that there are some things we ought not do continues to surface and garner support precisely because of the importance of what it seeks to preserve: a sense of boundaries drawn by respect for offspring as human persons, the character of parenthood as a reproductive trust, and the natural limits of our bodily and psychic natures.*[125]

In the New Zealand context, the New Zealand Interchurch Commission on Genetic Engineering stated:

> *There is a sense that we have an awesome responsibility on account of the power we have fashioned for ourselves… but we need to curb our natural hubris in this area and think of the awe with which we should approach a delicate balance which has been slowly evolving to its present state since before recorded time. We are not the autonomous masters of a world which belongs to us for our exclusive use. Rather, we are the inheritors of something that we have received as a previous gift in which many interwoven forces are bound up. We must be responsible in the use of the power we have and not get led astray by what seems a good idea at present, unless we understand significantly what its impact on our inheritance will be. To do less is to be negligent with a trust which we hold from all those who have gone before and for all those who will follow us.*[126]

In short, in the absence of an all-encompassing definition or constructive principles, what we can conclusively say about the 'playing God' objection is that it brings to the analysis a sense of limits. The objection initiates reflection on the necessity of boundaries and a framework to distinguish when reproductive medicine is used for 'assisting the courageous effort to conceive' from when it used for `encouraging self-abuse'.[127]

As is evidenced by the range of views and interpretations of religious stories of creation and the role of humans in creation, it is difficult to argue conclusively that the 'playing God' objection provides a basis for arguing that PGD is either wrong intrinsically or wrong because of the bad consequences. The analysis of religious viewpoints shows it will be no easy task for policy-makers to extract constructive principles that would help draw boundaries, and the task would not be made any simpler by adding the varieties of perspectives of secular versions of 'Playing God' to the mix. What can be concluded is that the phrase 'playing God' does not just mean one thing; it means different things to different people in different contexts,[128] and it sets different limits on the acceptable exercise of human powers for different people.

At the beginning of this section of the report a stanza from a poem by Colquhoun was cited. The stanza suggested that if we agree to play God, we should do so only within strict boundaries. We should play God in a way rather as we would in a tennis court where we will know whether the 'ball' is in or out. However, it will not always be easy to tell where the boundaries should lie. A specific use of PGD will not always be clearly 'in or out'. We need to engage in constant and careful reflection and discussion about the appropriate limits to the way in which we PGD.

### Making Sense of the 'Playing God' Objection

It is difficult to argue conclusively that the 'playing God' objection provides a basis for arguing that PGD is either intrinsically wrong or wrong due to the bad consequences it may lead to. Because 'playing God' means different things to different people, it is not possible to adopt a single interpretation of the phrase to draw principles for guiding action. 'Playing God' objections require us to consider the implications and limits of what we are doing very carefully, and to have true regard for concerns about boundary crossing in any PGD policy we adopt.

## ACKNOWLEDGMENTS

This section of the report is written by Helen Davidson, MBHL (Distinction) LLB (Hons, First Class). Helen would like to thank the researchers on this project for their support and many stimulating discussions, and particularly Professor Mark Henaghan, Professor Don Evans and Professor Nicola Peart for valuable comments and feedback.

# PART C: PREIMPLANTATION GENETIC DIAGNOSIS AND THE MORAL STATUS OF THE EMBRYO

## 1 INTRODUCTION

Preimplantation genetic diagnosis (PGD) was initially welcomed by some as a more acceptable alternative to prenatal testing because PGD involves screening embryos prior to implantation. PGD allows parents wishing to avoid the birth of children with certain genetic disorders to select one embryo over another, implanting only those which testing reveal do not have the genetic disorder. Hence, PGD substantially minimises or avoids the need for abortion. For this reason, it is seen in some cases to be less morally troubling than prenatal testing. PGD does, however, raise concerns in relation to the moral status of the embryo because it necessarily involves the destruction of embryos with genetic disorders.

Those who believe that the embryo is a moral being with a right to life argue that it is never permissible to destroy an embryo, and therefore that assisted reproductive technology (ART) is unacceptable. For others, the options PGD gives to prospective parents to take control of their reproductive decision-making outweighs the claim that the embryo has moral status and a right to life. The question is when, if ever, would creating and discarding an embryo be considered acceptable or justified.

There is no easy answer to this question. An examination of the debate about the moral status of the embryo uncovers a diversity of views and that it is an issue that society has constantly grappled with since the advent of in vitro fertilisation (IVF). The aim of this section of the report is to examine the debate on the moral status of the embryo in order to inform policy on the acceptable limits of PGD in New Zealand. What will be revealed is that there are many conflicting views and the debate is not easily resolved. Nevertheless, for policy purposes, it is necessary to move forward in spite of a lack of consensus on the moral status of the embryo.

## 2 THE RANGE OF VIEWS

The differing views about the moral status of the embryo in the following discussion will be broadly categorised as falling under three headings: the liberal, moderate and conservative views.

The conservative view states that the embryo has full moral status and deserves full moral respect. Although most conservatives welcome medical and scientific advances that promote health and alleviate suffering, those advances are not tolerated at the expense of fundamental moral values. According to the conservative view, PGD is unethical – respect for the embryo on the basis of moral status rules out discriminating against embryos on the basis of health or disability because embryo selection implicitly and explicitly devalues life that is already weak and marginalised. Allowing embryo selection for any reason, including for reasons related to the health of the child to be born, may open the way to significant pressure for eugenic or discriminatory activity.[129]

The ramifications of accepting the conservative view would be that the potential benefits of PGD (for example, to help infertile couples with genetic disorders to have healthy children) will not be realised – prospective parents would not have the choice to screen and select embryos on the basis of the genetic make-up of embryos. Whilst banning PGD would mean that embryos would not be destroyed or discarded on the basis of their genetic make-up, standard IVF processes create more embryos than necessary for implantation with the result that 'spare' embryos would likely perish anyway.

The liberal position takes the opposite view – the embryo has no moral status. It has no claim to a right to life and can be discarded or used for any purpose. If this view is accepted, PGD would be permissible in New Zealand not only in its current form but also for social or 'trivial' reasons. The wide availability and use of PGD technology would have positive consequences for prospective parents with genetic disorders to have 'healthy' children and for relieving children from painful suffering due to incurable and seriously disabling disease. However, arguments have been made that there may be negative consequences for society if PGD is allowed to proceed under a liberal umbrella, for example, the impact on the parent/child relationship and greater discrimination in the disability sector.

The moderate view, as the name suggests, lies somewhere between the two extremes. There are two different moderate perspectives – that the embryo gains moral status at a specific time between fertilisation and birth, or that the development of personhood is a gradual process and, as the unborn entity develops, it is accorded greater moral status and right to life. The moderate view maintains that the embryo deserves 'special respect' on account of a weak moral status and the embryo can be created, used and discarded for legitimate reasons where the benefits of the proposed use outweigh the embryo's weak moral status. Robertson refers to this view as 'modern traditionalism' – the view is modern in its acceptance of new technologies yet traditional in demanding that those techniques ordinarily serve traditional reproductive goals.[130]

The New Zealand Human Assisted Reproductive Technology Act 2004 (HART Act) rejects both the conservative and liberal views, and adopts the moderate view. PGD is permitted to proceed subject to certain constraints that connect it with reproduction and the absence of direct harm to offspring, families, women, society and others. This approach is similar to that adopted in other jurisdictions, including the United Kingdom in the Human Fertilisation and Embryology Act 1990.[131]

## 3 THE ETHICAL ARGUMENTS

There are several ethical theories underpinning the different views of the status of the embryo and what is or is not permissible to do. The following sections examine arguments based on a number of theories to determine whether any of them provide a convincing basis for policy on the acceptable limits of PGD in New Zealand.

## 3.1 RIGHTS-BASED ARGUMENTS[132]

Rights-based theorists use the well-established moral principle that the intentional killing of innocent persons is morally impermissible to argue that the key to the controversy lies in determining whether the embryo is a person. However, serious disagreement exists as to what constitutes a 'person' and at what stage of development the embryo becomes a 'person'.

Some rights-based arguments rely on biological definitions of development. In line with the principle that the intentional killing of innocent persons is morally impermissible, the protagonists in this debate look for a point of time in human biological development at which one can hold that the unborn entity is a person. As soon as it can be regarded as a person, it is morally impermissible to destroy it. While there is general agreement on the facts of embryonic development,[133] there is disagreement as to which facts are 'morally relevant'.

The conservative view relies on two particular claims. The first is that from the very beginning, the human zygote is an individual human life. The second is that although science alone cannot determine the point at which 'personhood' begins, recent scientific findings does indicate that human life is a continuum from fertilisation, and the resulting entity must therefore be treated and respected as a person.[134]

The liberal view maintains that the conservative premise makes no sense, because calling an embryo a human being is as false as looking at an acorn and calling it an oak tree.[135] Rather, the liberal argues, the biological facts of human development indicate that moral significance should attach at a much later stage in development: viability, birth, or for extreme liberals, even after birth.[136] Before that time, the zygote or embryo is too rudimentary in structure and development to be a member of the moral community and to be accorded moral rights, including a right to life. As such, for the liberal there can be no moral objection to destroying or discarding embryos.[137]

Those with moderate views who point to facts of biological development as the theory underlying their view argue that moral respect due to the pre-born human increases as it develops. Significant stages of development include key points in time, for example, at implantation, the attainment of human form, the achievement of the ability to move about spontaneously or quickening, the onset of brain activity, or the capacity to feel pain.[138]

Do any of these approaches to the moral status of the embryo provide a convincing view of the limits we should place on PGD in New Zealand? The answer is no. The conservative view is reliant on the supposition that from fertilisation, the human zygote is an individual human life. Whilst the embryo is living, and genetically unique, it is not an 'individual' in the sense in which a person is an individual.[139] At the point of fertilisation, the zygote is totipotent. This means that each cell of the zygote maintains the potential to divide and develop into a completely separate entity, which is what happens when identical twins are formed. Until the cells of the pre-embryo are 'restricted' in the course of their development, so as to be differentiated toward particular developmental outcomes in the one entity, it cannot be established that a human 'individual exists' – the zygote or pre-embryo is still potentially at least a pair of identical twins.[140]

The conservative response is that regardless of the zygote's totipotentiality, it is still a unified, self-directed human organism,[141] and the rare possibilities of twinning and fusion do not overturn the understanding that the pre-embryo itself is a single living human being composed of interdependent and unrelated cells, which operate under the direction of an overarching plan. It is the biological unity, not the scientific individuality, of the zygote that renders it a morally protectable human being. Opponents would argue that the conservative's claim is not supported by science, as there is no evidence that the zygote is unified in its function or has 'biological unity'. Whilst the biological norm may well be that twinning and fusion are rare, the biological norm does not provide that the zygote is a human person or individual, it only provides a reason for acting as if it were, which is different.[142] However, the fact that the embryo may yet be two persons rather than one person should be reason enough, it can be argued, to accord it even greater moral status.

Moving back from the science to the fundamental basis for many conservative views – that reproduction is a 'gift' from God or nature and that the resulting entity should be unconditionally cherished – also does not assist the conservative argument. This argument finds its roots in religious- and metaphysical-based views of reproduction – a view which many would not share. The argument has such breadth that it would render nearly all forms of technological assistance in reproduction objectionable regardless of the natural fact that people have strong interests in passing on their genes and having healthy offspring, and regardless of the fact that using this technology to accomplish that task is no more objectionable than using technology after birth to enable survival to continue.[143]

Rejection of the conservative view does not necessarily lead to acceptance of the liberal view. As with the conservative view, some protagonists believe that science does not support the liberal view that the embryo is too rudimentary in structure to be a person and therefore does not become a person until a much later stage in development. The moderate view is also problematic. If moral status is rightfully accorded at some stage between fertilisation and birth, what is the significant stage? Our knowledge of the biological facts of human development provide that the significant stage cannot be implantation – although implantation results in a pre-embryo as a developmentally single individual, developmental singleness is not limited to the human species and therefore is not, in itself, enough to establish the moral status of the pre-embryo.[144]

What becomes evident is that a rights-based approach based on facts of biological development is unhelpful. The debate does not help us determine whether the embryo has moral status that is harmed by intervention or destruction in the course of PGD, and provides even less guidance on what the acceptable limits on PGD should be. None of the three rights-based views establish there is one point at which the unborn entity can be accorded moral status and a right to life.

## 3.2 DEONTOLOGICAL ARGUMENTS

Different moral duties have been promoted as providing the foundation for what the embryo is and how we should treat it. One such moral duty is the duty not to harm innocent persons – a duty which is breached if we intentionally harm another. The question as to whether the embryo is a 'person' to which this moral duty applies is open to debate. If the embryo is a 'person', the possibility of its destruction in the course of IVF (whether or not with PGD) is likely to breach the moral duty not to harm innocent persons and therefore be morally impermissible. However, whether or not the embryo is a 'person' cannot be resolved and, in this respect, the deontologist theory encounters similar problems as a rights-based approach.

In response to the difficulty with definitions of 'personhood', some deontologists claim that an embryo should be respected because it has the potential to develop into a being that deserves respect in its own right, not necessarily because it does or does not fit a rigid list of criteria. It is the embryo's potential to become a person that gives it moral status and a right to life. Potentiality is determined at conception and accordingly, from that point on, the embryo should be treated as a person.[145] This is a popular argument but it is also problematic.

The prospective limits of 'potential' are undefined – all that can be said about the potential of a pre-embryo can also be said about the potential of human gametes. Does this therefore mean that gametes have moral status and the use of contraception is immoral?[146] This would seem an illogical conclusion, because neither sperm or egg, by itself, can become a human being, just as an atom of sodium or chlorine could not by itself properly be called salt.[147]

Buckle, who argues that the deontological 'potentiality' argument does not provide a basis for the moral status of the embryo, distinguishes two senses of potentiality – the potential to become and the potential to produce.[148] The potential to become is evident only in an entity that maintains its identity over time. However, the potential to produce does not provide that any form of identity in the entity be maintained, for example, hydrogen and oxygen have the potential to produce water.[149] While the embryo has the potential to produce a self-conscious entity, it lacks the potential to become a self-conscious individual, and the embryo's potential to produce a self-conscious entity is not grounds for saying that it has a right to life.

Even if we accept that the embryo is a potential person, or that its potential to become a self-conscious entity does mean it has a right to life, is the duty not to harm the embryo absolute? For example, there is no rule that a potential X has the same or all the rights of an X; Prince Charles is a potential King, but he does not now have the rights of a King.[150] Thus, the wrongness of killing a potential person is open to challenge. There is perhaps more value in a potentiality argument that, in recognising the logical difficulty of arguing potentiality as a means for a right to life, asserts that the embryo's potential to develop into a human being is indicative not of a right to life but of a need to accord it significant respect.[151]

Additionally, some philosophers argue that even if we grant that an embryo is a person, the moral duty not to harm or kill innocent persons is not absolute and therefore does not naturally and without question support an obligation not to destroy human embryos. Savulescu argues that even if the embryo is a person killing it may be justified in certain circumstances.[152] He reasons that it is acceptable to kill one person for the purposes of saving others (he terms this ‘cannibalization’) and he points to a number of examples: the accepted practice of ‘reducing’ higher order multiple pregnancies to triplets or twins to improve the survival chances of the foetuses that are not ‘killed’ through reduction; the practice of foetal craniotomy – the crushing of a foetus’s head during birth when necessary to save the mother’s life; and the practice of separating conjoined twins, particularly with the purpose of killing one of them to save the other. Only those who oppose all killing of any kind can rationally oppose the destruction of an embryo solely by virtue of its status as a human person.[153]

## 3.3 ARGUMENTS BASED ON THE SYMBOLIC STATUS OF THE EMBRYO

The difficulties apparent in approaching such novel issues from rights-based or deontological perspectives have led some to seek guidance on what we can and cannot do to an embryo based on its symbolic status. We should treat the embryo as a person because of our personal commitment to the sanctity of human life – although the embryo is neither a ‘person’ nor an entity possessing interests, it may be the object of duties based upon a need to demonstrate a symbolic commitment to, and respect for, human life. The way in which we treat a developing human life reflects and defines the value we place on human life generally.[154] In this respect, even if embryos do not have rights, they provide an occasion for expressing or symbolising one’s views about the importance or value of human life, ‘thereby constituting one’s moral or national character in the process.’[155]

This moves the debate away from being a dispute about whether embryos have a right to life, to the debate about *how* we demonstrate respect for the sanctity of human life.

A conservative may use this basis to argue that PGD – the creation of human life with the intention of genetic testing to ensure that the ‘best’ embryos are implanted and to destroy those embryos that are not – weakens or insults our communal respect for the sanctity of human life and therefore should be prohibited. In contrast, McGee and Caplan argue that even if embryos are ‘persons’, symbolically or intrinsically, that in no way entitles the embryo to a ‘risk-free pathway into maturation’.[156] In other words, symbolic respect for the embryo does not necessarily prevent its destruction for worthwhile means. Humans (including embryos), they argue, only have a negative right against unwarranted violence, not a positive right to life, for example, we do not have a right to be free of disease, disaster, adverse weather or other acts of nature that may kill us. The negative right of unwarranted violence against an embryo, whatever its moral status, requires that it be destroyed only under the most scrupulous conditions ‘for the best communal reasons’.[157]

What is evident is that people differ over the degree and intensity of the symbolic associations that attach to the embryo, and over what types of considerations outweigh that special status. This causes difficulty for the symbolic argument. Given the highly personal nature of symbolic claims, the argument can provide no definitive basis for acceptable limits of PGD in New Zealand.

It appears that there is wide disagreement on how to define a ‘person’ and, consequently, disagreement on what we can or can not do to an embryo. That is a reason why some seek guidance not from an assessment of what the embryo is or how a particular moral duty defines our actions towards the embryo, but rather by an approach that requires us to weigh up the consequences of treating embryos in particular ways or destroying them. Such an approach, which is discussed next, is traditionally known in philosophy as utilitarianism or consequentialism.

## 3.4 LOOKING TO CONSEQUENCES – A UTILITARIAN APPROACH

Many philosophers argue that it is not in answering the question 'when does human life begin' that we find guidance on how we ought to treat that human life but rather in assessing the consequences of our actions. The theory of looking to consequences to justify action is known as consequentialism, a derivative of utilitarianism.[158] In utilitarian theory there is only one basic principle of ethics: the principle of utility. The principle of utility provides that we ought always to act so as to produce the best possible outcome. The 'best possible outcome' is determined through an assessment of the consequences of the action, where the rightness of an action depends on the value of its consequences – the right action in any given case will be that action which produces the maximal possible balance of good consequences (or value) over bad consequences (or disvalue). 'Consequences', broadly defined, include all the good and bad produced by the act, whether arising before the act has been performed or during or after its performance, and not only the consequences incumbent on the person acting, but on everyone affected by the act. Consequences affecting all parties must receive equal and impartial consideration.[159]

One consequentialist approach to the moral status of the embryo begins with the assertion that only beings with interests can be harmed by the defeat of those interests. Having interests presupposes sentience and because embryos are not sentient, it is morally permissible to terminate an embryo – that is, the embryo's termination affects no one who has interests or, in other words, no one can be harmed because there is no identifiable individual with particular interests who exists at that time.[160]

Some consequentialists avoid debates about the moral status of the embryo, and instead argue we can determine what we should or should not do to an embryo through an assessment of the consequences of using the embryo for any proposed purpose. The course of action that should be followed is not determined by whether there is or is not an actually existing entity, but by determining the best outcome, regardless of whether this outcome is to be achieved by actual or merely possible entities.[161]

Applying this type of approach to the question of the permissibility and limits of PGD requires an analysis of the likely consequences of creating and destroying embryos with genetic mutations in the course of PGD. If the value of proceeding with PGD is greater than the value of not proceeding with PGD, then we should rightly use embryos for this purpose. Buckle poses the following scenario:

> *If allowing a present embryo to develop will produce a future state that is less valuable than preventing the development of this embryo, and developing instead another, not yet conceived, embryo (for example, if the present one is suffering from a congenital defect, or if the parents or other appropriately placed parties are unable to care adequately for it), then a straightforward application of consequentialist principles requires that we follow the latter course.*[162]

So the question is: will PGD produce a more valuable future state? This is a question at the core of the ethical controversy around PGD technology. If PGD is banned, parents, families and society will miss out on potential significant benefits and society must bear responsibility for those patients and future persons that society has chosen not to assist through permitting the use of this technology.[163] On the other hand, PGD without restraints may harm society. The types of harms that are feared include possible harms to the child (including both psychological and physical harms due to concerns about the safety of the technique), negative impacts on the parent/child relationship, discrimination against people living with disability, widening the gap between social classes,[164] and the concern that PGD takes us a step further down the slippery slope to 'designer babies' and eugenics. More broadly speaking, PGD risks compromising human dignity itself where each new application of PGD represents a further assault on fundamental values.[165] Much can be debated about the perceived harms of PGD and feared consequences that may eventuate.

Some observers fear that PGD will have a negative impact on the relationship between parents and children,[166] for instance, increased parental control over the characteristics of their children may subtly shift parental attitudes toward their child from unconditional acceptance to critical scrutiny,[167] and from selecting embryos without genetic disease to selecting 'better' children. Increased parental control over the characteristics of their children may undermine the child's self-esteem. In addition, children who are not 'perfect' may be viewed as 'avoidable mistakes', and their parents as responsible for that; children themselves may blame their parents for their 'imperfections'. These pressures, it is argued, will result in harm to the future child – the child may suffer emotionally and psychologically from learning they were 'chosen' on the basis of observable genetic preferences and their right to an open, not biologically pre-determined future, will be limited, particularly by overbearing parental expectations.

## The moral status of the embryo

What moral status should we attribute to the embryo? The conservative view advocates that the unborn entity becomes a person at conception – from the moment sperm penetrates the egg at fertilisation the embryo is a human individual. On this strict moral view the embryo has full moral status as a 'person', and it is wrong to attempt to change, direct, control, design, or destroy the embryo from the moment of conception onwards. In contrast to this strict position the liberal view states that the embryo has no moral status; it has no claim to a right to life and can be discarded or used for any purpose. If this view is accepted, PGD would be permissible not only to select against offspring with serious genetic disease, but also to select for non-health related characteristics. The view which intersects these two positions is one which dictates that the embryo gains moral status between fertilisation and birth. On this view, the development of personhood is a gradual process and, as the unborn entity develops, it is accorded greater moral status and right to life. On this view the embryo is deserving of respect, but has a weak moral status as compared with a foetus, especially closer to the time of birth.

## 3.5 RELIGIOUS PERSPECTIVES AND ETHICAL THINKING

Religious perspectives reveal a range of positions on the status of the embryo and on the permissibility or restrictions of using the embryo for therapeutic purposes. There appears to be a wide diversity of opinions, not just among religious traditions but also within each tradition itself. Even where a set of basic convictions may be shared by a particular tradition, individual members of that tradition may differ in their judgment about interpretation or practice.

It would be ideal if an international body could, if it were possible, undertake systematic consultation of each and every religion to help inform the extent, content and principles of ethical decision-making in this area. In the meantime, the declared positions by some religious traditions and the works of scholars in religious ethics may help in informing ethical thinking about the issues. The following discussion is illustrative, rather than representative, of some religious perspectives and positions and they are limited to a survey of three theistic religions: Islam, Christianity and Judaism.[168]

Islam comprise two principal schools, Sunni and Shi'a – each of which has theological and other differences but both refer to the same historical sources and take a developmental view of human life and personhood. The embryo is regarded as human life meriting some protection and is believed to be ensouled from the fortieth day after fertilisation, at which point it is thought to attain personhood. The use of embryos for therapeutic and research purposes may be acceptable before this time.

Christianity has numerous distinct traditions, denominations and church bodies. The Protestant tradition regards full human status as being acquired gradually. However, Protestant positions range from the highly restrictive to the non-restrictive. It is difficult to find a single source of authority and, particularly as individual conscience is the core of Protestant ethos, Protestant thinking may accept there are differing views that can be held which could be compatible with Christian beliefs.

The official position within Roman Catholicism takes the view that human life begins at the moment of conception and considers an embryo as a human individual with the right to its own life. The implications of this position is that it is not acceptable to use embryos for therapeutic purposes and impermissible to destroy or discard embryos.

Jewish thinking based on the Hebrew Bible and Talmudic law holds that the moral status of the embryo is dependent upon its developmental stage; the embryo is not considered to have the full status of a human being at time of fertilisation. Central to Jewish thought is the emphasis on healing and saving which would permit some uses of embryos for therapeutic and research purposes.

## 4 ETHICAL GRIDLOCK AND POLICY DEVELOPMENT

The preceding sections communicate one very important thing – that there are many conflicting views on the moral status of the embryo and no overriding reason for necessarily accepting one view over another. The outcome of the debate does not provide a universally acceptable definition of the status of the embryo or answer to the question as to whether the creation and destruction of embryos in the course of PGD is intrinsically wrong. It would seem that we have reached a point of ethical gridlock.

Arguments based on a definition of 'personhood' fail to convince because no one can quite agree on what it is to be a 'person' let alone whether the embryo meets any set of proposed criterion for personhood. Arguments based on moral duty fail to convince because moral duties are demonstrably not absolute and not easily applicable to the embryo. Consequentialist approaches are also inadequate because of their implication for using unjust means to achieve just ends. So where does this leave us? How do we overcome this ethical gridlock and reach moral consensus to help us decide if, and to what extent, we should allow PGD to proceed in New Zealand? Does our policy/law on PGD need to reflect an agreed moral principle on the status of the embryo?[169]

If there is no clear reason for accepting one view over another then we cannot proceed to draw conclusions about the intrinsic moral acceptability of PGD or make policy decisions on PGD on the basis of one particular view of the embryo. Ideally we may want to resolve this moral issue before we make policy on new technologies that involve the creation and discarding of the human embryo so that we can be sure we are doing what we ought to be doing. However, given the polarised views and lack of basis for accepting one view over another, we need to concede that this is an issue on which people may legitimately hold differing views and consensus may never be reached. Yet, for many reasons this is an area of biotechnology on which we do require clear policy.

Hare states that we should 'stop wasting our breath on the question of when human life begins' because it is going to make no difference to the moral question of what the law ought to be.[170] Distinction is drawn between moral principles that should govern public policy, including legislation, and moral principles which may be held 'often passionately' by individuals, including individual legislators. When considering public policy on matters of moral uncertainty, policy makers need to make reasoned decision. On this approach, a rational decision about new technologies that involve the creation and discarding of a human embryo can legitimately be made free from 'rhetoric' and 'propaganda' that attempt to pressure policy makers into accepting one point of view over another.

Robertson states that one group should not impose its own view of the matter onto public policy because people differ so deeply in their views of the embryo.[171] Policy makers need a way in which they can think about such matters in a reasoned manner and decide what ought to be done – an approach that does not first require moral consensus. But how can policy makers think rationally about matters where there is considerable moral uncertainty?

Hare argues that they can by falling back on a consequentialist approach that looks seriously at the consequences of enacting any proposed legislation and policy. If policy makers want to make their actions conform to morality (that is, to pass the laws they morally ought to pass and not those laws that they ought not to pass), they should look at what they would be doing if they passed or threw them out.[172] But as we saw earlier, consequentialist approaches are heavily criticised, particularly because the value of the embryo to be taken into account and weighed in the moral calculus is unclear. Indeed, when considering these issues in the United Kingdom, the Warnock Committee rejected an approach based on utilitarian ethics because: 'Moral questions, such as those with which we have been concerned, are, by definition, questions that involve not only a calculation of consequences, but also strong sentiments with regard to the nature of the proposed activities themselves.'[173]

The next section sets out some constructive approaches to moving forward in the embryo status debate and discusses where those approaches take us with regard to policy on the acceptable limits of PGD.

## 4.1 MOVING FORWARD AND FINDING COMMON GROUND

For policy purposes, there is much that can be said for an approach that tries to find common ground to help shape consensus so as to move the discussion forward, particularly in a pluralistic and democratic society like New Zealand. Such an approach to PGD, which will help us to steer through polarised standpoints, can 'win practical answers for pressing problems with a rather high rate of acceptance'[174] – practical answers as to whether, and to what extent, PGD should be limited in New Zealand in a way that respects and acknowledges both sides of the debate. This approach has been utilised in other countries to assist in moving forward in the debate to make decisions about public policy involving reproductive technologies. For example, the UK House of Commons Select Committee on Science and Technology recently noted:

> *We accept that [in] a society that is both multi-faith and largely secular, there is never going to be consensus on the level of protection accorded to the embryo or the role of the state in reproductive decision-making. There are no demonstrably 'right' answers to the complex ethical, moral and political equations involved. We respect the views of all sides on these issues. We recognise the difficulty of achieving consensus between protagonists in opposing camps in this debate, for example the pro-life groups and those advocating an entirely libertarian approach to either assisted reproduction or research use of the embryo. We believe, however, that to be effective this Committee's conclusions should seek consensus, as far as it is possible to achieve.*[175]

So are there any points of common ground or matters on which consensus can be achieved in the debate about what we should or should not allow to be done to embryos? Thévoz suggests that there are six premises regarding the embryo that attract a reasonable consensus:

- everybody now existing has developed from an embryo – accordingly, we can agree there is an aspect of continuity between embryos and human beings;
- not every embryo, however, develops into a full human being – there is a high failure rate;

- human embryos stem from human beings – there is a shared origin;
- human embryos grow and gain new faculties and potentialities through time;
- human embryos deserve some protection – the burden of proof belongs to those who want to diminish or withdraw protection;
- every embryo is the result of human intervention, but not all those interventions are equal.[176]

Effectively, the points of common ground noted by Thévoz are that the majority can recognise that embryos have a 'human element' – they have a shared origin with living human beings, and there is a sense of continuity between the embryo and living human beings. What does this mean for the discussion about what we may or may not do to embryos? It does not mean we ought to treat embryos as we would treat living human beings because of their conditional development. What we can say is that the 'human element' accorded to human embryos leaves us with the supposition that human embryos are something special and, although a range of divided opinions are expressed, it is implicit in the majority of arguments that embryos deserve respect.

Clearly conservatives would agree with the basic proposition that embryos are special and deserve to be respected. However, would more liberal theorists also agree that this is a point of common ground? A small group with extreme liberal views may argue not but those holding the view that embryos lack interests or rights because embryos are not persons, do not necessarily view embryos as identical to any other human tissue – even they may not be comfortable with anything at all being done with embryos, for example, using them for toxicology testing of cosmetics, buying and selling them, or eating them. Indeed, as noted by Robertson, many such persons would agree that although embryos lack rights or interests, they deserve special respect.[177]

Most would agree that the human embryo is special and deserves a level of respect, whether such respect confers the embryo full, moderate, or weak moral status. It is this common ground that can be used as a basis to move the discussion forward from the 'seemingly endless argument about the embryo's status'[178] to how we might go about deciding, for policy purposes, what we may or may not legitimately do with the embryo. However, in doing so, it is important to again acknowledge that this approach will not be supported by all protagonists in the debate, although lack of consensus does not render the approach invalid. As noted by Gorovitz:

> *[T]o say that the quest for consensus, like the quest for certainty, is hopeless, is not to say that just any policy will do. Even amidst the pluralistic currents of ethical argument, there are constraints on what we can defend morally. At the heart of these constraints are widely shared commitments to fairness, to a respect for persons, and to a derivative respect for the aspirations that people have. We should be guided as well as we can by those moral principles that capture, insofar as possible, the common moral ingredients that exist within our pluralistic culture. We will find that quite hard enough without insisting on consensus.*[179]

## THE MORAL STATUS OF THE EMBRYO: EXAMINING NEW ZEALAND POLICY AND GUIDELINES

While there is a contrasting range of views about the moral status of the embryo, Parliament has indicated that, in terms of policy, creating and discarding an embryo is justifiable in some circumstances. Prenatal screening and selective abortion have taken place in New Zealand for a number of years.[180] Additionally, in May 2005, the Minister of Health approved the Guidelines on Preimplantation Genetic Diagnosis developed by the National Ethics Committee on Assisted Human Reproduction (the NECAHR Guidelines), making PGD an established procedure under the HART Act. This means that PGD can proceed in New Zealand in accordance with the NECAHR Guidelines which permit testing and selection on the basis of single gene disorders, familial sex-linked disorders, non-familial chromosomal disorders associated with advanced reproductive age, non-familial chromosomal disorders associated with infertility[181] and HLA tissue typing when approved on a case-by-case basis by NECAHR. The Guidelines prohibit the use of PGD for specified reasons that include non-medical sex selection, alteration of the genetic constitution of an embryo, and selection of embryos with a genetic impairment seen in a parent. PGD beyond the scope of the approved NECAHR Guidelines or the HART Act is prohibited.[182]

While screening of embryos for genetic disorders and HLA tissue typing is already legal in certain circumstances, further discussion about the ethical issues raised by PGD is necessary. As science broadens the scope for identification and diagnosis of genetic disorders and traits, New Zealand will need to consider the parameters within which PGD will be allowed to develop. Should PGD technology also be used on diseases that people have a lower chance of getting and diseases that may occur later in life? Should the Guidelines be amended to allow for screening for genetic 'traits' and 'social' reasons? How will New Zealand deal with the technology of PGD as it develops? Should PGD be reconsidered and prohibited, should its use and availability be limited,; or should it be made available to everyone with no limits on its use? A balance will need to be struck between the uses of new PGD technologies and restraint.[183] As such, policy makers cannot ignore ethical and moral arguments pertaining to the use of PGD technology or the need for temperate and rational moral debate[184] in considering the limits of PGD. Ethical analysis serves an important role in informing policy makers. It is through examination and reflection of the diversity of views on highly contentious issues that we can begin to consider the limits of regulation in a manner that is informed and representative of the broadest consensus.

The moral status of the embryo has already been debated in the context of abortion and, more recently, embryo research. The question therefore arises: why is the debate being revisited in the context of PGD? Can we not just accept that it is an issue plagued by controversy and conflicting views and seek to move forward from there? Hare has argued that 'to put the matter bluntly: we should stop wasting our breath on the question of when does human life begin' because the question will make no difference to the moral question of what the law in this area ought to be.[185] However, Hare also notes that, to be helpful, committees set up to advise Governments on such issues need to examine and assess the arguments on both sides and clarify the issues between them. Repeating intuitions that are current without going carefully into the arguments that might support them does not enlighten public discussion and 'will not do as a means of arriving at rational guidance for governments on moral questions affecting policy'.[186] In other words, when considering and advising on such issues, it is important to look for and test the arguments on both sides - while consensus may be difficult or impossible, all voices need to be heard in the deliberations. There is still a strong body of opinion in New Zealand opposed to PGD on the basis of the moral status of the embryo[187] and it is important that these views are considered and given weight in the assessment of how far we should permit this technology to develop.

## 5 CONCLUSION

There are many differing views on the moral status of embryos, and what we may or may not legitimately do with or to them. No one particular view of the status of the embryo stands out as an overriding 'correct' view. It can be concluded that we have reached a point of ethical gridlock on the moral status of the embryo, and that this is an issue on which people may legitimately hold differing views. Despite that, it is clear some principles are needed to govern the development and use of new technologies that involve the creation and destruction of embryos.

In moving forward, we need to consider our policy options in the face of lack of consensus on the moral status of the embryo by changing the focus of discussion from debating the moral status of the embryo to finding the appropriate way to treat the embryo for policy purposes in a pluralistic society. For the purpose of developing constructive policy, we have to investigate whether a common policy can be developed which takes all perspectives into consideration. Common policy can be founded on the most significant point shared by the majority of views on the moral status of the embryo – that the embryo is something special and deserves a level of respect. We can demonstrate respect for embryos in what we allow embryos to be used for, and the manner in which they are treated. The most appropriate and widely used way to do so is to take a consequentialist-based approach. Concerns about consequentialist approaches can be addressed by framing the consequentialist assessment with agreed bottom-line principles about what respecting the embryo means (for example, that embryos should not be destroyed for trivial reasons and should be used only for reasons that maintain respect for the sanctity of human life). On such an approach, utilising PGD in the limited therapeutic circumstances currently provided for in the NECAHR Guidelines would seem consistent with respecting the embryo. The consequentialist approach, whilst not unproblematic as an approach to resolving moral dilemmas, is an attractive, pragmatic, and reasonable solution to moving forward to make policy about new technologies that involve the human embryo. Although useful for policy making, this approach will not completely satisfy all protagonists in the ethical debate about the moral status of the embryo. It is important to acknowledge that this approach is a pragmatic solution for policy purposes only – it is not an approach that attempts to make conclusions about the intrinsic moral status of the embryo.

## ACKNOWLEDGMENTS

This section of the report is written by Helen Davidson, MBHL (Distinction) LLB (Hons, First Class). Helen would like to thank the researchers on this project for their support and many stimulating discussions, and particularly Professor Mark Henaghan, Professor Don Evans, Professor Nicola Peart and Mr Richman Wee for valuable comments and feedback.

# PART D: PUBLIC OPINION AND PERCEPTIONS OF REPRODUCTIVE GENETIC TECHNOLOGIES

## 1 INTRODUCTION: WHAT IS SO IMPORTANT ABOUT PUBLIC OPINION?

The term 'public' is usually used to refer to a group of people, often referred to as *the* people. It is intended to be completely inclusive, such that every person is accounted for by reference to the public. The scope of the term can be deliberately restricted, such that it is used to refer to a certain subset or subsets of all possible people, through appropriate qualification, as in 'the New Zealand public' or 'the lay public' for example. This highlights two related facets of the concept of the public. First, that it is composed of individuals who, depending on the purpose, may be usefully grouped according to relevant common features. Second, that this may indicate a potential, or perhaps even inevitable, tension among individuals and groups that comprise the public. This presents problems for identifying what is the public opinion about something.

The most basic unit of which the public is composed is the individual. This fact has many implications for the concept of the public. Individuals differ greatly in a vast number of aspects. These include age, sex, social situation, physical location, intellect, education, religion, ethnicity, culture, financial situation, areas of knowledge, understanding and expertise, and so forth. Each of these categories is perhaps best regarded as a conceptual tool, which is unlikely to 'carve the individual at the joints'. This is particularly important in the empirical analysis of public opinion, where the effect of various factors (often equated with these categories) may be inferred from statistical analysis. These inferences can lead to simplistic interpretations being given to the roles of these categories in influencing and determining public opinion, and their relevance as categories of differentiation between subsets of the public. There is also an important temporal aspect to these categorisations. Accounting for an individual's current qualities in terms of these categories may poorly reflect the actual attributes of the individual which influence their opinions. These qualities or attributes are gained at different times during an individual's life, and their effects can persist regardless of their immediate presence at any subsequent time. Gaining these qualities or attributes over time may be seen as part of the story which informs an individual's life and actions. This is often termed the narrative of the individual, and forms the basis of the emerging subject of narrative ethics. It is unlikely that this narrative will be adequately represented by categorisation of individuals based on specific attributes at any single time, if such representation is required.

How significant are these issues for determining public opinion? The answer depends upon the purpose of surveying and analysing public opinion. It may be perfectly adequate to have no idea of the narrative of the individual – in fact, many individuals may not wish to reveal information about themselves to the degree that would permit analysis of narratives, rendering such a project difficult or impossible. The purpose of any investigation into public opinion will likely be the single greatest factor determining the character both of any empirical research conducted to examine public opinion and the information elicited by such research. For example, the purpose could be to determine overall acceptability of a particular use of a specific technology, such that a simple expression of approval or disapproval is sufficient. Or the purpose could be to investigate what factors inform an individual's opinion about such a practice, how they influence it, the nature of these factors, how they interact, how justifiable they may be, and so on. The latter will require a quite different empirical approach in order to achieve its aims, if they can be achieved at all.

Discussing the purpose of research into public opinions and perceptions also raises a more fundamental question: Why look into public opinion at all? As already mentioned, any public group will comprise a variable number of individuals all of whom are likely to differ to greater or lesser degrees in their opinions and perceptions of any single issue or object of interest. Even if they do agree about a simple opinion, such as the acceptability or otherwise of a practice, they may differ in their reasons for holding this opinion, and this basic continuity of opinion may not necessarily be extended to include other, similar practices, despite the presence of seemingly relevant similarities. Opinions, be they aligned or opposed, can be based to varying degrees on information, which will be of varying quality. Information may be factually incorrect or illogical, to varying degrees objective or subjective, or could conceivably be so different as to be incommensurable with other information. Each individual's ability to assimilate information and reason to a conclusion will also vary. As a result of these and other factors, any individual is likely to hold opinions that are variably logical or illogical, rational or irrational, and coherent or contradictory. The range of opinions given by an individual or groups of individuals therefore may be of dubious status as a coherent framework for decision-making, judged on these attributes.

However, perhaps this is to give undue authority to qualities such as objectivity, factuality, logic, rationality and consistency in determining the legitimacy of opinions and decisions. Do our opinions only attain validity and legitimacy to the extent to which they embrace these qualities? Authority may also be given to factors such as subjective experience, emotion, and partiality. These two broad sources of justification are often dichotomised, such that the use of one is thought necessarily to exclude or at least restrict use of the other as an unavoidable consequence. Debate about the role of emotion, rationality and subjectivity in ethics is as old as ethics itself, but is also enjoying something of a renaissance presently, with the emergence of feminist ethics and renewed interest in the virtue ethics articulated by Aristotle. These and other systems of ethics seek, among other things, to redress what they see as an unjustified emphasis on logic and rationality in ethics, which, they contend, limits its usefulness.

Ignoring for the moment the consequences of such a debate, we are left with the issue of the usefulness and relevance of public opinion for ethics, and the roles that both public opinion and ethics might play in society and how they might interact. Perhaps the most passive role that ethics could play in society is to act as an assimilator and communicator of public opinion. In this model, ethics would simply reflect the values expressed by the public. At the other extreme, the most active role that ethics might play is to formulate moral values and frameworks of thought derived independently from public opinion, which may or may not reflect or in any way resemble public opinion. A third model falls somewhere between these two extremes. The role of ethics may be to review public opinion and values, and subject them to critical analysis in an attempt to reduce the presence of unethical values and practices[188]. None of these three models is unproblematic, and, for good or ill, in practice a variable mixture of some or all of these is likely to occur in many situations.

The two models that make use of public opinion seem to require a depth of knowledge about public opinion that extends beyond mere expressions of approval or disapproval for certain practices and conduct. This is less the case for the passive, reflective model, but it is unlikely to be very efficient if it does not attempt to ascertain some general rules held by the public to be useful guides for decision-making. It therefore appears that, if public opinion is to be incorporated into ethical deliberation, something more than a superficial knowledge of it is required. These requirements must translate into the methodology of any empirical research into public opinion, if this research is designed to inform ethical deliberation on any topic.

Many investigations into public opinions relating to science and technology have been conducted. Often, this is to discern perceptions and opinions relating to a specific area of science or technology, particular scientific practices, or individual technologies. The increasing use of molecular genetic science and technology is one area that has been a locus of research interest in this regard. Characterising the public morality regarding these technologies can usefully inform the ethical scrutiny they are subject to. Estrangement of this scrutiny from public opinion and public morality can reduce the relevance and acceptance of any public policy that it informs. In the case of genetic science and technology, their applications within the sphere of human reproduction raise many ethical issues which are often central determinants of public perceptions and opinion. The purpose of much research has therefore been to explore and characterise public perceptions and opinions relating to human reproduction *per se*, and practices involving the intersection of this with genetic science and technology. Current research from outside New Zealand suggests that public perceptions and opinions of particular relevance to this area concern the following:

~ Conception, the embryo, foetus and pregnancy

~ Children, families and relationships

~ Freedom of control over aspects of ourselves and others

~ Naturalness of biological processes, technological and scientific involvement in reproduction

~ Attitudes to human genetic attributes and genetic inheritance

~ What constitutes desirable or undesirable features of a future society

~ What constitutes harm and suffering and the value of these

Perhaps the largest bodies of research into these issues have investigated public opinions and perceptions in the USA and UK. Other research have also been conducted in Australia and Asian countries. Research in New Zealand has focussed largely on a different area of genetic science and technology: that of genetic modification. The New Zealand research into this, particularly as exemplified by the Royal Commission of Inquiry in Genetic Modification released in 2001,[189] has generally been viewed as a highly proactive and thorough scrutiny of an emerging area of science and technology prior to large scale use of its practices in a country. This provides a large body of research into opinions and perceptions of the New Zealand public about this range of genetic practices. However, the relevance of this information to genetic practices related to human reproduction is a matter of some uncertainty. The use of genetic techniques in human reproduction is briefly addressed, but it is not a focus of the Royal Commission or its report. It is possible for some degree of inference to be made from opinions about other genetic technologies to reproductive matters, however the reliability of this is likely to vary greatly among individuals and objects of consideration. This is particularly likely when considering human reproduction, an issue that is often held in special regard. These inferences therefore do not provide a sound basis for ethical reasoning about an issue, or conclusions to be drawn about matters relating to the development of public policy, although they may be used judiciously to inform such undertakings.

Another approach is to use information derived from other public groups, such as those from other countries, and apply this to the New Zealand situation. The assumption that the same or similar opinions will arise in different countries may, to some degree, be borne out by an analysis of the data. It is also suggested by the concept of a 'common morality' within ethics. This is the theory that, ultimately, there are some common factors which, implicitly or explicitly inform ethical deliberation, regardless of any other differences thought to be involved (such as between explicit moral frameworks, cultures etc.). This theory is by no means universally accepted, but does offer a theoretical account of some commonalities in moral conduct and reasoning among different groups. However, there are other factors that militate in favour of conducting research specifically into the New Zealand public's opinions about reproductive genetic technologies. These include the recognition of the New Zealand public as an independent group, which presents the possibility of unique moral considerations and opinions, or at least a unique mixture of opinions existing elsewhere. Of particular consideration in this regard is the presence of different ethnic groups in New Zealand, including, but not limited to Māori and Pākehā, who may draw on unique moral concepts or apply these in ways different from other public groups. Indeed, the assumption that the common morality concept can account for a Māori moral framework, which has itself not been well-characterised in the context of academic ethics, is dubious. Even accepting the common morality concept does not negate the value of research into particular expressions of this morality in different contexts. Moral conduct appears to be heterogeneous in many situations in the world, and is likely to be influenced in sophisticated ways by circumstances and other factors particular to these situations. This phenomenon is of ethical interest even if viewed as an expression of a single common morality. Also, the fact that New Zealand is alone in the world in having conducted a Royal Commission of Inquiry into genetic modification suggests that the New Zealand public may be particularly concerned, or at least have a particular interest, in influencing the development and use of genetic technologies in New Zealand. However, as noted previously, it is difficult to have a high degree of confidence in these generalised inferences in the absence of direct evidence.

It is therefore recommended that research be conducted into perceptions and opinions of the New Zealand public relating to the use of genetic practices in human reproduction. Aside from the value of this research in informing ethical considerations, there are pragmatic and political reasons in favour of conducting this research. Given that the benefits as well as the costs of the use of new technologies are ultimately borne by the public, there are significant arguments in favour of them exerting some control over the use of such technologies. Politically, free expression of public opinion is fundamental to democratic government, and the use of this opinion to inform the development of public policy is essential to the legitimacy of such policy.

Pragmatically, any public policy estranged from public opinion and morality is unlikely to be widely accepted.

In the New Zealand situation, very little empirical research has been conducted into opinions and perceptions of the public relating to PGD. New Zealand is a world-leader in research into the use of genetic modification, and public perceptions of these, which were presented in the Report of the Royal Commission on Genetic Modification. This showed the diverse interests that the public possessed and how they perceived them to be, or potentially to be, affected by genetic modification technologies. Unfortunately, these opinions and interests are not easily extended to encompass new and different technologies such as PGD. As already mentioned, complex factors can affect an individual's perception and attitude regarding objects of consideration, even when the object itself remains constant. The implications of changing the object of consideration, say from genetic modification of a foodstuff or animal, to genetic testing of human embryos prior to implantation in the uterus, can be unpredictable.

In order to be of greatest use, this research must be conducted according to a methodology that is appropriate both to the characteristics of the New Zealand public, and the purposes for which such information is to be used. This will involve accounting for many methodological factors, some of which have been mentioned briefly. In terms of purpose, an attempt must be made to characterise the moral frameworks used by members of the public, since this is likely to be of broadest ethical use and will most usefully inform the development of public policy. Simple surveying of public approval or disapproval of technologies and practices is likely to provide a weak basis for justification of any normative conclusions reached. However, knowledge of the quantitative presence of opinions and moral values held by the public can usefully inform ethical deliberation. It is therefore recommended that a combination of quantitative and qualitative research be conducted into the opinions and perceptions within the New Zealand public regarding the use of genetic technologies in human reproduction. These may then be analysed in the context of New Zealand research concerning other genetic technologies, international research concerning other public groups, and current ethical thought.

### What's so important about public opinion?

The public is an extremely complex and diverse group of individuals. They differ in many characteristics, such as age, level of knowledge and education, social situation and cultural background. These factors may affect the value of individuals' opinions for ethical deliberation. The question of how to handle differences in views, especially those that are diametrically opposed, also arises. Not all individuals may be able to represent themselves equally in the public sphere. Despite these problems, critical use of public views and perceptions can usefully inform ethical deliberation and the formulation of policy.

## 2 WHAT GROUPS OF PUBLIC OPINION ARE OF PARTICULAR RELEVANCE TO STUDIES OF PGD?

Any group of the public that is affected by a particular technology is relevant to ethical investigations of the technology. Indeed, it would be difficult to conceive of a group that was unaffected by a technology being of any great relevance to ethical deliberation about it. This is not to say that unaffected individuals or groups may not be involved in the deliberation *per se*. It is merely to say that any ethical deliberation must take account of the ethically relevant aspects of a technology, and one of the ethically relevant aspects is the technology's effect, i.e. the consequences of its use. If a technology has no consequences for any morally considerable party, the views of that party ought to be apportioned an amount of weight proportional to these consequences in ethical deliberation.

This is not to say that all ethical deliberation about technologies ought to be consequentialist; rather that consideration of consequences is an important part in ethical reasoning. Consequences are often contrasted with intrinsic factors relating to an object of ethical inquiry. An intrinsic objection would posit that something is morally wrong *regardless* of the consequences that it may engender: as an example, it might be argued that guns are intrinsically wrong, and therefore ought not to be used, *even if* they were the only means of procuring food to feed a starving population which would otherwise die. One of the most prominent systems of ethics which is predicated on intrinsic factors is deontology, which was developed primarily by Immanuel Kant. Deontology posits formal rules dictating actions that are intrinsically good, regardless of their consequences. Both intrinsic and consequentialist considerations come into play in the ethics of PGD.

In fact, even groups who are mainly thought to hold intrinsic objections to technologies such as PGD may be affected by its use, but in a broader sense. If I had the intrinsic objection to guns mentioned in the previous example, I might be affected by the knowledge that guns were being used in the manner described, and this might cause me some degree of suffering, which means that I am being affected by the situation and ought to be accorded some degree of consideration.

In the case of PGD, there are many parties that can potentially be affected. These may include (but may not be limited to): the embryo(s); the resulting child, the female undergoing the procedure; the person(s) who provided gametes for fertilisation; those involved in a relationship with any of these parties, such as partners, husbands, wives, family, friends and so forth; and those who live with the genetic diseases which may be tested for. As mentioned previously, other parties can be affected in a more indirect manner. For example, as a member of society, I may say that I would like to live in a society that is as free from disease and suffering as possible, and therefore that I will be positively affected by the use of PGD simply by living in a society that as closely as possible resembles my ideal. PGD may not have any more direct effect on me than that, but I may hold my experiences to be worthy of some consideration alongside those of people more directly affected by it.

But how much consideration ought each party's experiences to be accorded? This is a subject of great debate in ethics, and will not be resolved here. It is especially problematic when experiences and interests conflict or encourage incompatible resolutions to a problem. There are many examples of these in PGD. One is the conflict that can occur between, on the one side, potential parents who would like to selectively implant an embryo free of a certain genetic disease, and, on the other side, the community of those who have genetic disease. The potential parents may have certain desires for their child-to-be, their family, themselves, society, and so forth, which they think may be promoted by the use of PGD to produce a baby free from this genetic disease and be frustrated by being prevented from using it. The community which has this disease (and potentially those with other diseases) may have certain desires for the same objects of concern, which would be frustrated by the use of PGD and be promoted by prevention of its use. These concerns have been discussed in section 1 of this chapter, and the example serves to illustrate some of the conflict of desires, experiences and interests that can arise between the different groups affected by PGD.

**What groups of public opinion are of particular relevance to studies of PGD?**

In the case of PGD, there are many parties that can potentially be affected, and in different ways. These may include (but may not be limited to): the embryo(s); the resulting child, the female undergoing the procedure; the person(s) who provided gametes for fertilisation; those involved in a relationship with any of these parties, such as partners, husbands, wives, family, friends and so forth; and those who live with the genetic diseases which may be tested for. Other parties can also be affected in a more indirect manner. The degree to which individuals and groups of individuals are affected by PGD is an important determinant of how much consideration they should be accorded in reasoning about this issue.

## 3 THE USE OF PUBLIC PERCEPTIONS AND OPINIONS IN ETHICS

As mentioned in the introduction, the use of public perceptions and opinions in ethics is not as clear as is often thought. We are all aware of ill-considered actions that we and others have performed at times. Sometimes, with hindsight, we become conscious of many aspects of our conduct and those of others that we did not consider ethical or unethical. Sometimes we may conduct ourselves in ways that we think actually *are* unethical, but feel compelled to continue anyway. Sometimes we are mistaken about ethically relevant aspects of a situation, which can lead us to perform unethical actions without being aware of it. If, as a purely hypothetical example, we were to discover (contrary to all current scientific knowledge), that the embryos used in PGD were capable of experiencing pain, we may judge the destruction of embryos rather differently than we do currently, and may seek to improve our practices by, for example, ensuring that embryo destruction occurred painlessly. (Note that this may not be all that we do to remedy the situation, but is an example of a minimal step that may be taken.)

The hypothetical example of the embryo is one in which we are unaware of the interests and preferences of the being in question (say, the interest the hypothetical embryo may have in avoiding pain), which leads to lack of awareness of a potential harm, in that case, the harm done by causing a being to experience pain needlessly. Unfamiliarity with the range of interests of those affected in a situation or by an action can similarly lead to unawareness of the potential benefits that may be produced by an action.

It is here that public perceptions and opinion are of great importance to ethics. In order to be effective, ethics must as completely as possible account for the realities experienced by those within its sphere. A relatively easy way of obtaining this information is by inquiring into whose experience is being affected by an action, and then what the qualities of their experience may be. In the case of PGD, there are many parties who are able to express themselves to a greater or lesser degree on this issue, such as adults and children. The degree to which these groups are capable of articulating their views will vary according to their ability and the forum in which the views are solicited and presented (this will also be discussed in the later section addressing methodological considerations).

Of particular interest is the variable ability of individuals to express themselves. This is particularly the case for certain groups which often represent minorities in society, such as children and people with physical and intellectual disabilities. Both groups have suffered, and continue to suffer, from diminished presence in public discussions. The situation for the disabled community is described well by Gerber:

> *So powerful is the voice of disabled people becoming, and so powerful are the intellectual and ideological forces that seek to give that voice centrality in shaping the discussion of disability, that it may soon become difficult to recall that a short time ago people with disabilities were little more than the objects of study. Their voice had less legitimacy and less authority than that of the medical, rehabilitation, educational and welfare bureacracy [sic] professionals who studied and worked with them. Generally, these experts have been well-meaning people, who have often urged compassion and responsibility on societies guilty of cruelty or indifference. But their conceptions of disability and of disabled people gave rise to the development of social policy that imposed, in the name of a benign paternalism, bureaucratic manipulation and socio-economic dependence, and ultimately dead-end lives, on people with disabilities.*
>
> *Perhaps since Bogdan & Taylor (1976) published their widely cited article consisting largely of the oral testimony of a man diagnosed as retarded, and challenged readers to grant him the authority to speak about his understanding of his life, researchers have increasingly sought to have retarded people speak for themselves. These researchers are urging a conceptual reorientation not only out of a sense of fairness or of the need to recognize the human dignity of retarded people, but as an essential step in recasting social welfare policy. […] For example, working with the written testimonies produced for a literary expression workshop, of people considerably more impaired developmentally than Bogdan & Taylor's "Ed Murphy", Susan Lea (1988) revealed coherent self-understandings and personal aspirations and fears among them.* [190]

The situation described by Gerber relates well to that of children too, whose experiences are now being heard. One study of particular relevance to PGD is that of Sartain *et al.*,[191] who interviewed children suffering from chronic illnesses such as cystic fibrosis, concluding that "children can communicate competently their experiences of ill health and health-care"[192]. However, they discovered that the experiences of these children are not uniform and concluded that they ought not to be considered a homogeneous group.[193,194]

Ethics may be done without taking into account these sorts of real-world experiences, but, to use the distinction of the ethicist James Rachels, this would be classed as *pure* ethics, or moral philosophy. He contrasts this with *applied* ethics, which takes into account the real-world factors that affect an ethical scenario:

> *It has been argued by many philosophers that there is nothing immoral in mercy-killing, when it is requested by a dying person as a humane alternative to a slow, painful death. Others have objected that if mercy-killings were permitted it would lead to further killings that we would not want – we might begin by killing people at their own request to put them out of misery, it is said, but then we would begin to pressure sick people into making such requests, and that would lead to killing old people who have not requested it (for their own good, of course), and then we would go on killing the feeble-minded, and so on. […] What would follow? It would not follow that mercy-killing is immoral in the original case. The objection would show, paradoxically, that there are good reasons why we should not perform actions that are moral and humane. Those reasons would have to do with the imperfections of human beings – the claim is that people are so flawed that they would slide down the slippery slope from the (moral) practice of euthanasia to the additional (immoral) practices described.*
>
> *This suggests that moral philosophy might be idealistic in a way that applied ethics is not. […] Applied ethics […] takes into account the messy details of the real world, including the prejudices, faults and vices of real human beings, and recommends how we should behave considering all that as well as the ideals of perfect conduct.*[195]

Incorporation of the factors mentioned by Rachels into ethical analysis yields applied ethics, which is likely to produce the most workable solution to an ethical issue such as the use of PGD, embedded as it is in the human social and psychological context. The effectiveness of applied ethics in the human context is therefore predicated partly on the degree to which ethicists understand the attitudes, perceptions, opinions and motivations of the public (another predicate being a sound understanding of ethics!).

This is also why a sound understanding of these human factors is crucial to the successful development of public policy. A public policy estranged from the characteristics of the public which it involves can have unintended consequences (as illustrated by Rachels). These consequences may not *necessarily* be bad, but ought not to be left to chance if this is avoidable. Public policy that does not fit well with aspects of the public psychology also risks being ignored by the public and therefore being simply ineffective.

There are therefore ethical and pragmatic reasons for understanding public psychology relating to objects of ethical and policy deliberation: ethical reasons such as avoiding problems of unintended and potentially unethical consequences, and pragmatic reasons such as finding effective ways to apply moral philosophy in the messy world of human affairs as either applied ethics or public policy.

**The use of public perceptions and opinions in ethics**

Ethical deliberation could be entirely driven by public views and opinions, or it could be conducted with no regard given to these factors. Both of these extremes engender problems, and a middle ground between them is likely to be most reasonable and effective. This is the domain of practical ethics, the aim of which is to produce the best solution to ethical problems considering the practical realities within which we live. This solution must account for the diverse interests of the public, which necessitates a thorough understanding of public views, perceptions and opinions, which express these interests. In this way empirical research into the ways individuals relate to issues such as PGD plays an important role in informing ethical reasoning.

# 4 AN EXPLORATION OF PUBLIC PERCEPTIONS AND OPINIONS RELATING TO PGD

## 4.1 SOME METHODOLOGICAL CONSIDERATIONS

Methodological considerations of empirical research into social elements such as public opinions, perceptions and attitudes, constitutes an extremely broad topic which has been the subject of a great deal of research[196,197,198, 199, 200, 210, 202]. This will be condensed into those methodological aspects of immediate relevance to the provision of empirical data that is of greatest use for ethical deliberation and analysis. It is important to note that, due to practical impediments, it may be impossible to realise fully some of the aims of empirical research. However, this does not negate the use of such aims in shaping the research.

A primary consideration of empirical research is that the range of opinions held by the public be represented in the data as completely and accurately as possible. This representation can be proportional, such that opinions are present in the data to a degree representative of their proportional presence in the public. Or opinions can be represented qualitatively, which does not allow ready inferences to be made about the prevalence of opinions in the public repertoire, but aims to characterise accurately the often sophisticated qualities of these opinions. There is some practical tension between these two aims, since achieving a statistically accurate representation of the range of public opinion usually comes at the expense of the depth and accuracy with which that opinion can be characterised, and *vice versa.* Both types of information are of ethical value, and the absence of either will restrict the types of conclusions that may be reached through ethical analysis. However, it is likely that the absence of significant qualitative data would be of greater detriment to most ethical analysis, although this is, of course, a generalisation.

Opinions and perceptions are not generally static entities – they are usually subject to constant assessment and revision over time, in light of various factors. This temporal quality can be addressed methodologically through the incorporation of a longitudinal element into the research design. In its simplest form this may involve repeating the investigation with some or all of the participants, to discern any changes in opinion. This approach provides interesting information, but it is likely to be of limited use if the reasons for change, or indeed absence of change, in public opinion are not investigated. This will necessitate a more qualitative aspect, and again highlights the significance of the qualitative/quantitative dichotomy for this type of research.

Another approach to investigating factors thought to be capable of changing public opinion is to incorporate these in a controlled way into the research method. An example of this is the influence that knowledge about a practice or issue plays in determining an individual's perceptions and opinions of it. The effect of this factor may be investigated by characterising the opinions of individuals before and after an intervention which is designed to increase their knowledge of the object of opinion (the issue, practice, etc.), such as the provision of information in some meaningful form. This technique has advantages and disadvantages over other ways of attempting to discern the same information. One of these, which is emblematic of a general problem in research, is the resemblance of such an intervention to what goes on in reality, and therefore what can legitimately be inferred from the results of such research.

This approach also changes the explicit nature of the inquiry from passive observation of certain aspects of the experimental subjects, to attempting to influence actively these aspects in the course of the research. This complex issue can be approached in different ways, one of which is to undermine the belief in passive observation as a realistic and achievable aim for experimental research generally. These and other objections notwithstanding, observation may, to varying degrees, be active or passive, and the attempt to control this is reasonable and valuable in a research context. For example, the act of recruiting an individual who then answers some questions is, in essence, one of active observation. The possibility that the data provided by this individual have, to some extent – however small – been influenced by the act of observation should not be dismissed lightly, if at all.

However, steps can be taken to minimise this by identifying sources of influence and taking them into account in the experimental design. Two simple examples of this are the wording of questions and the format within which individuals will present data. The wording and framing of questions can profoundly affect the types of responses elicited. Framing questions within the context of a scenario illustrating the issue or object of questioning can help participants who have difficulty responding to more abstract or general questions. However, scenarios are inevitably rather specific and care must be taken to use examples of as broad relevance and appeal to participants as possible, to minimise bias in participant response. Alternatively, attempts can be made to use scenarios that are tailored to specific participant groups, if groups are based on relevant characteristics. When questions are used, care must be taken to present the objects of interest in as neutral a light as possible. This can often be much harder than anticipated in practice, and neutrality can easily be construed as another unachievable goal. With regard to the format of interviewing participants, this can take many forms, each of which has advantages and disadvantages, and will alter the character of response received. Some examples include one-on-one interviews, questionnaire-based surveys, focus groups, phone-based interviews and surveys, and questionnaires. Each of these will entail further considerations, such as whether to group participants randomly or based on common characteristics in the case of focus groups, which can affect the willingness of individuals to participate and share information, and so forth.

## An exploration of public perceptions and opinions relating to PGD

### Some methodological considerations

The diversity and size of the public poses problems for empirical determinations of public opinion and for the use of public views and perceptions in ethics & policy. One problem is how to obtain and represent accurately the multitude of individual views and perceptions existing in the public. Some antagonism exists between quantitative and qualitative accuracy in this aspect of empirical research. In planning empirical research it is therefore crucial to decide the relative importance of these two basic aims viz. to determine accurately either the prevalence of views among the public and the nature of those views. The former requires a quantitative approach, the latter qualitative, and it is very difficult to achieve both at once. Both types of information are likely to be useful in different contexts.

## 4.2 CONCEPTION, THE EMBRYO, THE FOETUS, PREGNANCY AND LIFE

PGD can alter the way in which many aspects of reproduction are experienced. This can be because it alters the actual phenomenon of reproduction, for example by the introduction of IVF into the process of conception. This displaces sex in these instances of procreation, which has been raised as an important moral consideration by the Catholic Church in particular. In Catholic morality, reproduction has two meanings, one unitive and one procreative, and the inseparability of these is something that ought to be protected.[203] In this respect, IVF is unacceptable because it "voluntarily dissociates the two meanings of the conjugal act, promoting sexual intercourse devoid from its procreative meaning, and second, that assisted reproduction is unacceptable because it promotes procreation in the absence of sex".[204] This is thought to be particularly significant in countries such as Latin America, where almost 90% of the population identify themselves as Catholic. However evidence suggests that this may not be the primary factor determining reproductive decision-making in these countries, with individuals often primarily influenced by social and personal considerations.[205]

In couples undergoing IVF and particularly PGD the value of the sexual act in reproduction is usually offset to varying degrees by the stress and anxiety of its lack of poor or absent conception, miscarriage, or the birth of a child affected by a genetic disorder, or the potential of these to occur.[206,207] For these patients the decision to undertake PGD has been described as "a 'choice out of necessity', or not really a 'choice' in the normal sense at all".[208] For these individuals the choices available are not having or raising children, adoption, gamete donation, spontaneous conception with the possibility or likelihood of having an affected child, prenatal testing with the option of termination, or PGD.[209] Faced with this situation, other factors are often of greater significance in decision-making. Indeed, the notion that a disadvantage of PGD is that it interferes with natural reproduction was given high importance by only 16% and 24% of English males and females, respectively, who were carriers of recessive disorders (Table 1). Other factors such as health risks for the patients and their partners, the creation of surplus embryos, and the likelihood of success were given higher weightings.

*Table 1. Ratings of importance in decision-making (5 representing 'very important', 0 'not important') of disadvantages of preimplantation genetic diagnosis in English carriers of recessive genetic conditions.*[210]

| Disadvantage | % Giving rating of 4 or 5 | |
|---|---|---|
| | **Women** | **Men** |
| May not be successful | 49 | 37 |
| Can be painful | 17 | 42 |
| Possible health risks for you (and your partner) | 46 | 79 |
| Long waiting lists | 60 | 49 |
| Dilemma of what to do with spare embryos | 51 | 30 |
| It's interfering with nature | 24 | 16 |

The participants in this study have lived with the consequences of the condition they carry, nearly all of them having had an affected child, a third having had that child die, over half undergoing prenatal testing and 19% terminating a pregnancy as a result. This is a common history for couples presenting for PGD.[211] These experiences can colour people's attitudes to the factors mentioned, in favour of more concrete considerations which have been experienced over those which are more abstract.[212,213,214,215,216] This is exemplified by a study in which all females at risk of beta-thalassaemia who had prior experience of a therapeutic abortion judged PGD as acceptable, compared to 30% of those women who had no experience of therapeutic abortion. This may account for the fact that participants in Snowden and Green's study who had not terminated a pregnancy rated what may be considered the more abstract objection of 'interfering with nature' as more important.[217]

*Table 2. Ratings of importance in decision-making (5 representing 'very important', 0 'not important') of advantages of preimplantation genetic diagnosis in English carriers of recessive genetic conditions.*[218]

| Advantage | % Giving rating of 4 or 5 | |
|---|---|---|
| | **Women** | **Men** |
| Child would be genetically related to both of you | 86 | 83 |
| Child would not inherit the disorder | 94 | 91 |
| Can find out whether the child is a carrier | 56 | 44 |
| Can know from the start that child won't have the disorder | 94 | 94 |
| No need to terminate pregnancy for the disorder | 96 | 88 |

In contrast to the disadvantages examined (Table 1), carriers of genetic conditions generally rated the advantages of PGD as being of much greater importance (Table 2). Of particular relevance to perceptions of pregnancy, the embryo and foetus are the advantages of knowing from conception that the child does not have the genetic condition and that there will therefore be no need to consider termination of the pregnancy as a result of this. It has been shown that women undergoing prenatal testing often psychologically distance themselves from the embryo and foetus, often referring to 'the pregnancy' instead, until the status of the foetus is established.[219] There is less need for this phenomenon if the genetic status of the foetus is known throughout pregnancy. The absence of these and other stresses goes some way towards accounting for the reported reduction in stress experienced by 40% of couples undergoing PGD who had previous experience of prenatal testing (PNT).[220]

However in the same study 35% of couples felt more stress when undergoing PGD compared to PNT, perhaps due to the disadvantages mentioned and the added stress associated with undergoing IVF.[221,222] However, despite these observations, 76% of the couples contemplating a further pregnancy would choose PGD, 16% would opt for prenatal diagnosis and 8% no tests at all.[223]

These preferences are supported by other research.[224,225,226] However, one study has shown a preference for PNT over PGD in carriers of recessive genetic disorders, despite support for PGD as a useful reproductive option.[227] The authors attributed this to methodological differences between their study and others, which serves to highlight the importance of methodological considerations in empirical research of this kind. Notably, the provision of information and the nature of the information provided differed between the studies, the population sampled, and the life situation of the participants were cited as factors which may account for the difference. The authors conclude:

> *In many ways, the preference for [PNT over PGD] found in our study is quite logical in that it is the most practical option for carriers of recessive disorders. Where a reliable test is available, they do not have to cope with the complications of other options such as limited accessibility, financial expenditure or possible problems over genetic relationships. A factor which is not addressed in this study but which is likely to be important is that for infertile couples intending to use [PNT], conception of their children remains a private affair rather than being placed in the public domain and assisted by doctors, scientists and technology.*[228]

Notably absent from the considerations mentioned above are those relating to the embryo and foetus. This is an issue which is often central to discussions of PGD and PNT, since the two technologies differently involve and affect the embryo and foetus. The significance of this will depend on the ethical status which is attributed to the embryo and foetus. A thorough analysis of this issue has been presented in Section 3 of this Chapter and will not be reiterated here. However, it is important to note that the embryo and foetus are perceived differently by individuals, and this is affected in complex ways by innumerable factors. Often many individuals involved in the process of PGD, such as the clinician, the people seeking PGD, genetic counsellors, midwives and so on, will have different and potentially conflicting perceptions of the embryo. Examples of these are considering the embryo as a person, a patient, a 'nobody' or a commodity[229,230], as a child or potential child, or as human life or not.[231] To further complicate the picture, these categories are not necessarily accorded the same level of moral worth among members of the public. A selection of quotes from the American public illustrates the differing perceptions of the embryo and foetus:

> *[N]either of us felt that the embryo was a living thing until it was living inside me.*[232]
>
> *[P]reimplantation genetics has almost redefined that life, in my opinion, would start upon implantation and not upon conception. Because it's in the lab. An embryo at that stage cannot be sustained by itself. If it's not implanted or frozen it will not turn into a human being. It needs to be implanted into a woman in order for it to become a human, so that's why I don't have a problem with preimplantation genetics.*[233]
>
> *I approach this from a non-religious point of view… I don't really believe in abortion, and it's not a religious view; it's just a view that I think life is great, and I think everybody should be alive. I think the more life the better, you know? And let life run its course.*[234]
>
> *What I would call [PGD] is selective abortion because I believe that life begins at conception, which is when the sperm and egg unite. So, whether it is eight to ten cells, or a fully developed baby, I think that what you have done is scientifically produce twenty embryos, which I would call a baby.*[235]

The following demonstrates the reasoning of a patient undergoing PGD, who summarises the harms and benefits of PGD for them, as they relate to the embryo, the potential child and the people involved in the PGD process, and compares this with PNT:

> *PGD… is more costly; almost as emotionally draining; and more painful, physically, than doing prenatal testing, but ethically, I feel better about doing it. Because I know that I'm not ending a life… to me, a ball of cells is not a child until it starts growing, so I don't feel that I'm doing something bad or evil or unethical by not using certain embryos. So I just feel like I'm doing everything I can to create a healthy, happy child, rather than wait and find out if I've created a healthy and happy child.*[236]

A common element of the reasoning in these examples is an emphasis on the ethical significance of life. Each person mentions the presence of life as an important characteristic in the embryo, which endows it with moral significance and causes some actions regarding the embryo to be considered wrong. It is interesting to note that the perception of life is, in most of these examples, discursively linked to the embryo being perceived in its potential states: that of being a baby or child.[237] It is unclear whether these people regard the embryo as an *actual* baby, and therefore as possessing the same attributes which necessitate moral consideration. Another explanation is that the perception of life, which is often qualified as the potential for the embryo to become a baby, or child, or person, endows the embryo with moral status equal to that accorded to these states, by virtue of having this potential.

## 4.3 CHILDREN, FAMILIES AND RELATIONSHIPS

Other considerations that arise in public discussion of reproductive technologies such as PGD concern the desires of parents for their children. This is a source of some of the greatest controversy surrounding PGD, which is often criticised for allowing parents to choose the attributes of their children – the so called 'designer babies'. Some conceptual confusion exists about what is meant by this term. It is sometimes taken to mean choosing a child based on frivolous or complex characteristics, such as eye and hair colour in the former case, or intelligence and musical ability in the latter. This criticism is often dismissed as naīvely optimistic about the current and future potential of genetic science to test for genetic traits. However, a designer baby can also be considered to be the selection of an embryo based on any characteristic(s), such as the absence of a genetic disease. The only difference between these two examples is arguably the significance of the attribute being selected for; in both cases the children-to-be are selected in the same way, albeit potentially for different reasons.

Fear of losing the opportunity to select against the presence of serious disorders as a result of criticisms levelled at selection based on non-medical attributes has led carriers of genetic disease to call for strict regulation of the technology:

> *I think it's one of those things that's got to be taken out of the individual's decision-making process. I don't think an individual should be allowed to make that decision about the baby…. It's got to be a higher level because if – you know, like we've got a problem, that's why we're going through it. Unless there's a problem, a genetic problem, then – that's the only reason you should go through it! It should have nothing to do with, you know, whether folks are interested in how intelligent, or prefer a baby boy.*[238]

However, public opinion regarding PGD is generally favourable for traits that are considered of great significance, such as severe or fatal genetic disorders.[239,240,241,242,243,244,245,246,247,248] There is also a clear difference in public approval of this application of PGD over the testing for traits that are seen as non-medical, or less serious, which is generally thought to be unacceptable in these studies. Interestingly, even those members of the public who accord the embryo maximum moral status do not necessarily disagree with PGD to select for embryos free of serious genetic disease.[249]

The following quotes from members of the public illustrate the consideration that is given to the seriousness of the disease being tested for:

> *It's how you approach the word "choice" isn't it? This gives us the choice of healthy from unhealthy, as opposed to choosing, you know, a blonde or a brunette, or a boy or a girl. This is choice out of necessity. Not for any other reason. […] So, I don't think we have a choice really.*[250]
>
> *Female: I mean if we was to find out that we was carriers of something else, and we were just going to produce a child that would inevitably be disabled, or whatever, we wouldn't use PGD. You know, we see it as something that can… prevent children dying, basically, that's why we're using PGD.*
>
> *Male: And it's not even a case of um, I think with spinal muscular atrophy, it's not even a case of "Well they might die". They will! There's no question about it, they will!* [251]

These individuals express a sense of parental obligation to prevent the occurrence of suffering in their children, where this may be possible with PGD. This has been reflected in other research conducted in the US, with some members of the public expressing the opinion that: "You have a responsibility to bring a child into the world with a certain quality of life."[252]

That judgments of quality of life are difficult to decide upon was expressed by an English woman who lost her first child to spinal muscular atrophy at 11 months of age:

> *I find myself […] saying, "That's not what it's about!" There's nothing "designer" about having child that lives longer than 11 months…." …But I can understand that it is a very grey area. Because obviously … we've used PGD because we didn't want to have another child that was going to within 12 months. But, I mean, at what point do you draw the line. At a child that dies at 2 years, 5 years, 10 years, 20 years, 30 years? Where?... What conditions are we going to allow PGD to be used for?... I don't know where the line should be drawn.*[253]

The above quote demonstrates the difficulty in distinguishing between reasons which are considered important enough to warrant the use of PGD. Examples of this are testing for late-onset genetic diseases, and testing for diseases whose manifestation is more uncertain.[254] Another example is human leucocyte antigen (HLA) testing to select an embryo that will be able to provide tissue to improve the health of an existing sick sibling (so-called 'saviour siblings'). In this case the aim of selection is not solely or necessarily to create a child free of genetic disease, but to create a child that can provide benefits to another. Another contentious example is sex selection, which may have different motivations such as achieving a desired sex ratio within a family, or because of other preferences for specific sexes of children. This can be a particular concern in societies where a preference exists for a certain sex of child, such as China, India and Korea.[255,256] It is thought that a sex imbalance could occur as a result of PGD use for this purpose in susceptible countries, with negative consequences for population dynamics.[257]

However, the use of PGD to select for a child that is a HLA-match for a sibling with a serious disease is often viewed favourably by the public, as an instance of using PGD to remedy a serious genetic disorder: "I don't think anyone wants to see their child die… you'd do anything to save the child's life". [258] This could be an instance of individuals deciding that, under these circumstances (the saving of an existing child's life), they feel compelled to act in ways they nevertheless still judge to be unethical. A USA mother of a child with genetic disease stated "I think that there's a lot worse things than having a child to save another child" [259], which still doesn't mean the same thing as it being morally *right* to do so, although that may be her implication. However, it appears more likely to be a judgement that conceiving a 'saviour sibling' is not morally wrong in this situation, which is reflected in the majority approval of this use of PGD in countries such as the USA.[260]

There is evidence that individuals also take into account their own interests, and those of others affected by their decision about what child to conceive. What follows is a metaphorical description of life caring for a child with a serious genetic disease, which emphasises the desperation of the situation for the care-givers:

> *There's water gushing in your boat, you're sinking, you have a bucket. And you just keep taking the bucket and you throw water [out] to keep from sinking and there's no break. It's seven days a week, 24 hours a day. You don't get a vacation. That's it. You are stuck in this boat in the middle of the ocean with a hole in it with a bucket. And that is what life is like raising a boy with [cystic fibrosis].*[261]

Other individuals undergoing PGD describe the network of people who they expect to be affected by the results of their decision, indicating a broad sphere of consideration in some deliberation about reproductive decisions:

> *We are very, very open – really open about it, and it's just every decision we take is primarily for ourselves, but it affects everyone as well, all our friends, our families. Every decision we make is indirectly going to affect somebody else, and I think that's where a lot of people don't seem to get [PGD and] … IVF.*[262]

However these considerations can also lead to fears that choices can be made for more frivolous self-regarding reasons. As two individuals from the USA stated, 'We always want the best for our children. But we always want the best children, too.'[263] An unacceptable example of this was identified by a patient undergoing PGD:

> *I think if parents are doing it for selfish reasons – like if they want to have the best-looking kids on the block – I think there should be a line drawn there. That's for the vanity of the parents… [If] I want the tallest kids because I want my kid to be a basketball player – that, I think, is over the bounds.*[264]

## 4.4 FREEDOM OF CONTROL OVER REPRODUCTIVE DECISIONS

The preceding discussion explored some notions regarding acceptable and unacceptable uses of PGD, and introduced the idea of some uses being restricted or prohibited. These two issues are linked by the stance taken on reproductive liberty and related issues. For example, an individual may judge a certain use of a reproductive technology such as PGD to be unacceptable – they may prefer it not to occur. However, the same individual and/or others may also have a commitment to protecting reproductive liberty, autonomy and privacy. Given that these two values refer to the same area of activity, and appear to be in conflict in some situations, there will need to be some negotiation between them if an individual or the public is committed to both. This tension is illustrated in the following quotes:

> *We have to depend on people's morality to draw their own lines. We cannot legislate it… We can't legislate any of this stuff.*[265]
>
> *Why would you want someone else involved… what about your privacy? You have to have the permission of the government to do what you want with your sperm and egg?*[266]
>
> *I am very uncomfortable with [using reproductive genetic testing to avoid] obesity, depression, those types of things. That is too big of a decision to give those parents, I mean, to say this child can't exist because of these things or those things.*[267]
>
> *I say yes if it all leads to eradicating horrifying diseases, and not wanting to pick their perfect little baby – whether it be a boy or a girl, blonde and blue-eyed.*[268]

Within the public there is a competition between these two attitudes, which are often diametrically opposed in terms of their normative implications. For example, in one survey of the USA public, 67% of respondents agreed with the proposition that the consequences of undertaking PGD were so personal that individuals should be allowed to decide for themselves, with the remainder disagreeing.[269] Expressing a similar sentiment, in the same survey 70% of respondents were concerned about government regulators invading private reproductive decisions.[270] However, in the same group of respondents 84% were concerned about unregulated reproductive technology getting out of control, with only 16% being unconcerned.[271] Making policy decisions in such a situation of ethical grid-lock was discussed in Section 3 of this Chapter.

## An exploration of public perceptions and opinions relating to PGD

### Public opinion and perceptions relating to PGD

The views of the public regarding PGD generally converge on certain issues as being morally significant, and important to consider. It is thought that PGD has the potential to affect aspects of human life such as conception, the embryo, the foetus, and the nature of pregnancy. The introduction of technology into these aspects of life can dramatically alter the nature of it. For example, conception using PGD bares little resemblance to traditional methods. A pregnancy with knowledge of the absence of a genetic disorder in the foetus is also substantially different for those involved. The way we consider and relate to children, and the relationships within a family and in wider society are also considered to be affected by PGD. Discussion often centres on whether a child born through PGD is experiencing a conditional form of acceptance into a family or society, and what impact the use of this technology might have on children, parents, and society. Another strong theme in public views and perceptions is the importance of individual reproductive decisions. This includes whether or not decisions to use PGD should be unrestricted and private, and how much influence others should have on individual reproductive decisions. There is considerable disagreement among the public about the effect of PGD on these issues, and whether such effects might render the technology acceptable or unacceptable.

## 5 CONCLUSION

Thorough knowledge and consideration of public opinions and attitudes to issues relating to PGD are important components of any robust moral reasoning on the subject. Any deliberation that does not account for the 'real-world' in which technologies such as PGD will, and do exist, can have undesirable and unpredictable consequences. These include lack of public acceptance which renders policy ineffective or difficult to implement, or unintended social consequences, such as stigmatisation or poorer regard for individuals with genetic disorders or at-risk parents who eschew PGD. Perhaps the best way to gain an awareness of these factors is through conducting empirical research into the attitudes, perceptions and opinions of the public regarding technologies such as PGD. Research from overseas can provide a great deal of this information. However, several characteristics of New Zealand suggest that the New Zealand public may differ from those overseas in pertinent ways. These include the presence of many cultures in a relatively small population, and particularly the bicultural emphasis on Māori and Pākehā in New Zealand society. All of these public groups may have views which differ from those examined overseas. The particular combination of attributes that PGD possesses make it different from other technologies introduced to New Zealand, and make it unwise to infer public perceptions and attitudes from extant research relating to other technologies, such as genetic modification. Conducting robust empirical social research into specific technologies such as PGD in New Zealand is therefore recommended in order to usefully inform ethical deliberation and the formulation of public policy.

In general, however, the public has sophisticated concerns about technologies which are implemented in the sphere of human reproduction. Some of these appear to be in conflict, which makes the formulation of public policy difficult, particularly if there are compelling reasons to formulate policy in spite of unresolved conflict. Different members of the public can have vastly different opinions about the proper uses of a technology such as PGD, and these are not necessarily accounted for by the categories which the members of the public fall into (such as disabled or non-disabled, male or female, etc.). Two, often heavily weighted considerations in the mind of the public, seem to be the relief or prevention of suffering and the related notion of improving well-being, and the autonomy of decision-making (particularly in the sphere of reproduction). Even in isolation from all the other factors that affect the public's moral deliberation, these two factors are not straight-forwardly compatible. Ethical reasoning that takes into account all of the morally relevant facets of a technology such as PGD is therefore massively complex and simple answers are not easily forthcoming. However, this should encourage, rather than discourage, open, wide-ranging, patient and rigorous academic, political and public debate about these issues.

## ACKNOWLEDGMENTS

This section of the report is written by Mike King, PhD. Mike would like to thank the researchers on this project for their support and many stimulating discussions, and particularly Professor Don Evans for valuable comments and feedback.

# ENDNOTES

1 *Advisory Committee on Health Research, World Health Organisation, Genomics and World Health (2002) at p. 11.*

2 *Ibid, at p. 2.*

3 *Outlined more fully in Wensley, D; Acceptable Limits of Reproductive Genetics: A Discussion of Ethical Principles and Regulatory Mechanism of Control (August 2004). A report prepared for the Law Foundation of New Zealand.*

4 *In 2000, the International Working Group on Preimplantation conducted an investigation into PGD, reporting that more than 25000 cycles had been performed worldwide, with 600 pregnancies resulting. These pregnancies resulted in nearly 500 births, with only seven misdiagnoses reported. (International Working Group on Preimplantation, '10th Anniversary of Preimplantation Genetic Diagnosis' (2001)18 Journal of Assisted Reproduction and Genetics 66-72.*

5 *International Bioethics Committee of UNESCO, Report of the IBC on Pre-implantation Genetic Diagnosis and Germ-line Intervention (2003). The position in the UK is outlined in Human Genetics Commission, Choosing the Future: Genetics and Reproductive Decision Making (July 2004).*

6 *International Bioethics Committee of UNESCO, Report of the IBC on Pre-implantation Genetic Diagnosis and Germ-line Intervention (2003).*

7 *See discussion in report prepared by the Working party on the Protection of the Human Embryo and Fetus (CDBI-CO GT3) for the Steering Committee on Bioethics, The Protection of the Human Embryo In Vitro (June 2003) at p. 14.*

8 *Id.*

9 *Robertson, J, 'Extending Preimplantation Genetic Diagnosis: Medical and Non-medical Uses' (2003) 2 J Med Ethics 213-216.*

10 *Id.*

11 *See concerns expressed in the following reports; Human Fertilisation and Embryology Authority and Advisory Committee in Genetic Testing, Consultation Document on Preimplantation Genetic Diagnosis (November 1999) and President's Council of Bioethics, Reproduction and Responsibility: The Regulation of New Biotechnologies (Washington, D.C: 2004).*

12 *House of Commons Science and Technology Committee Human Reproductive Technologies and the Law (Fifth Report of Session 2004-05, volume one), at p 22.*

13 *'Sex selection and preimplantation genetic diagnosis', Fertility and Sterility, Vol 72, No 4, October 1999 595-598, at p. 596.*

14 *The President's Council on Bioethics, Beyond Therapy: Biotechnology and the Pursuit of Happiness, Washington. D.C, October, 2003, at p. 47.*

15 *Id.*

16 *Ibid, at p. 32.*

17 *Ibid, at p. 35.*

18 *Based on a helpful discussion of this issue in The President's Council on Bioethics, Beyond Therapy: Biotechnology and the Pursuit of Happiness, Washington D.C, October, 2003, 68.*

19 *President's Council on Bioethics, Human Cloning and Human Dignity: An Ethical Enquiry (July, 2002) at p. 7.*

20 *President's Council on Bioethics, Human Cloning and Human Dignity: An Ethical Enquiry (July, 2002) at pp 100 – 101.*

21 *The President's Council of Bioethics justifies this distinction by arguing that: 'While current negative screening is guided by the standard of a healthy or disease-free baby, the goals of prospective positive use are in theory unlimited, governed only by the parents' ideas of what they want in their child. Today, parents using PGD take responsibility for selecting for birth children who will not be chronically sick or severely disabled; in the future, they may also bear responsibility for picking and choosing which 'advantages' their children shall enjoy. Such an enlarged degree of parental control over the genetic endowments of their children cannot fail to alter the parent-child relationship. Selecting against disease merely relieves the parents of the fear of specific ailments afflicting their child; selecting for desired traits inevitably plants specific hopes and expectations about how their child might excel.' President's Council on Bioethics op cit, at, p 53.*

22 *Id.*

23 *See discussion in the Human Genetics Commission, Making Babies: Reproductive Decisions and Genetic Technologies (January 2006) at pp 23-24.*

24 *Heyd, D; Moral Issues in the Creation of People University of California Press, 1994 at p 22.*

25 *See Kavka, G; 'The Paradox of Future Individuals' Philosophy and Public Affairs (1981) 11 at p 100 and discussion in Roberts, M; 'Present Duties and Future Persons: When are Existence-Inducing Acts Wrong?' Law and Philosophy (1995) 14 p 297 at p. 327.*

26 *The arguments are outlined more fully in Wensley, D; Acceptable Limits of Reproductive Genetics: A Discussion of Ethical Principles and Regulatory Mechanism of Control (August 2004). A report prepared for the Law Foundation of New Zealand.*

27 *Public opinion on eugenics and its possible links to genetic technology is reviewed more thoroughly in Wensley, D; 'The Eugenic Implications of Genetic Screening' PhD Thesis, Centre of Medical Law and Ethics, King's College London (2006).*

28 *Human Genetics Commission, Debating the Ethical Future of Human Genetics, First Annual Report of the Human Genetics Commission (2001) Annex D: Report from Newcastle at p 36.*

29 *Human Genetics Commission, Debating the Ethical Future of Human Genetics, First Annual Report of the Human Genetics Commission (2001) Annex D: Report from Newcastle at p 36.*

30 *See, for example, McCarthy, D., 'Why sex selection should be legal', J. Med Ethics 2001;27:302-307*

31 *Id.*

32 *Human Genetics Commission, Choosing the Future: Genetics and Reproductive Decision Making (July 2004) at p 5.*

33 *An in depth analysis of the Nazi euthanasia programme, and others that have occurred through history is contained in Wensley, D; 'The Eugenic Implications of Genetic Screening' PhD Thesis, Centre of Medical Law and Ethics, King's College London (2006).*

34 *See Human Genetics Commission, Public Attitudes to Human Genetic Information (2001) at p 17 and p. 50.*

35 *Genetics and Public Policy Centre, The Genetic Town Hall: Making Every Vote Count (2004) at p 17 and p. 48.*

36 *House of Commons Science and Technology Committee, Human Reproductive Technologies and the Law (2005) at p 54.*

37 *Ibid, at p 55.*

38 *Id.*

39 *Human Genetics Commission, Making Babies: Reproductive Decisions and Genetic Technologies (January 2006) at p 53.*

40 *Ibid, at p 84.*

41 *Ibid, at p 84.*

42 *Based on a helpful review of the disability rights argument of genetics contained in Wensley, D; 'The Eugenic Implications of Genetic Screening' PhD Thesis, Centre of Medical Law and Ethics, King's College London (2006).*

43 *Parens, E and Asch, A; 'The Disability Rights Critique of Prenatal Genetic Testing' in Parens, E and Asch, A (eds) Prenatal Testing and Disability Rights, Washington D.C., Georgetown University Press, 2000, at p. 13.*

44 *Id.*

45 *Saxton, M, 'Disability Rights and Selective Abortion' in Solinger, R (ed) Abortion Wars: A Half Century of Struggle, 1950-2000 Berkley and Los Angeles: University of California Press, 1997, at p 391 cited in Parens, E and Asch, A; 'The Disability Rights Critique of Prenatal Genetic Testing' in Parens, E and Asch, A (eds) Prenatal Testing and Disability Rights Washington, D.C Georgetown University Press, 2000, at p 14.*

46 *These views are discussed in Shakespeare, T; 'Rights, Risks and Responsibilities: New Genetics and Disabled People' in Williams S, Birke L, and Bendelow G (eds); Debating Biology: Social Reflections on Health, Medicine, and Society London, Routledge 2003 198-209, at p 203.*

47 *Jennings, B; 'Technology and the Genetic Imaginary: Prenatal Testing and the Construction of Disability' in Parens, E and Asch, A (eds) Prenatal Testing and Disability Rights, Washington, D.C. Georgetown University Press, 2000 124-144, at p 134.*

48 *Saxton, M; 'Why Members of the Disability Community Oppose Prenatal Diagnosis and Selective Abortion' in Parens, E and Asch, A, op cit, at p. 148.*

49 *Kallianes, V and Rubenfeld, P; 'Disabled Women and Reproductive Rights', Disability and Society (1997) Vol. 12, No. 2, 203-221*

50 *Ibid, at p 204.*

51 *Ibid, at p 205.*

52 *Ibid, at p 205.*

53 *See Hyler, D; 'To choose a child' in Browne, S.E. et al (eds) With the Power of Each Breath: a disabled women's anthology, San Francisco, Cleis Press, 1985, discussed in Kallianes, V and Rubenfeld, P, loc cit, at p 205.*

54 *Kent, D; 'Somewhere a Mockingbird' in Parens, E and Asch, A, op cit.*

55 *She reports the relief she felt when the specialist said: 'You have a good life, don't you?…If you have a child with Leber's, it can have a good life, too. Go home and have a dozen kids if you want to!'*

56 *DPI Europe Position Statement on Bioethics and Human Rights: 'Disabled People Speak on the New Genetics' available online www.dpieurope.org (accessed 16 January 2004.) at p 4.*

57 *Ibid, at p 3.*

58 *Ibid, at p 4.*

59 *Parens, E and Asch, A; 'The Disability Rights Critique of Prenatal Genetic Testing' in Parens, E and Asch, A op cit, at p 17.*

60 *Id.*

61 *Parens, E and Asch, A; 'The Disability Rights Critique of Prenatal Genetic Testing' in Parens, E and Asch, A op cit, at p 18.*

62 *The President's Council on Bioethics, Reproduction and Responsibility: The Regulation of New Biotechnologies, Washington D.C: 2004, at p 98.*

63 *Hurst, R; 'Ethics and Disability, Celebrating Diversity', paper presented to the 5th World Congress on Bioethics (2000), cited in Campbell, J; 'Valuing Diversity: the Disability Agenda- We've Only Just Begun', Disability and Society (2002) Vol. 17, No. 4, pp 471-478, at p 474.*

64 The International Sub-Committee of the British Council of Disabled People; The New Genetics and Disabled People : Official Position Statement (February 2000) Available on the internet at http://www.bcodp.org.uk/about/genetics.shtml (accessed 26 September 2004).

65 Shakespeare, T; 'Rights, Risks and Responsibilities: New Genetics and Disabled People' in Williams S, Birke L, and Bendelow G (eds); Debating Biology: Social Reflections on Health, Medicine, and Society, London, Routledge, 2003, 198-209, at p 207.

66 See Shakespeare, T; 'Rights, Risks and Responsibilities: New Genetics and Disabled People' in Williams S, Birke L, and Bendelow G, op cit, at p 202.

67 Ibid, at p 207.

68 Ibid, at p 206.

69 Id.

70 See discussion of the principle of reproductive autonomy and its relationship to genetic technologies in Human Genetics Commission, Making Babies: Reproductive Decisions and Genetic Technologies (January 2006).

71 A helpful discussion of some of these, particularly the enforced sterilisations of mentally disabled persons, is contained in McLean, S; Old Law, New Medicine London, Pandora, 1999.

72 Making Babies, supra cit, at p. 19, para 1.5

73 Colquhoun, G., Playing God, (New Zealand), Steele Roberts, 2002 at p93.

74 A survey of over two thousand New Zealanders, undertaken in the early 1990s, revealed that opposition to the concept of genetic manipulation increased from plants (15%) to microbes (29%) to animals (44%) to humans (58%). Concerns about 'interfering with nature' were identified as a significant concern for those that considered such manipulation unacceptable. See Macer, D., Bezar, H., and Gough, J., Genetic Engineering in New Zealand: Science, Ethics and Public Policy (Information Paper No 27, Centre for Resource Management, Lincoln University, 1991) cited in Hughson, Rev G., 'Theogenethics and the Integrity of Creation' (1993) 2 Methodist Theological Review 12.

75 Mohler, R.A., 'The Brave New World of Cloning: A Christian Worldview Perspective' http://www.mercola.com/2001/mar/10/cloning.htm. (accessed on 6 October 2005).

76 Id.

77 Grey, W., 'Playing God' (1998) The Concise Encyclopedia of the Ethics of New Technologies, Academic Press, at p 336.

78 Instruction on Respect for Human Life in its Origin and on the Dignity of Procreation: Replies to Certain Questions of the Day Statement from the Congregation for the Doctrine of the Faith, 22 February 1987 available at http://www.vatican.va/roman_curia/congregations/cfaith/documents/rc_con_cfaith_doc_19870222_respect-for-human-life_en.html ( accessed on 10 October 2005).

79 Pope John Paul II Discourse to the Participants in the 35th General Assembly of the World Medical Association (29 October 1983: AAS 76 (1984) 392).

80 Instruction on Respect for Human Life in its Origin and on the Dignity of Procreation: Replies to Certain Questions of the Day Statement from the Congregation for the Doctrine of the Faith, 22 February 1987 (http://www.vatican.va/roman_curia/congregations/cfaith/documents/rc_con_cfaith_doc_19870222_respect-for-human-life_en.html on 10 October 2005).

81 Id.

82 Peters, T., 'Designer Children: The Market World of Reproductive Choice' 111:36 Christian Century 1193.

83 Ramsey, P., Ethics at the Edges of Life: Medicine and Legal Intersections, New Haven, Yale University Press, 1978, at p 205.

84 Peters, T., ''Playing God' and Germline Intervention' (1995) 20 The Journal of Medicine and Philosophy 365.

85 National Bioethics Advisory Commission Cloning Human Beings: Report and Recommendations of the National Bioethics Advisory Commission, Rockville, Maryland, June 1997, at p 46.

86 Id.

87 Verhey, A., ''Playing God' and Invoking a Perspective' (1995) 20 The Journal of Medicine and Philosophy 347 at p. 360.

88 Peters, T., ''Playing God' and Germline Intervention' (1995) 20 The Journal of Medicine and Philosophy 365 at p. 376.

89 Id.

90 Cohen, J., 'Playing God' http://reformjudaismmag.net/998jc.html. (accessed on 6 October 2005)

91 To illustrate this point, Cohen refers to a teaching of Baal Shem Tov that there are two types of fruit in the world: fruit that grows in vineyards, and fruit that grows in the wild. Vineyard-grown fruit is usually large, shapely, tasty, and consistent. Fruit grown in the wild tends to be blemished, but is often sweet and flavourful. When asked how to these two types of fruit compare, the answer is that both are pleasing in God's eyes. Cohen, J., 'Playing God' http://reformjudaismmag.net/998jc.html. (accessed on 6 October 2005)

92 Ryan, M., 'The New Reproductive Technologies: Defying God's Dominion?' (1995) 20 The Journal of Medicine and Philosophy 419 at p. 430.

93 For example, Jesus healed the blind man (Mark 10:46-52; John 9:1-41; and Mark 8:22-26), Jesus healed the paralysed man (Mark 2: 5-12; and John 5:6), and Jesus healed the leper (Mark 1: 40-45; Matthew 8:1-4; and Luke 5: 12-16).

94 World Council of Churches Manipulating Life: Ethical Issues in Genetic Engineering (Geneva, 1982).

95 Verhey, A.,"Playing God' and Invoking a Perspective' (1995) 20 The Journal of Medicine and Philosophy 347 at p. 353.

96 Ibid, at p. 361.

97 Cahill, L., "Playing God': Religious Symbols in Public Places' (1995) 20 The Journal of Medicine and Philosophy 341 at p. 343, summarizing the argument of Verhey, A., "Playing God' and Invoking a Perspective' (1995) 20 The Journal of Medicine and Philosophy 347.

98 Peters, T., "Playing God' and Germline Intervention' (1995) 20 The Journal of Medicine and Philosophy 365 at p. 368.

99 McGee, G., The Perfect Baby: Parenthood in the New World of Cloning and Genetics, Rowman & Littlefield Publishers Inc, 2002, at p. 56.

100 Grey, W., 'Playing God' (1998) The Concise Encyclopedia of the Ethics of New Technologies, Academic Press, at p. 336.

101 Ryan, M., 'The New Reproductive Technologies: Defying God's Dominion?' (1995) 20 The Journal of Medicine and Philosophy 419 at p. 422.

102 McGee, op cit, at p. 57.

103 http://genetics.nbii.gov/GeneticDiversity.html (accessed on 21 October 2005).

104 Harris, J., Wonderwoman and Superman: The Ethics of Human Biotechnology, New York, Oxford University Press, 1992, at p. 172.

105 Suzuki D., and Knutdson, P., Genethics, London, Unwin Hyman, 1989, at p. 346.

106 Harris, J., Wonderwoman and Superman: The Ethics of Human Biotechnology, New York, Oxford University Press, 1992 at p. 165.

107 Grey, W., 'Playing God' (1998) The Concise Encyclopedia of the Ethics of New Technologies, Academic Press, 336 at p. 338.

108 Harris, J., Wonderwoman and Superman: The Ethics of Human Biotechnology, New York: Oxford University Press, 1992, at p. 172.

109 McGee, G., The Perfect Baby: Parenthood in the New World of Cloning and Genetics, Rowman & Littlefield Publishers Inc, 2002, at p. 51.

110 Ryan, M., 'The New Reproductive Technologies: Defying God's Dominion?' (1995) 20 The Journal of Medicine and Philosophy 419 at p. 422.

111 Bagaric, M., 'Eugenics – so what's wrong with Improving the Quality of the Human Species?' (2001) 20:2 Monash Bioethics Review 11 at p. 23.

112 Bagaric, M., 'Eugenics – so what's wrong with Improving the Quality of the Human Species?' (2001) 20:2 Monash Bioethics Review 11 at p. 21.

113 Ryan, M., 'The New Reproductive Technologies: Defying God's Dominion?' (1995) 20 The Journal of Medicine and Philosophy 419 at p. 427.

114 Grey, W., 'Playing God' (1998) The Concise Encyclopedia of the Ethics of New Technologies, Academic Press, at p. 336.

115 Ibid, at p. 352.

116 Id.

117 Clark, T., 'Playing God, Carefully' May/June 2000 The Humanist 37 at p. 38.

118 Id.

119 Id.

120 Id.

121 President's Commission for the Study of Ethical Problems in Medicine and Biomedical and Behavioural Research Splicing Life: A Report on the Social and Ethical Issues of Genetic Engineering with Human Beings, Washington DC: US Government Printing Office, 1982, cited in: Verhey, A., "Playing God' and Invoking a Perspective' (1995) 20 The Journal of Medicine and Philosophy 347 at pp. 348-9.

122 Verhey, loc cit, at p. 353.

123 Ryan, M., 'The New Reproductive Technologies: Defying God's Dominion?' (1995) 20 The Journal of Medicine and Philosophy 419.

124 Ibid, at p. 421.

125 Ibid,, at p. 436.

126 The Interchurch Commission on Genetic Engineering: 'Interested Person Submission' to the Royal Commission on Genetic Modification (New Zealand, 2000-2002) Available at: http://www.casi.org.nz/ge.

127 Ryan, loc cit, at p. 435.

128 Verhey, A., "Playing God' and Invoking a Perspective' (1995) 20 The Journal of Medicine and Philosophy 347 at p. 348.

129 See the submission on NECAHR's draft Guidelines on PGD from the New Zealand Catholic Bioethics Centre. The corollary of this argument is that IVF should also be prohibited, or limited such as it was recently in Italy (see: Legge 19 Febbraio 2004 n 40 'Norme in Materia di Procreazione Medicalmente Assistita'. The Italian law bans the testing of embryos for research and experimental purposes, freezing embryos or embryo suppression, and PGD. It also prohibits donor insemination, limits fertility treatment to stable heterosexual couples, and states that no more than three cells

*may be fertilized in vitro and that all three cells must be transferred into the womb simultaneously). For an argument for prohibiting IVF see: Spoerl, J., 'Making Laws on Making Babies: Ethics, Public Policy, and Reproductive Technology' (2000) 45 American Journal of Jurisprudence 93. For an argument for limiting IVF in a way that protects the moral status of the embryo see: Dickman, D., 'Social Values in a Brave New World: Toward a Public Policy Regarding Embryo Status and In Vitro Fertilisation' (1984-1985) 29 Saint Louis University Law Journal 817.*

130 *Robertson, J., 'Procreative Liberty in the Era of Genomics' (2003) 29:4 American Journal of Law and Medicine 439.*

131 *The Warnock Report (which preceded the Human Fertilisation and Embryology Act 1990) considered that it was inappropriate to endow the embryo with the full panoply of human rights, but also felt that it was inappropriate to consider it as nothing more than a ball of cells. Instead, the report concluded that the embryo should be afforded some protection in law. A recent review of the law on human reproductive technologies by the House of Commons concluded that the approach adopted in the Warnock report provided a firm foundation for legislation, and represents the most ethically sound and pragmatic solution – it recognizes the special status of embryos whilst allowing IVF and embryo research to proceed within certain constraints thereby also respecting the legitimate interests of intending parents and the wider society. However, the House of Commons recommended that the specified stage (currently 14 days) should be capable of amendment by Parliament as reproductive technology advances (see: House of Commons Science and Technology Committee Human Reproductive Technologies and the Law (Fifth Report of Session 2004-05, volume one).*

132 *The section 'Rights-based arguments' is largely informed by Davidson, H., 'Embryonic Stem Cell Research: An examination of issues surrounding the regulation of embryonic stem cell research in New Zealand' (A Dissertation submitted in partial fulfillment of the requirements of the degree of Master of Bioethics and Health Law: University of Otago, Dunedin, New Zealand, 15 October 2003).*

133 *For a discussion about the facts of biological development see: Grobstein, C., 'Fetus: Human Development from Fertilisation to Birth' (1995) Encyclopedia of Bioethics 847.*

134 *Werpehowski, loc cit.*

135 *Wertheimer, R., 'Understanding the Abortion Argument' (1971) 1:1 Philosophy and Public Affairs 67 at p. 74.*

136 *Although some extreme liberals contend that moral significance does not attach to the human entity until birth or just after birth, many do not advocate that this therefore means that it is permissible to destroy the pre-born entity at any time up until birth. This is evidence of a logical inconsistency in the basis of some extreme liberal analysis.*

137 *See: Goodman, M.F., (ed.) What is a Person?, Clifton NJ, Humana Press, 1988; King, P.A., 'The Judicial Status of the Fetus: A Proposal for Legal Protection of the Unborn' (1979) Michigan Law Review 77; Strong, C., and Anderson, G., 'The Moral Status of the Near-Term Fetus' (1989) 15:1 Journal of Medical Ethics 25-27.*

138 *Goodman, ibid., for a discussion of different moderate views, including Baroch Brody, who argues that once brain activity is initiated (at about six weeks gestation), the human foetus has a full set of rights because brain activity is 'the essence of humanity'. A recent US study, undertaken at the University of California, defines pain as 'a subjective sensory and emotional experience that requires the presence of consciousness to permit recognition of a stimulus as unpleasant', and suggests that vital brain connections relating to pain perception form only between 23 to 30 weeks gestation, and even if formed, are unlikely to be functional until 30 weeks gestation. Prior to that time fetuses may show some withdrawal reflexes and 'facial movements similar to those of adults experiencing pain', but those movements may not necessarily be controlled by the cortical area of the brain. (http://www.newscientist.com/article.ns?id=dn7900 published on 24 August 2005 (accessed on 26 August 2005.)*

139 *Werpehowski, W., 'Persons, Practices, and the Conception Argument' (1997) 22:5 The Journal of Medicine and Philosophy 479 at p. 482. For detail on the individuation argument see: Evans, D., 'Pro-attitudes to Pre-embryos' in Evans, D., (ed.) Conceiving the Embryo, Netherlands, Kluwer Law International, 1996; Evans, M., 'Human Individuation and Moral Justification in Evans, D., (ed.) Conceiving the Embryo, Netherlands: Kluwer Law International, 1996; Ford, N.M., When Did I Begin? Concept of the Human Individual in History, Philosophy, and Science, Cambridge, University Press, 1988; McCormick, R.A., 'Who or What is the Pre-embryo?' (1991) 1 Kennedy Institute of Ethics Journal 1-16; Shannon, T., and Wolter, A., 'Reflections on the Moral Status of the Pre-embryo' (1990) 51 Theological Studies 603-626; Parker, J., 'Individuality, Personal Identity, and the Moral Status of the Pre-embryo: A response to Mark Johnson' (1995) 56 Theological Studies 763-770.*

140 *'Restriction' occurs when the 'primitive streak' appears in the pre-embryo, at approximately 14 days post fertilisation. A further biological fact in support of this view is that until restriction, the pre-embryo also retains the (rare) possibility of 'fusion', in which the cells of two or more different genotypes combine to form one embryo.*

141 *Johnson, M., 'Delayed Humanization' (1995) 56 Theological Studies 743.*

142 *Parker, J., 'Individuality, Personal Identity, and the Moral Status of the Pre-embryo: A Response to Mark Johnson' (1995) 56 Theological Studies 763 at p. 768.*

143 *Robertson, J., 'Procreative Liberty in the Era of Genomics' (2003) 29:4 American Journal of Law and Medicine 439.*

144 *Grobstein, C., 'Fetus: Human Development from Fertilisation to Birth' Encyclopedia of Bioethics (1995) 847 at p. 850.*

145 *McCormick, R.A., 'Who or What is the Pre-embryo?' (1991) 1 Kennedy Institute of Ethics Journal 1-16. The potentiality argument is strongly advocated by Noonan, J., 'How to Argue about Abortion' in: Beauchamp, T., and Walters, L., (eds.) Contemporary Issues in Bioethics, California, Dickenson Publishing Company, 1978. Also see the arguments of Brian Johnson in Walters, W., and Singer, P., Test-Tube Babies: A Guide to Moral Questions, Present Techniques and Future Possibilities, New York: Oxford University Press, 1982, who supports the potentiality argument by distinguishing between three uses of the term 'potential'.*

146 *Mahowald, M., 'Fetus: Philosophical and Ethical Issues' Encyclopaedia of Bioethics (1995) 854 uses arguments from Hare, Kuhse and Singer to suggest that a moral issue would be unlikely to arise if ova and sperm obtained for IVF were flushed separately down the sink. However, those who advocate the potentiality principle would logically need to accept that if there was a blockage in the sink that caused the gametes, disposed separately, to fuse, the embryo created would have moral status that would make it wrong to destroy it. The blockage would need to be cleared, and the fertilised ova rescued and kept alive by all efforts.*

147 *Wertheimer, R., 'Understanding the Abortion Argument' (1971) 1:1 Philosophy and Public Affairs 67 at p. 79.*

148 *Buckle, S., 'Arguing from potential' (1998) 2 Bioethics 227-253.*

149 *Ibid at p. 237.*

150 *This argument is advocated by Peter Singer.*

151 *Kass, L., 'Ethical Issues in Human In Vitro fertilization, Embryo Culture and Research, and Embryo Transfer' in Ethics Advisory Board, Department of Health, Education and Welfare, Appendix: New Support of Research Involving Human In Vitro Fertilisation and Embryo Transfer, Washington D.C, US Government Printing Office, 1979 pp. 6-8, cited in: Szawarski, Z., 'Talking About Embryos' in: Evans, D., (ed.) Conceiving the Embryo, Netherlands, Kluwer Law International, 1996, at p. 119.*

152 *Savulescu, J., 'The Embryonic Stem Cell Lottery and the Cannibalization of Human Beings' (2002) 16:6 Bioethics 508-529.*

153 *Meilaender, G., 'The Point of a Ban' (2001) January-February Hastings Center Report 9-16 at p. 12.*

154 *Robertson, J., 'Symbolic Issues in Embryo Research' (1995) 25:1 Hastings Centre Report 37.*

155 *Robertson, J., 'Ethics and Policy in Embryonic Stem Cell Research' (1999) 9:2 Kennedy Institute of Ethics Journal 109-36 at p.127.*

156 *McGee, G., and Caplan, A., 'The Ethics and Politics of Small Sacrifices in Stem Cell Research' (1999) 9:2 Kennedy Institute of Ethics Journal 151-158 at p. 153.*

157 *Id.*

158 *As is evident in the preceding section, consequentialist arguments are often used to rebut deontological perspectives about the moral status of the embryo and what is or is not permissible to do to an embryo.*

159 *As noted in Beauchamp, T., and Walters, L., (eds.) Contemporary Issues in Bioethics, Wadsworth Publishing Company, 1999, pp. 10-13, it is in this respect that utilitarianism stands in sharp contrast to egoism because egoism proposes maximizing consequences for oneself, rather than for all parties affected by the action. 'In seeking a blinded impartiality, utilitarianism aligns good and mature moral judgment with moral distance from the choices to be made.' The types of consequences that need to be considered when assessing the limits of PGD in New Zealand were discussed by the New Zealand Catholic Bioethics Centre in its submission on NECAHR's draft Guidelines on PGD. The Centre pointed 'to the need for New Zealanders to use their moral imaginations and to consider the implications of PGD beyond the obvious and immediate consequences of using or not using it', and argued that, 'consideration of the broader effects must include, but also go beyond, the need to deal with the pragmatic issues of genetic disability/illness and infertility faced by particular couples contemplating having children. It will also draw on and reflect upon the various perspectives about human life offered by different cultures, in particular, Māori culture.'*

160 *Glannon, W., 'Genes, Embryos, and Future People' (1998) 12:3 Bioethics 187-211 at p. 191.*

161 *Buckle, S., 'Arguing from Potential' in: Singer, P., et al. (eds.) Embryo Experimentation: Ethical, Legal and Social Issues, Canada, Cambridge University Press, 1990. Glannon also argues that persons can be harmed or wronged by what we do or fail to do to embryos even if embryos do not strictly speaking become persons (see: Glannon, W., 'Genes, Embryos, and Future People' (1998) 12:3 Bioethics 187-211).*

162 *Id.*

163 *Juengst, A., and Fossel, M., 'The Ethics of Embryonic Stem Cells – now and forever, cells without end' (2000) 284 Journal of the American Medical Association 3180-3184 at 3183.*

164 *Due to the expense of the technology, the widespread use of PGD could exacerbate existing societal inequalities and widen the gap between social classes, if some people have the means to select their embryos on the basis of a range of 'desirable' traits, while others do not.*

165 *Brownsword, R., 'Biotechnology and Rights: Where are we Coming From and Where are we Going?' in: Klang, M., and Murray, A., (eds.) Human Rights in the Digital Age, London, Glasshouse Press, 2005, 219-234 at p. 220.*

166 *In the report of the President's Council on Bioethics Beyond Therapy: Biotechnology and the Pursuit of Happiness (Washington D.C: October 2003), the Council expresses significant concern that the use of genetic technology in reproduction will ultimately change the nature of parenthood and the way we view children. The President's report is available on the Council's website: http://www.bioethics.gov.*

167 *President's Council on Bioethics Reproduction and Responsibility: The Regulation of New Biotechnologies (Washington D.C: March 2004). The President's report is available on the Council's website: http://www.bioethics.gov.*

168 *The brief discussion set out here is principally derived from material provided in two reports: The Use of Embryonic Stem Cells in Therapeutic Research, Report of the IBC on the Ethical Aspects of Human Embryonic Stem Cell Research, International Bioethics Committee (Rapporteurs: Alexander McCall Smith and Michel Revel), United Nations Educational, Scientific and Cultural Organisation (Paris: 6 April 2001), and Ethical Issues in Human Stem Cell Research, Volume I, Report and Recommendations of the National Bioethics Advisory Commission, National Bioethics Advisory Commission (Rockville, Maryland: September 1999).*

169 *The preceding question to this one is whether the law should be involved in such issues at all – a question about the relationship between law and morality, which is outside the brief of this paper (see: Hart, H.L.A., Law, Liberty and Morality, London, Oxford University Press, 1963; Mill, J.S., On Liberty, New York, W.W Norton & Company Inc., 1975; and Devlin, P., The Enforcement of Morals, London, Oxford University Press, 1965. The generally accepted position is that if one can establish an identifiable harm to society, then a ground for intervention by way of the law is established.*

170 *Hare, R.M., 'Embryo experimentation: public policy in a pluralist society' in Fulford, K., Gillett, G., and Soskice, J., (eds.) Medicine and Moral Reasoning, New York, Cambridge University Press, 1994, 29 at p. 38.*

171 *Robertson, J., 'Ethics and Policy in Embryonic Stem Cell Research' (1999) 9:2 Kennedy Institute of Ethics Journal 109-136 at p. 131.*

172 *Hare, R.M., 'Embryo experimentation: public policy in a pluralist society' in Fulford, Gillett and Soskice, op cit, 29.*

173 *Cited in House of Commons Science and Technology Committee, Human Reproductive Technologies and the Law (Fifth Report of Session 2004-05, Volume 1) recommendation 2, p21.*

174 *Thévoz, loc cit, at p. 53.*

175 *See House of Commons Science and Technology Committee, Human Reproductive Technologies and the Law (Fifth Report of Session 2004-05, Vol.1) recommendation 2.*

176 *Thévoz, loc cit, at pp. 52-53.*

177 *Robertson, J., 'Ethics and policy in Embryonic Stem Cell Research' (1999) 9:2 Kennedy Institute of Ethics Journal 109-136.*

178 *Meilaender, loc cit, at p. 9.*

179 *Cited in Dickman, D., 'Social Values in a Brave New World: Toward a Public Policy Regarding Embryo Status and In Vitro Fertilisation' (1984-1985) 29 Saint Louis University Law Journal 817 at 829.*

180 *The Contraception, Sterilisation and Abortion Act 1977 and the Crimes Act 1961 regulate abortion in New Zealand. Section 33 of the Contraception Sterilisation and Abortion Act makes abortion unlawful except in so far as any of the paragraphs of (a) to (d) of subsection (1), or subsection (3) of section 187A of the Crimes Act applies. In short, abortion is illegal except in the circumstances provided for in those Acts. For example, it is lawful to perform an abortion, up to 20 weeks gestation, where the continuance of the pregnancy would result in serious danger to the life, or to the physical or mental health, of the woman, or where there is a substantial risk that the child, if born, will be so physically or mentally abnormal as to be seriously handicapped. The matters that may be taken into account in determining whether the child will be seriously handicapped are not defined in either Act.*

181 *Screening for these conditions may only take place in the following circumstances: On single gene disorders where the disorder has been identified in the family/Whanau; there is a 25% or greater risk of an affected pregnancy; and there is evidence that the future individual may be seriously impaired as a result of the disorder; for familial sex-linked disorders the same limitations apply, with the added provision that there be no specific test for the particular mutation that causes the disorder; for familial chromosomal disorders where the disorder has been identified in the family and there is evidence that the future individual may be seriously impaired as a result of the disorder; for non-familial chromosomal disorders associated with advanced reproductive age where the woman is of an advanced reproductive age; for non-familial chromosomal disorders associated with fertility when the woman has had recurrent implantation failure or recurrent miscarriage. 'Serious disorder' is not defined in the Guidelines – the Guidelines note that it is the responsibility of providers in collaboration with a clinical geneticist to determine whether a disorder is likely to be serious in the offspring.*

182 *The New Zealand Government seems to have made a clear statement that, in so far as policy is concerned, in some circumstances it is permissible to abort a foetus or create and destroy/discard an embryo on the basis of its genetic make-up. The corollary of this is that, in law, the embryo is not a person and does not have a right to life equivalent to that of a child outside the womb.*

183 *Brooke, J.H., 'Commentary on: The Person, the Soul, and Genetic Engineering' (2004) 30 Journal of Medical Ethics 597.*

184 Polkinghorne, loc cit.
185 Hare, R.M., 'Embryo experimentation: public policy in a pluralist society' in [eds.] Medicine and Moral Reasoning at pp 29 – 40.
186 Id.
187 The Nathaniel Centre/New Zealand Catholic Bioethics Centre, Right to Life New Zealand Incorporated, and Voice for Life Incorporated, entered strong submissions against the draft National Ethics Committee on Assisted Human Reproduction's Guidelines on PGD, with particular reference to the moral status and rights of embryos.
188 These models of ethical deliberation are adapted from the recent paper of Simon Clarke (2005) 'Two Models of Ethics Committees' Journal of Bioethical Inquiry 2:41-47.
189 Royal Commission on Genetic Modification (2002) Report of the Royal Commission on Genetic Modification. Online at: http://www.mfe.govt.nz/publications/organisms/royal-commission-gm/index.html
190 Gerber, D.A. (1990) 'Listening to Disabled People' Disability, Handicap and Society 5: 3-23 at p. 4
191 Sartain, S.A., Clarke, C.L. and Heyman, R. (2000) 'Hearing the voices of children with chronic illness', Journal of Advanced Nursing 32: 913-921.
192 At p. 920
193 Id.
194 This also serves to illustrate the point made in the introduction that conceptual categories into which we may divide the public will not necessarily be isomorphic with their experiences, attitudes and opinions, but are often pragmatically useful in analysis nonetheless.
195 Rachels, J. 'Morality, Parents and Children' in Lafolette, H. (ed). Ethics in Practice, (2nd Ed), Oxford, Blackwell Publishing, 2002, pp. 167-177 at p. 174
196 Allport, F.H. (1937) 'Toward a Science of Public Opinion' Public Opinion Quarterly 1: 7-23.
197 Carter, G.L. Empirical Approaches to Sociology, (4th Ed). Boston, Pearson, 2004.
198 Edwards, J. (2002) 'Taking 'Public Understanding' Seriously' New Genetics and Society 21: 315-325.
199 Labaw, P.J. Advanced Questionnaire Design, Massachusetts. ABT Books, 1982
200 Payne, S.L. (1951b) 'Thoughts About Meaningless Questions' The Public Opinion Quarterly 14: 687-696.
201 Payne, S.L., The Art of Asking Questions, Princeton University Press, Princeton, NJ, 1951
202 Ubel, P.A. (1999) 'The Challenge of Measuring Community Values in Ways Appropriate for Setting Health Care Priorities', Kennedy Institute of Ethics Journal 9: 263-284.
203 Ciudad del Vaticano (1987) Congregación para la Doctrina y la Fe, Instrucción sobre el Respeto a la Vida Humana Naciente y la Dignidad de la Procreación.
204 Zegers-Hochschild, F. (1999) 'Attitudes towards reproduction in Latin America. Teachings from the use of modern reproductive technologies' Human Reproduction Update 5: 21-25, at p. 22.
205 Id.
206 Marteau, T.M., Dundas, R. and Axworthy, D. (1997) 'Long-term cognitive and emotional impact of genetic testing for carriers of cystic fibrosis: the effects of test result and gender', Health Psychology 16: 51-62.
207 Williams, L.S., 'No relief until the end: the physical and emotional costs of in-vitro fertilisation', In Overall, C.,(ed), The Future of Human Reproduction, Toronto, The Women's Press, 11989
208 Roberts, C. and Franklin, S., 'Experiencing new forms of genetic choice: Findings from an ethnographic study of preimplantation genetic diagnosis', Human Fertility 7: 285-293, at p. 288. (2004)
209 Lavery, S.A., Aurell, R., Turner, C., Castellu, C., Veiga, A., Barri, P.N. and Winston, R.M., 'Preimplantation genetic diagnosis: patients' experiences and attitudes', Human Reproduction 17: 2464-2467. (2002)
210 Adapted from Snowden, C. and Green, J.M. 'Preimplantation diagnosis and other reproductive options: attitudes of male and female carriers of recessive disorders', Human Reproduction 12: 341-350, (1997)
211 Katz, M.G., Fitzgerald, L., Bankier, A., Savulescu, J. and Cram, D.S., 'Issues and concerns of couples presenting for preimplantation genetic diagnosis (PGD)', Prenatal Diagnosis 22: 1117-1122, (2002)
212 Donnai, P., Charles, N. and Harris, R., 'Attitudes of patients after 'genetic' termination of pregnancy', British Medical Journal 282:621-622, (1981)
213 Black, R.B., 'A 1 to 6 month follow up of prenatal diagnosis patients who lost pregnancies', Prenatal Diagnosis 9: 795-804, (1989)
214 Kenyon, S., 'Support after termination for fetal abnormality', Midwives Chronicle 101: 190-191, (1988)
215 Reif, M. and Baitsch, G., 'Psychological issues in genetic counseling', Human Genetics 70: 193-199, (1985)
216 Palomba, M.L., Monni, G., Lai, R., Cau, G., Olla, G. and Cao, A. 'Psychological implications and acceptability of preimplantation diagnosis', Human Reproduction 9: 360-362. (1994)
217 Snowden and Green, loc. cit. (1997)
218 Adapted from Snowden and Green, loc cit (1997)
219 Williams, C., Alderson, P. and Farsides, B, 'Conflicting perceptions of the fetus: person, patient, 'nobody', commodity?', New Genetics and Society 20: 225-238, at p. 232, (2001)

220 *Lavery, et al., loc cit.*
221 *Id.*
222 *Roberts and Franklin, loc cit.*
223 *Lavery, et al., loc cit*
224 *Pergament, E., 'Preimplantation diagnosis: a patient perspective', Prenatal Diagnosis 11: 493-500, (1991)*
225 *Miedzybrodzka, Z., Templeton, A., Dean J., Haites N., Mollison J. and Smith N., 'Preimplantation diagnosis or chorionic villus biopsy? Women's attitudes and preferences', Human Reproduction 8: 2192-2196, (1993)*
226 *Palomba, M.L., Monni, G., Lai, R., Cau, G., Olla, G. and Cao, A., 'Psychological implications and acceptability of preimplantation diagnosis', Human Reproduction 9: 360-362, (1994)*
227 *Snowden and Green, loc cit*
228 *Snowden and Green, loc cit, at p. 349.*
229 *Williams, et al., loc cit.*
230 *The Genetic Town Hall: Making Every Voice Count , Genetic and Public Policy Centre, Washington DC, 2004*
231 *Reproductive Genetic Testing: What America Thinks, Genetic and Public Policy Centre, Washington DC., 2004*
232 *PGD patient, interview, USA, loc cit, at p. 25.*
233 *Adult with genetic disease, interview, USA, loc cit, at p. 25.*
234 *Male participant from mixed sex/race focus group of people 55 yrs and older, USA, loc cit, at p. 23.*
235 *Participant from Evangelical female focus group, USA, loc cit, at p.24.*
236 *PGD patient, interview, USA, loc cit, at p. 25.*
237 *This finding is also evident in research conducted in Germany; see Krones, T. & Richter, G, 'Preimplantation genetic diagnosis (PGD): European perspectives and the German situation', Journal of Medicine and Philosophy 29: 623-640, (2004)*
238 *Male undergoing PGD, U.K. Roberts and Franklin (2004), loc cit, at p. 289.*
239 *The Genetic Town Hall: Making Every Voice Count, supra cit.*
240 *Reproductive Genetic Testing: What America Thinks, supra cit..*
241 *Public Attitudes to Human Genetic Information, London, Human Genetics Commission, 2001.*
242 *Meister, U., Finck, C., Stōbel-Richter, Y., Schmutzer, G. and Brāhler, E., 'Knowledge and attitudes towards preimplantation genetic diagnosis in Germany', Human Reproduction 20: 231-238, (2004)*
243 *Krones, T. 'Public, expert and patients' opinions on preimplantation genetic diagnosis (PGD) in Germany', Reproductive Biomedicine 10: 116-123, (2005)*
244 *Simpson, J.L. and Edwards, R.G., 'Public objections to designer babies and cloning in USA: not quite what was expected', Reproductive Biomedicine 6: 147-148, (2002)*
245 *Singer, E., 'Public attitudes towards genetic testing', Population Research and Policy Review 10: 235-255, (1991)*
246 *Marteau, T., Michie, S., Drake, H. and Bobrow, M., 'Public attitudes towards the selection of desirable characteristics in children', Journal of Medical Genetics 32: 796-798, (1995)*
247 *Biotechnology Australia (2003) Biotechnology Public Awareness Survey Final Report. Available at: http://www.biotechnology.gov.au/assets/documents/bainternet/MB2003Final20050713094939%2Epdf*
248 *Kalfoglou, A.L., Doksum, T., Bernhardt, B., Geller, G., LeRoy, L., Mathews, D.J., Evans, J.H., Doukas, D.J., Reame, N., Scott, J. and Hudson, K., 'Opinions about new reproductive technologies: Hopes and fears for our genetic future', Fertility and Sterility 83: 1612-1621.*
249 *Genetics and Public Policy Centre (2004) Reproductive Genetic Testing: What America Thinks. Genetics and Public Policy Centre, Washington DC, at pp. 26-27.*
250 *Patient undergoing PGD, U.K. Roberts & Franklin (2004), loc. cit., at p. 288.*
251 *Couple who lost their first child to spinal muscular atrophy at 11 months of age, U.K. Roberts and Franklin (2004),loc cit., at p. 288.*
252 *Female participant from mixed sex/race focus group. Genetics and Public Policy Cetre (2004), op. cit., at p. 13.*
253 *Roberts and Franklin, loc cit, at p. 289.*
254 *This can be described as testing for predisposition to develop a particular disease. Genes that predispose individuals to diseases such as cancer are examples of this. In these cases it is not certain that the disease will actually develop. However, testing for most genetic diseases has some element of this uncertainty; it is, of course greater in some cases than others though (such as Tay-Sachs disease vs. some cancers).*
255 *Allahbadia, G.N., 'The 50 million missing women', Journal of Assisted Preproduction and Genetics 19: 411-416, (2002)*
256 *Plafker, T., 'Sex selection in China sees 117 boys born for every 100 girls', British Medical Journal 324: 1233, (2002)*
257 *Benagiano, G. and Bianchi, P., 'Sex preselection: an aid to couples or a threat to humanity?', Human Reproduction 14: 870-872, (1999)*
258 *Male participant, mixed sex focus group, USA. Genetics and Public Policy Centre (2004) Reproductive Genetic Testing: What America Thinks, Genetics and Public Policy Centre, Washington DC, at p. 13.*

*259 Genetics and Public Policy Centre (2004) Reproductive Genetic Testing: What America Thinks, Genetics and Public Policy Centre, Washington DC, at p. 13.*

*260 Genetics and Public Policy Centre (2004) Reproductive Genetic Testing: What America Thinks. Genetics and Public Policy Centre, Washington DC.*

*261 Father of child with cystic fibrosis, USA. Genetics and Public Policy Centre (2004) Reproductive Genetic Testing: What America Thinks. Genetics and Public Policy Centre, Washington DC., at p.12.*

*262 Woman undergoing PGD, UK. Roberts & Franklin (2004), op. cit., at p. 289.*

*263 Genetics and Public Policy Centre (2004) Reproductive Genetic Testing: What America Thinks. Genetics and Public Policy Centre, Washington DC, at p. 39.*

*264 PGD patient, USA. Genetics and Public Policy Centre (2004) Reproductive Genetic Testing: What America Thinks. Genetics and Public Policy Centre, Washington DC, at p. 17.*

*265 Participant from White Protestant female focus group, USA. Genetics and Public Policy Centre (2004) Reproductive Genetic Testing: What America Thinks. Genetics and Public Policy Centre, Washington DC, at p. 50.*

*266 Participant from female with no children focus-group, USA. Ibid, at p. 51.*

*267 Participant from Mexican American female focus group, USA. Ibid, at p. 16.*

*268 Participant from female focus group, USA. Ibid., at p. 11.*

*269 Genetics and Public Policy Centre (2004) Reproductive Genetic Testing: What America Thinks. Genetics and Public Policy Centre, Washington DC, at p. 50.*

*270 Ibid.*

*271 Ibid.*