

‘You shouldn’t have been born:’ Does the
regulation of Preimplantation Genetic
Diagnosis send a discriminatory message to
the Disabled Community?

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Table of Contents

Chapter One: Introduction.....	1
Chapter Two: Pre-implantation Genetic Diagnosis (PGD).....	3
2.1 PGD: The technology.....	3
2.2 Benefits and Associated Ethical Concerns of PGD Technology.....	4
Chapter Three: Reproductive Autonomy and the Welfare of the Child.....	10
3.1 Reproductive Autonomy.....	10
3.2 Welfare of the Child.....	11
3.3 The Non-Identity Theory.....	12
3.4 Possible Responses to the Non-Identity Theory.....	13
Chapter 4: The ‘Expressivist’ argument.....	17
4.1 The Expressivist Argument outlined.....	17
4.2 Defining ‘Disability’.....	17
4.3 Effects of this Message.....	20
4.4 The Need for Regulation?.....	25
Chapter 5: The Regulation of PGD in New Zealand.....	26
5.1 The Structure of New Zealand Law on Assisted Reproductive technologies.	26
5.2 The HART Act.....	26
5.3 Guidelines on Preimplantation Genetic Diagnosis.....	28
5.4 The Implications of these Guidelines.....	33
Chapter 6: The Effect of This Regulation on the Expressivist Claim...	34
6.1 Does the Regulation of PGD Express Disvalue for People with ‘Disabling’ traits?.....	34
Chapter 7: Alternative Approaches to Regulation.....	36

Chapter One: Introduction

‘The specter of designer babies is no longer science fiction, and one can presume disability is not part of that design’¹.

Ask a future parent what sex they wished their unborn child to be, the traits they wish their offspring to possess or how they want their young to look and a common response is, “I just want my child to be healthy.” Pre-implantation Genetic Diagnosis (hereafter PGD) is a modern procedure whereby parents may greatly improve their chances of fulfilling this desire.

PGD, as I will discuss in more detail in Chapter 2, involves screening embryos to detect potential genetic abnormalities. Those embryos that contain undesirable genetic traits are destroyed while ‘healthy’ embryos are inserted into a mother’s uterus through IVF, increasing the likelihood of a successful pregnancy and healthy baby. This process effectively improves the chances that a child will be born free from disabling traits; traits that many parents hope and pray that their child will not be burdened with.

While PGD has many benefits, especially for potential parents who may be at risk of passing on genetic defects, opposition to the use of the technology has come in many forms. Resistance ranges from the conservative view which believes an embryo has full moral status from the moment of conception, to opponents believing that use of the technology will lead us down a ‘slippery slope’ towards ‘eugenic’ social selection of traits, in effect causing ‘designer babies.’

The concerns raised from various groups have led to many countries worldwide choosing to regulate this controversial area. In this paper, I will investigate the legal boundaries of PGD that have been set in New Zealand. In particular, I will examine the effect of this regulation on a vulnerable group in our society, the disabled community.

Of all the opposition to the use and regulation of PGD, I believe the strongest objection is the ‘expressivist’ argument advanced by and on behalf of members of the disabled community. This argument maintains that the use of PGD to eliminate certain disorders sends a hurtful message to people who live with those same traits, expressed in statements such as,

It’s a terrifying thought that people out there believe my life isn’t worth living, isn’t worth replicating – so they would try to breed that out.²

It is claimed that far reaching effects of the technology will affect attitudes towards disabled citizens, creating a climate where genetic disability is increasingly seen as preventable. Coupled with this are fears that societal changes may lead to a lessening of public support for disability rights and reduced funding into cures for genetic diseases.

I will analyse the ‘expressivist’ claim and whether the use of PGD is discriminatory towards the disabled society. Following this, I examine the regulations that are currently in place in New Zealand. I will revisit the expressivist argument at this point, analysing

¹ Tim Stainton “Missing the Forest for the Trees? A Disability Rights Take on Genetics.” (2007) Commentary on Stowe et al, *Journal on Developmental Disabilities*: 13(2)

² Paul Gibson *NZ Herald* (New Zealand 17 September 2005)

whether our regulatory framework minimises any apparent discrimination, or alternatively, whether the regulations amplify the hurt felt by members of the disabled community. Finally I will suggest certain changes to the regulatory structure that I believe are necessary to address the problems with the current regulation of PGD.

Chapter Two: PGD

2.1 PGD: The Technology

PGD is a procedure whereby human embryos are tested for serious inherited genetic conditions and chromosomal abnormalities. In contrast to prenatal screening³, PGD analyses an embryo prior to its transfer into the uterus. Preimplantation techniques have been routinely used since 1968⁴ in order to control the sex of animals for breeding purposes.

Successful human pregnancies following a PGD screen to test for sex-linked disorders were first reported in 1990.⁵ By 2000, PGD had successfully been used in order to screen for single gene disorders, examples being beta-thalassaemia and muscular dystrophy, and chromosomal abnormalities such as Down, Turners and Edwards syndromes.

The procedure involves several steps:

1. An embryo is created via *in vitro* fertilization (IVF). Egg and sperm are brought together for fertilization *in vitro* to create embryos, which are grown in an incubator.
2. One or two cells are removed from the embryo at a stage where the embryo only consists of about 8 cells (blastomeres) about three days after fertilization.
3. An embryo biopsy is carried out on these cells using genetic screening. Specific genetic markers (single genes or combinations of genes known to lead to certain traits) are tested for.
4. 'Healthy' unaffected embryos are transferred into the uterus using IVF.
 - i. I note here that the term 'designer baby' is commonly used⁶ when describing the process of PGD. However this term is deceiving. One cannot actively *choose* the characteristics they desire their child to have, as PGD is simply a process of *deselecting* undesirable traits. Therefore even if parents were able to use PGD to select for any trait they desired,⁷ the characteristics present in the offspring are conditional on the parents carrying the desired combinations of genes.⁸
5. Cells that show undesirable traits are destroyed.

³ Pre-natal screening involves screening for genetic abnormalities in an established pregnancy. If a disorder is located, couples may opt to terminate the pregnancy.

⁴ R.L Gardner & R.G Edwards "Control of the Sex Ratio at Full Term in the Rabbit by transferring Sexed Blastocysts" (1968) Nature 218, 346-348

⁵ Two couples known to be at risk of transmitting adrenoleukodystrophy and X-linked mental retardation successfully had their embryos screened in order to select female embryos, which wouldn't be affected from the disorder.

⁶ Dave Andrusko "PGD and Designer Babies: Same Problem Only Worse" (2009) Today's News & Views. <http://www.nrlc.org/news_and_views/Feb09/nv021209.html>

⁷ The regulations in New Zealand only allow PGD in specific circumstances to test for medical purposes which I will further describe in chapter Six.

⁸ For a child to have certain characteristics, their parents must have certain genes that make this possible. For example, two redheaded people would both contain two genes recessive for red-hair and therefore are only possible of producing red-haired children. Thus, even if they were able to select for traits in their children using PGD, they would be incapable of having a child with anything other than red-hair.

PGD generally provides a reliable diagnosis and following implantation, a pregnancy results as usual. The process is expensive and relatively rare.

2.2 Benefits and associated ethical concerns of PGD technology

PGD allows couples at a high risk of passing on a genetic disease to greatly increase the chance that they will produce a baby free from certain defects. Carriers of chromosomal or sex-linked gene disorders will most greatly benefit from the technology, as well as women of advanced maternal age with increased risk of producing a child with a chromosomal abnormality.

PGD enables couples in such situations to pursue biological children when otherwise they may not have done so due to the risk of producing a child with a serious disability. For such couples, PGD is often seen as the preferable option than facing the prospect of a termination decision a few months into the pregnancy, as might occur following a pre-natal screen.

PGD as an alternative to pre-natal screening

PGD may be seen as more morally acceptable option as the choice made following PGD can be considered ‘ethically neutral,’ as the positive result (‘healthy’ pregnancy) simultaneously balances out the negative result (the destruction of affected embryos), assuming a pregnancy proceeds to full term. The net result of a prenatal screen followed by abortion would be negative as it results in the destruction of a foetus without a positive ‘balancer.’⁹ Although a healthy pregnancy may later occur if the couple conceives again, this process does not happen simultaneously.¹⁰ Furthermore, in a pregnancy termination the woman is intimately involved in the invasive procedure, while this does not occur in the *in vitro* PGD procedure.¹¹

PGD is also thought the more ethically desirable option as the destruction of embryos occurs at a far earlier stage in development. However, this contention depends on the view one takes of the moral status of the embryo. I will now discuss these differing views.

Views on the moral status of an embryo

1. The pro-life position considers an embryo to have full moral status from the moment of conception and thus embryo destruction is wrong and the equivalent of murder. PGD involves greater ethical transgressions than pre-natal testing followed by abortion as a larger number of embryos are created and discarded in the process.¹²

⁹ C Cameron & R Willaimson “Is there an ethical difference between preimplantation genetic diagnosis and abortion?” (2003) 29 J Med Ethics 90 at 90

¹⁰ *ibid*

¹¹ *ibid* at 92

¹² I will not focus on this line of reasoning; the pro-life arguments advanced opposing PGD revisit the arguments advanced opposing any pre-birth intervention such as abortion, stem-cell research and pre-natal testing. This ‘graduating view’ has been largely accepted in society and is reflected in our current abortion law.

2. At the other extreme is the ‘personhood’ belief, which holds that the pre-implantation embryo lacks any moral status and therefore the destruction of embryos would not be morally questionable. Proponents of this view believe that life obtains moral value when it comes to possess certain attributes such as “rationality, autonomy, and self-consciousness.”¹³
3. A frequently held position is in between these poles, maintaining that the moral status of an embryo increases gradually throughout development.¹⁴ This graduating view of embryonic status is the most common approach taken and is implied in our legislation. In New Zealand abortion law,¹⁵ if certain conditions are met,¹⁶ a foetus can be terminated until 20 weeks of gestation, thus implying that after 20 weeks a foetus is ‘more of a person’ and deserving of additional legal protection. After 20 weeks, an abortion may only be performed in order to save the life of the mother¹⁷, implying that after this time the law accords a higher moral status to the embryo.

This ‘graduating’ view of the moral status of the embryo is likely to see PGD as morally more acceptable than pre-natal testing as the procedure is performed before implantation, when the embryo consists of just a few cells, in comparison to a foetus that may be up to 20 weeks old. For the purposes of this paper I have chosen to adopt the ‘graduating’ view of the embryo. An embryo must be treated with respect at all times but that there should be stricter limits imposed on interventions as the embryo develops.

‘Sibling Saviours’

PGD can be used in conjunction with human leukocyte antigen (HLA) tissue typing to create a donor child.¹⁸ Following the birth of the donor child, the umbilical cord cells are used to treat the affected sibling.

The use of PGD to create ‘sibling saviors’ is ethically concerning in that one is effectively creating a child for a particular purpose, as a ‘means to an end.’ There are fears that this could be psychologically damaging to the donor child growing up knowing that he/she was created for a particular purpose. I will discuss these fears in detail when examining concerns about the welfare of a child born following a PGD procedure.¹⁹

Sex selection

PGD can be utilised to choose the sex of a child. Sex determination may be necessary to ensure a sex-linked genetic disorder such as haemophilia or Duchenne muscular dystrophy is not passed on.

However, sex selection is controversial when parents pursue this option for ‘social

¹³ Peter Singer *Practical Ethics* 2nd edition Cambridge. P182

¹⁴ N.C Gillespie “Abortion and Human Rights” (1977) 87 *Ethics* at 237-243

¹⁵ Contraception, Sterilisation, and Abortion Act 1977, Crimes Act 1961, ss182-187.

¹⁶ Contraception, Sterilisation, and Abortion Act 1977, ss32,33

¹⁷ *ibid*, s37

¹⁸ This donor child is commonly referred to as a ‘sibling saviour.’

¹⁹ See chapter 3.2

reasons.²⁰ This is *prima facie* discriminatory in that one sex is devalued in favour of the other.²¹ Parents might wish to pursue this option for ‘family balancing’ purposes,²² which is problematic as it is a departure from ‘medical’ uses of the technology.

The libertarian perspective supports PGD being used for sex selection. Advantages may be that parents can adequately ‘balance’ their families as desired without having to resort to ‘trying again,’ leading to more satisfactory family sizes. Rhodes,²³ points out that where there is no empirical evidence to show that sex selection leads to discrimination against women or an imbalance in the sex ratio, there is no sufficient reason to restrict this liberty through prohibition. She dismisses the arguments that parents may choose to have a child of a particular sex based on unethical reasons, by pointing out that selfish components of parenting are wholly natural and not capable of justifying the prohibition of sex selection.²⁴

In a report by the New Zealand Bioethics Council, after supporting sex selection for sex-related conditions, the report noted that in relation to ‘family balancing’:

We have not heard sufficient cultural, ethical or spiritual concerns to justify banning it — providing PGD is undertaken at the parents’ own cost.²⁵

Opponents point out that if non-medical sex selection for purposes as trivial as ‘family balancing’ goes unchallenged, we are beginning to venture down a ‘slippery slope.’

Selecting for non-medical traits: ‘slippery slope’

A common concern with is that using PGD technology is beginning a descent down the hypothetical ‘slippery slope.’ It is pointed out that in using this technology to de-select certain traits, it is not long before we will be using PGD in order to *positively* select for traits in order to improve our species. Opponents claim this individualized and market-based ‘new eugenics’ will see children will become regarded as made-to-order consumer products.²⁶ Selecting and designing children under the guise of “parental choice” instrumentalises children as a means to the parents’ ends, limiting a child’s right to an open future.

It is claimed that allowing PGD to select against certain traits effectively opens the door to other eugenic technologies such as selecting the ‘best’ children based on an increasing list of genetic indicators. It also *normalises* the idea that a child’s particular genetic make-up be viewed as an extension of parental choice.²⁷

²⁰ This is currently illegal in New Zealand but it can be done in other countries, the USA for example.

²¹ In countries such as India and China it has been noted that sex selection often reflects a bias against females.

²² John Robertson “Extending preimplantation genetic diagnosis: The ethical debate” (2003) 18 Human Reproduction 465 at 470

²³ R Rhodes “Ethical issues in selecting embryos” (2001) 943 Ann N Y Acad Sci 943: 360- 7

²⁴ *ibid*

²⁵ “Who Gets Born? A report on the cultural, ethical and spiritual aspects of pre-birth testing by Toi te Taito: the Bioethics Council” (2008) at 54

²⁶ “Pre-Implantation Genetic Diagnosis: Ethical Guidelines for Responsible Regulation” (2003) Submitted to the President’s Council on Bioethics By The International Center for Technology Assessment.

²⁷ *ibid*

The ‘slippery slope,’ claim further alleges we are heading towards situations where PGD could be exploited to enable parents to choose the sex, characteristics and traits off their offspring; in effect ‘producing ‘designer babies.’²⁸ This contention has led to grave concerns that we are entering a eugenic world where trait selection would become common and certain ‘undesirable’ traits would be eventually ‘bred out.’ Alongside this are concerns that the expense of PGD would lead to greater social inequality, as only those who could afford the procedure would be able to reap the rewards.

New Eugenics’

The term ‘eugenics’ is often used in slippery slope discussions concerning the use of PGD,²⁹ the expression conjuring up emotive images of the Nazi regime and atrocities that have occurred throughout human history in the process.³⁰ The conventional definition of ‘eugenics’ as described by King involves:

Coercion of people’s reproductive choices, for social ends, which may include improving the quality of the population, preventing suffering of future generations, or reducing financial costs to the state³¹

Savulescu defines eugenics as being ‘selective breeding to produce a better population.’ This public interest justification can be distinguished from the essentially private enterprise undertaken by parents in creating a child.³² PGD is a completely voluntary process undertaken by couples as a facet of their right to reproductive autonomy. The choice to undertake a PGD/IVF procedure is a private decision between couples that is in no way imposed by the state. The technology is rarely used, the procedure being expensive and the process of IVF invasive to women.

However, it has been claimed that the process of PGD has the potential to lead to a ‘new eugenics,’ whereby a combination of reproductive autonomy, social pressures and ‘eugenic attitudes’ could lead to similar outcomes without any state involvement.³³ The term ‘eugenics by default’ has been used to describe how a ‘eugenic’ effect is being created by,

Countless decisions by loving and caring mothers and fathers...who are simply trying to alleviate potential suffering/improve the quality of life of people they are bringing into the world.³⁴

²⁸ Although I note again that PGD can only be used to ‘design’ a baby to the extent that the parents have the appropriate combination of genes for such desirable traits to occur. See fn 8

²⁹ Dorothy Wertz “Did eugenics ever die?” (2002) 3 *Nature Review Genetics* 408

³⁰Garland Allen. “Was Nazi eugenics created in the US?” (2004) 5 *EMBO reports* 451-452. Lombardo. P (1996) 13(1) “Medicine, Eugenics, and the Supreme Court: From Coercive Sterilization to Reproductive Freedom” *The Journal of Contemporary Health and Law Policy* 1-25

³¹David King “Preimplantation genetic diagnosis and the ‘new’ eugenics” (1999) 25 *Journal of Medical Ethics* 182 at 176-177.

³² Julian Savulescu “Procreative Beneficence: Why we should select the best children” (2001) 15 (5/6) *Bioethics* at 424

³³ King, above, n31 at176

³⁴ Elizabeth Schiltz “Confessions of a ‘Genetic Outlaw’” (2006) *Bloomberg Businessweek* <http://www.businessweek.com/technology/content/jul2006/tc20060720_148057.htm>

Some feel that these collective decisions may have the same consequences as traditional eugenics. King goes so far as to claim that due to wealth disparities we will move towards a society with a 'genetically privileged ruling elite and an underclass.'³⁵

In answer to these objections, I point out that these assumptions are based on speculation. Compared to the huge potential benefits of PGD, I do not find such speculation sufficient. It must be remembered that PGD has the potential to save lives through the creation of sibling saviours, allow parents to conceive happy in the knowledge that their child is less likely to have a life-shortening, painful or debilitating trait, and prevent the incredibly painful decisions some couples have to make about whether to terminate a foetus. To give these fears, based on speculation, too much weight would be to 'overvalue anxiety at the expense of logic,'³⁶ limiting PGD because of this seems an unjustifiably cautious approach to take.

Such speculation also overlooks influential factors other than genetic inheritance. While genes are clearly important factors in the expression of many traits and diseases, societal attitudes towards PGD and other technologies often appear to overlook the fact that a vast number of human traits are greatly influenced by environmental, social and institutional factors. Claims that PGD will be exploited in order to select for traits such as beauty, intelligence and behaviour are simply the result of over-excitability journalists trying to bolster public opinion.³⁷ It is not certain that PGD will ever be used to screen for such traits due to the combination of complex interactions of genes as well as a multitude of environmental factors being involved.³⁸

Furthermore, 'techno-fix' solutions using modern genetic technologies such as PGD should not replace efforts to avoid disease, to offer those less able the support they deserve, to replace efforts of developing new treatments or to address broad environmental and social factors which may lead to disease.

'Slippery slope' objections claim we are heading down a 'new eugenic' path where parents will be able to choose a variety of traits they wish their children to possess.³⁹ However, this selection remains a natural phenomenon. What is often overlooked by those that speculate as to dangers of the hypothetical 'slippery slope,' is that the process of 'designing' a child using PGD is restricted by the specific gene combinations of the parents. A child cannot be created through PGD that could not be created by a completely natural process, PGD simply being a way of 'improving the odds' of having an individual with or without particular traits.

³⁵ King, above, n31 at 181

³⁶ Sheila McLean *Modern Dilemmas: Choosing Children* (Edinburgh, 2001) at 92

³⁷Gautam Naik "A Baby, please. Blond, Freckles – Hold the Colic. Laboratory Techniques That Screen for Diseases in Embryos Are Now Being Offered to Create Designer Children" (2009) *The Wall Street Journal, Health*. <http://online.wsj.com/article/SB123439771603075099.html>

³⁸ For example, one may have a combination of genes that makes one more susceptible to certain types of heart disease. However, knowledge of this susceptibility (often obtained through looking at family history), can allow one to make such lifestyle changes as to minimize this risk. A great number of environmental factors such as diet, exercise, and smoking are often the real telling signs as to whether one will actually get the disease.

³⁹Naik, above, n37

Even if one was to accept that PGD might become more widespread in future, it is highly improbable that every prospective parent would want to utilise the technology.⁴⁰ Aside from the fact that disability cannot be eliminated due to accidents and injuries sustained throughout life, some genetic disabilities will ‘slip through the net’ due to PGD imperfections. Also, considering the number of groups who regard PGD as ethically problematic, one would assume many people would choose to conceive naturally.⁴¹

Playing God

This opposition to PGD often comes from a Christian perspective whereby ‘interfering with the natural order’ through manipulation of ‘God’s gift’⁴² is seen as a rejection of God’s creation. This objection is not an argument I will focus on. Similar to the pro-life stance, the Christian objection is a minority view and highly contestable. The modern view can be taken that humans, seen as co-creators with God, have a duty to strive to realise the existence of a better world.⁴³ Christian justifications to avoid sufferings can be applied to certain modern medical techniques, thus it would be inconsistent not to justify certain applications of PGD to avoid horrendous suffering from certain disorders.⁴⁴

Viewing reproduction as a ‘gift’ also exists outside the theological context. In a study considering lay persons views on social sex selection⁴⁵ it was found that the idea of reproduction being a ‘gift’ was used metaphorically, outside the context of there being a divine ‘giver,’⁴⁶ to convey the idea that children should be accepted as they are. Manipulation of this ‘gift’ by selection of the traits in offspring was seen as an inappropriate acceptance of the gift and viewed children as a ‘commodity’⁴⁷ that was seen as objectionable by a number of study participants.

However, citing such a metaphor is not an argument in itself.⁴⁸ Instead the ‘gift’ concept should serve as an important reminder that children are neither a commodity nor a right and are thoroughly deserving of their parents’ love and respect.

⁴⁰ Colin Gavaghan “Right Problem, Wrong Solution: A pro-choice Response to ‘Expressivist’ Concerns about Preimplantation Genetic Diagnosis” (2006) 16 Cambridge Quarterly of Healthcare Ethics 20 at 21

⁴¹ *ibid*

⁴² “Considerations on Assisted Human Reproduction” (2010) Seventh Day Adventist Church. <<http://adventist.org/beliefs/other-documents/other-doc10.html>>

⁴³ Mark Henaghan and others *Choosing Genes for Future Children: Main Findings* (University of Otago, 2006)

⁴⁴ *ibid*

⁴⁵ Jackie Scully, Tom Shakespeare & Sarah Banks “Gift not commodity? Lay people deliberating on social sex selection” (2006) 28(6) *Sociology of Health & Illness* 749

⁴⁶ *ibid* at 753

⁴⁷ *ibid* at 754

⁴⁸ *ibid* 760

Chapter Three: Reproductive Autonomy and the welfare of the child

The use of PGD creates a *prima facie* tension between individual autonomy to make reproductive choices and social responsibility to ensure that human dignity is not respected.⁴⁹ It must be considered whether society's interest is so great that the state has a right to dictate the reproductive decisions individuals should make when using this technology.

3.1 Reproductive Autonomy

As famously stated by John Stuart Mill:

The only purpose for which power can be rightfully exercised over any member of a civilised community, against his will, is to prevent harm to others.⁵⁰

The concept of 'reproductive autonomy'⁵¹ suggests couples should be free to decide when and how they wish to procreate. The importance of reproductive freedom is that individuals must be given the autonomy to independently judge what a life of prospect entails. For centuries humans have chosen mates with whom they wish to reproduce based on traits they find desirable. PGD can be seen as an extension on this autonomy we have long afforded to prospective parents to mate with whomever they desire. Following Mill's harm principle,⁵² this reproductive liberty means that generally there are only restrictions on this process where there is harm to others.

The importance of reproductive liberty against actions from the state have long been recognised by significant writers. As stated by Ronald Dworkin this liberty involves

A [couple's] right to control their own role in procreation unless the state has a compelling reason for denying them that control⁵³

This rationale is based on a fundamental presumption of a liberal democracy, being that the state should not interfere with the freedom of its citizens in the absence of sufficient justification.

John Robertson notes that as a result of reproductive liberty the state cannot restrict decisions about reproduction except in a case of serious harm, although he states that this right is not absolute and therefore may be limited in appropriate cases.⁵⁴

I believe that in the absence of a good reason for the state to justify limitation of PGD, reproductive liberty must be afforded to potential parents. While PGD may appear easier

⁴⁹ Mark Henaghan and others. *Choosing genes for future children: the regulatory implications of preimplantation genetic diagnosis* (Brookers Press, Dunedin, 2006.)

⁵⁰ John Stuart Mill *On Liberty* (Longman, Roberts & Green, London, 1869)

⁵¹ Often termed 'reproductive liberty' or 'procreative liberty/autonomy'

⁵² Mill, above, n50

⁵³ Ronald Dworkin *Life's Dominion An argument about abortion, euthanasia and individual freedom* (Vintage Books ed, New York 1993)

⁵⁴ John A Robertson "Procreative Liberty and Harm to Offspring in Assisted Reproduction" (2004) 30 American Journal of Law & Medicine 7 at 20.

to regulate than sexual intercourse⁵⁵ as the procedure can only be carried out by a licensed professional,⁵⁶ this does not automatically justify state interference with a fundamental right.

Accepting that we have a right to reproductive liberty in the absence of harm requires examination into the possibility that this right may be limited by potential harm caused by PGD. Those who may be potentially harmed by the technology are:

- a) Children born as a result of a PGD procedure.
- b) Members of the disabled community who claim that the use of PGD devalues their identity as they live with genetic impairments which PGD specifically selects against. This has been termed the ‘expressivist argument.’

I will firstly examine the claim that children born as a result of a PGD procedure may be harmed.

3.2 Welfare of the child

Many opponents of PGD base their views on the welfare of the child, pointing out that a child brought into the world in this way may be somewhat affected due to the manner he/she was selected. Such arguments note that parental pressure to perform or exhibit strong characteristics could be present, impairing the welfare of the resulting child. It has been suggested that allowing parents the power of additional choice over their child’s traits may fundamentally alter the parent/child relationship from one of love to one of ‘designer’ expectations.⁵⁷

Michael Sandel raises this concern, stating:

To appreciate children as gifts is to accept them as they come, not as objects of our design, or products of our will, or instruments of our ambition. Parental love is not contingent on the talents and attributes the child happens to have...That is why parenthood, more than other human relationships, teaches what the theologian William F. May calls an ‘openness to the unbidden.’⁵⁸

There are fears donor children born as ‘sibling saviours’ could be profoundly psychologically affected by the knowledge they were bought into the world simply as a means to save the life of their brother or sister.

Another concern based on child welfare is if the technology were to be used in order to deliberately choose *for* a disabling trait⁵⁹ as it can be claimed that the process has deliberately harmed the child.

⁵⁵ Which in reality would be seemingly impossible to regulate against and enforce, notwithstanding that it would be severely ethically problematic due to the huge restriction on personal autonomy.

⁵⁶ This is an offence pursuant to the Human Assisted Reproductive Technologies Act, s16(1).

⁵⁷ Henaghan and others, above n49

⁵⁸ Michael Sandel *The case against Perfection* (Harvard University Press, 2007) at p.45.

⁵⁹ This is currently illegal in NZ through section 3 of The guidelines on Preimplantation Genetic Diagnosis.

However, the notion that the use of PGD may be damaging to a future child presents an intriguing ethical paradox, known as the ‘non-identity theory.’

3.3 The non-identity theory

PGD is used to avoid producing children with certain disorders but it cannot correct these disorders. The use of PGD to select certain embryos comes at the expense of other embryos, thus the alternative for a particular child born following a PGD/IVF procedure is not to be born at all. This is the famous ‘non-identity conclusion’ coined by Derek Parfit.⁶⁰

This non-identity principle relies on the acceptance of the ‘zygotic principle,’ which states:

The identity of human beings...lies in the union of two given gametes:
if either the sperm or ovum had been different, a different human
being would have been formed.⁶¹

Accepting the non-identity conclusion, one cannot claim that PGD either improves or harms the welfare of a particular child as the use of PGD affects the *identity* of the child itself. This effectively negates the argument that creating a sibling saviour would be harmful to the donor child as, had PGD and subsequently selection of that particular embryo based on tissue type *not* been performed, that particular donor child would not have been born at all. As the alternative is non-existence, so long as a life is not so worthless as to be ‘wrongful,’⁶² a child cannot claim that the use of PGD has been detrimental to their welfare.

The same rationale applies to cases where PGD may be used controversially to select *for* a genetic impairment. Although one may see it as ‘morally wrongful’⁶³ to select an impaired embryo for implantation, for the particular child born as a result of selection through PGD, their very existence relies on the selection. The alternative for that particular child is not to be born at all. Thus, the process of using PGD to prevent a disability is of no value to that particular child; on the contrary it denies the child a worthwhile, albeit handicapped life.⁶⁴ Unless a life was so miserable as to be ‘wrongful,’ a child has benefited from being born, rather than being harmed by it.

An interesting example was evidenced in practise when Sharon Duchesneau and Candy McCullough,⁶⁵ a deaf couple, wished to have a baby through donor insemination. The controversy arose when they selected a deaf sperm donor in order to increase the chances of having a deaf baby. One might consider that their son, Gauvin, is harmed by his parent’s choice that he be born deaf. However, applying Parfit’s non-identity

⁶⁰ Derek Parfit *Reasons and Persons* (Oxford University Press, Oxford, 1984) at chapter 16.

⁶¹B Williams “Who might I have been?” (1990) In: Chadwick D, Bock G, Whelan J, et al. (eds.) *Human Genetic Information: Science, Law and Ethics*, pp. 167–179.

⁶² I will examine the claim of ‘wrongful life’ further in this chapter.

⁶³ Dan Brock “The non-identity problem and genetic harms – The case of wrongful handicaps” (1990) *Bioethics* 9 ¾ at 270

⁶⁴ *ibid* at 271

⁶⁵ Colin Gavaghan “Disability, Identity and Choice: Embryo Testing and the Human Fertilisation and Embryology Act 2008” (2007/2008) 9(3) *Contemporary Issues in Law* at 138

conclusion to this example, one can see that, for Gauvin, his deafness and his very existence are inseparable. If his parents had elected to have a ‘hearing’ child, Gauvin would never have been born. Therefore Gauvin has not been ‘harmed’ by their choice.

Using PGD to enable the birth of certain individuals cannot harm those particular individuals as a person cannot be harmed by an act that brings about their existence.⁶⁶ It can be reasoned that parents can do no harm to their future child in choosing to create them through PGD, unless the child was so severely disabled that their life was worthless. Therefore, one cannot justify placing limits on reproductive technologies based on the welfare of the child. This theory grants future parents virtually unlimited parental autonomy in the use PGD. The only possible claim a child could make is one of wrongful life.

Wrongful Life

A controversial and rare claim of ‘wrongful life,’ as explained by Robertson is one in which,

‘...rare cases of truly wrongful life...every postpartum moment is excruciatingly painful. In such a case, one would have a moral obligation to end that child’s life.’⁶⁷

This is essentially a claim brought by, or on behalf of, a child that their quality of life is so poor that they would have been better off had not been born. A case of wrongful life has never been accepted in New Zealand. Following the High Court of Australia’s majority conclusion the life cannot be a compensatable harm in *Harriton (by her tutor Harriton) v Stephens*,⁶⁸ it appears doubtful that such a claim would be recognised in New Zealand.

3.4 Possible responses to the non-identity theory

Ever since Parfit formulated the non-identity theory attempts have been made to offer alternative approaches.

Procreative beneficence

One such approach is the ‘person-affecting claim,’ which has been termed the duty of ‘procreative beneficence.’ The idea of ‘procreative beneficence’ as outlined by Savulescu is that:

Couples (or single reproducers) should select the child, of the possible children they could have, who is expected to have the best life, or at least as good a life as the others, based on the relevant, available information.⁶⁹

The claim states that parents have a moral obligation to their children to choose the embryo with the combination of genes most likely to have the best life, based on known

⁶⁶ Parfit, above, n60

⁶⁷ Robertson, above, n54

⁶⁸ [2006] HCA 15

⁶⁹ Savulescu, above n32 at 415

information. If embryo A had a genetic combination that predisposes the future individual to asthma and embryo B was free from such genetic disposition, all other things being equal, parents would be morally obliged to choose B as a predisposition to asthma would likely lead to a state with reduced well-being.⁷⁰

Janet Malek essentially supports the same position, noting that the decision by parents to bring a person into the world generates responsibilities for those parents. It is inevitable that a child will be subject to harms following their creation and therefore parents have moral obligations to mitigate this vulnerability wherever possible.⁷¹ The use of reproductive genetic technologies such as PGD is one such way to reduce a future child's vulnerability to harm, therefore a way in which parents can fulfill this responsibility.⁷² Malek defends this claim by drawing analogies with other parental responsibilities such as providing children with adequate nutrition and seeking medical care when required.⁷³

However, the moral obligation idea fails to answer the non-identity conclusion because it does not explain *which* child is owed the beneficent duty.⁷⁴ The concept appears to be based on an overly simplistic view of genetic determinism as Parker, points out,

Complex concepts, such as those of the good life, the best life, and human flourishing, are not reducible to simple elements or constituent parts which might be identified through the testing of embryos.⁷⁵

Parker noted that the 'best possible life' is in no way one lived by a person with the least flaws of biology. While it may be possible that some conditions may make a life unlikely to go well, inevitably 'the good life' will encompass a mixture of good and ill.⁷⁶ Thus Parker concludes,

The assessment of whether any particular possible child has a reasonable chance of a good life—will be inseparable from relatively complex intersubjective and social practices and values.⁷⁷

The idea of procreative beneficence also runs into difficulties when one considers testing for low penetrance genetic disorders. For example, a woman may be a carrier of a BRCA1 gene.⁷⁸ It does not follow that having a genetic susceptibility to a certain condition that may manifest later in life would mean that she acts immorally by not undertaking PGD. The child is not harmed and may still lead a full and flourishing life.⁷⁹

⁷⁰ Savulescu, above, n32 417

⁷¹ Janet Malek "Disability and the duties of potential parents" (2008) 2 Saint Louis University Journal of Health and Law Policy at 124

⁷² *ibid*

⁷³ *ibid* 125

⁷⁴ Colin Gavaghan "Disability, Identity and Choice: Embryo testing and the Human Fertilisation and Embryology Act 2008" (2007/2008) 9(3) Contemporary Issues in Law 133 at 145.

⁷⁵ Michael Parker "The best possible child" (2007) 33 279 at 281.

⁷⁶ *ibid* 282

⁷⁷ *ibid* at 282

⁷⁸ Susceptibility genes increase one's chance of developing a disorder in contrast to the general population. A woman who carries the BRCA1 gene is at a higher risk of developing breast cancer. However these conditions are also largely dependant on environmental factors.

⁷⁹ Jeanne Snelling "Preimplantation genetic Diagnosis for susceptibility conditions: A new frontier or a logical extension?" (2008) 16 Journal of Law and Medicine 263 at 274.

Finally, the concept seems to erode the concept of reproductive liberty.⁸⁰ Savulescu himself concluded the right to procreative beneficence must be balanced with the right to autonomy in reproductive decision-making:

For the purposes of public policy, there should be a presumption in favour of liberty in liberal democracies. So, ultimately, we should allow couples to make their own decisions about which child to have.⁸¹

Although Savulescu attempts to reconcile the two concepts, the idea of procreative beneficence imposes a ‘burden’ on reproductive autonomy by suspecting one choice is morally preferable to another. I do not believe that imposing this burden by way of moral obligation can sit comfortably with the concept of reproductive autonomy, as the importance of such a freedom would be severely diminished if it could not be used in situations of divergence from the majority.

‘Non-person-affecting’

This argument, sometimes termed ‘maximising consequentialist approach,’ avoids the claim that person may be affected, as the non-identity conclusion makes this impossible. Instead it claims that we should make choices that make the *world* a better place. Thus, on this view, the fact that no particular person has been harmed is irrelevant. The focus is on society as a whole.

I find this claim problematic in numerous respects. Claiming that one should avoid choices that make the world a worse place can be applied to situations more generally. Arguably, if one chooses to donate to charitable foundations, takes time out to help the impoverished, or takes proactive steps to reduce pollution, these would all make the world a better place. However, it does not follow that a failure to do so, choosing to spend our time and money differently, are necessarily immoral choices.

Another way of stating the non-person-affecting argument would be that we have a duty to balance harms and benefits, discharged when we choose so as to maximise the benefit over the harm.⁸² Thus, if having a handicapped child were the only possible option available to a couple, choosing to have a handicapped child would discharge this duty, as Harris feels:

For those who can only have children with disabilities, having such children may well be morally better, for the parents and for the children, than having no children at all.⁸³

A problem with this analysis is that it appears to impose an obligation to have children. Arguably it would appear that in not reproducing, one has not ‘contributed to the collective pot of human happiness’⁸⁴ and discharged their duty to balance harms over benefits to the fullest extent.

⁸⁰ A concept I will discuss in detail in the next chapter

⁸¹ Savulescu, above, n32 at 425

⁸² *ibid* at 150

⁸³ *John Harris Enhancing Evolution: The Ethical Case for Making Better People* (Princeton University Press, Princeton, 2001) at 108

⁸⁴ Gavaghan, above, **nError! Bookmark not defined.** at 148.

Again, I find this approach irreconcilable with the right to reproductive liberty. There is no harm done that justifies limiting this important right; the non-identity claim silencing any arguments based on the welfare of the child, while the vague concept of producing a net benefit seems to impose an obligation to have children. Further, similar to the 'person-affecting-claim,' it would appear arbitrarily discriminatory and simplistic to judge concepts of 'net benefit to the world' based on genetic traits which might simply predispose one to a minor impairment.

In summary, claims that PGD harms the welfare of the resulting child can be answered quite simply by pointing out that without the use of PGD that particular child would never have existed. Attempts to answer the non-identity conclusion prove unsatisfactory.

Thus, the second group I identified as claiming to be 'harmed' due to PGD is the group that possesses the traits that PGD is commonly used to select against. This group claims that the use of the technology expresses a negative and discriminatory attitude towards their lives. I consider this objection, the so called 'expressivist argument' the strongest opposition to the use of PGD and the most difficult to address.

In the following chapters I will thoroughly examine this argument, the opposition to this line of reasoning and the way in which our law has dealt with these concerns before concluding on whether I believe this to be an adequate solution.

Chapter four: The ‘expressivist’ argument

4.1 The expressivist argument outlined

The expressivist argument⁸⁵ proceeds from the view that discrimination results when people in one group fail to imagine that people in some other group lead lives as rich and complex as their own.⁸⁶ It is claimed that techniques such as PGD inherently judge the value of certain lives. In contrast to opposition based on the welfare of a ‘potential’ child, the expressivist argument is more troubling as those claiming to be affected are living people with rights.

Much of the literature surrounding the expressivist claim refers to the practice of pre-natal screening. In practical terms the expressivist claim is virtually identical in relation to the use of PGD and pre-natal screening, both being objectionable to those who claim the technologies express disvalue for their lives. PGD arguably has the greater potential to be capable of discriminatory selection due to the availability of multiple embryos. This generates additional choice and arguably, this abundance of choice creates an in-built imperative to select. Because no pregnancy has yet been established, there may be greater pressure to eliminate impairment.⁸⁷

Those claiming to be ‘disvalued’ are members of the disabled community. When examining this claim, it is first necessary to determine just who is a member of the ‘disabled community.’ Obviously disability can come in a variety of different forms; physical or mental, permanent or short-term. It can result in a number of different restrictions on ones life, some barely noticeable, while others render their sufferer dependent on carers.

4.2 Defining ‘disability’

The World Health Organisation defines ‘disabilities’ as follows:

Disabilities is an umbrella term, covering impairments, activity limitations, and participation restrictions. An impairment is a problem in body function or structure; an activity limitation is a difficulty encountered by an individual in executing a task or action; while a participation restriction is a problem experienced by an individual in involvement in life situations.

Thus disability is a complex phenomenon, reflecting an interaction between features of a person’s body and features of the society in which he or she lives.

Glover addresses the issue of disability as being,

⁸⁵ Or ‘disability critique’ as labeled in Erik Parens & Adrienne Asch “The Disability Rights Critique of Prenatal Genetic Testing: Reflections and Recommendations” (2003) 29 *Hastings Centre Report*

⁸⁶ Erik Parens & Adrienne Asch “Disability Rights Critique of Prenatal Genetic Testing: Reflections and Recommendations” (2003) 9 *Mental Retardation and Developmental Disabilities Research Reviews* 40 at 41

⁸⁷ Human Genetics Alert “The regulation of pre-implantation genetic diagnosis” (2010) Human Genetics Alert <<http://www.hgalert.org/topics/geneticSelection/pgd.htm>>

A functional limitation, which (either on its own or – more usually in combination with social disadvantage) impairs the capacity for human flourishing.⁸⁸

He notes that conditions with a purely social disadvantage are excluded from this definition as, if the only disadvantage results from reactions by other people, this would encompass such disadvantages as being gay in a homophobic society.⁸⁹ However it was noted that, in comparison to the ‘average’ person, almost every one of us has a functional limitation in some form or another, be it a reduction in height, coordination or vision, without being thought of as ‘disabled.’ Thus, ‘disability’ has a continuum of severity where at times the boundaries between normality and disability may become blurred.⁹⁰

Interestingly the New Zealand Disability Strategy notes that:

‘Disability is not something individuals have. What individuals have are impairments. They may be physical, neurological, psychiatric, intellectual or other impairments. Disability is the process which happens when one group of people create barriers by designing a world only for their way of living, taking no account of the impairments other people have.’⁹¹

The Strategy views the term ‘disability’ as a barrier created by society against people with impairments, evidenced through statements such as, ‘disability is in society, not in me.’⁹²

What exactly constitutes a ‘disability’ is an unsettled issue. However, to properly consider the expressivist claim, one first has to see the disability as ‘identity constituting.’⁹³ The expressivist objection hinges on one’s disability being a part of their self-identity. The necessity for this relationship between disability and self-identity precludes nonsensical claims that could otherwise occur. For example, a view typically advanced against the expressivist claim would be that that reducing the incidence of disabling traits no more sends a negative message to disabled people than reducing the incidence of flu sends a negative message to flu sufferers.⁹⁴ Holding that the disability must be identity constituting also removes such disorders that can be cured, such as removing cancer genes. As discussed by Gavaghan, Reinders noted that it is possible to destroy cancer cells while leaving a person alive. However, when screening for genetic disorders, the means to avoid the disorder necessarily entails avoiding the person as well.⁹⁵

Thus, for the purposes of analysing the expressivist claim, I consider those claiming to be disvalued by the use of PGD are those who have identity-constituting functional limitations which impair their capacity for human flourishing in some way. It is noted by

⁸⁸ Jonathan Glover *Choosing Children: Genes, Disability and Design* (Clarendon Press, Oxford, 2008) at 9

⁸⁹ *ibid*

⁹⁰ *ibid* at p 10-11

⁹¹ New Zealand Disability Strategy (Ministry of Health, Wellington, 2001) at 1

⁹² *ibid* at 3

⁹³ SD Edwards “Disability, identity and the ‘expressivist objection’” (2004) 30 *J Med Ethics* at 418

⁹⁴ John Harris. “Is there a coherent social conception of disability?” (2000) 26 *J Med Ethics* 95-100. Cited in Edwards, above, n93 at 418

⁹⁵ Gavaghan, above, n40 discussing H Reinders *The Future of the Disabled in a Liberal Society: An Ethical Analysis*. (University of Notre Dame Press, Notre Dame, 2000) at 93

Gavaghan that identity-constituting traits do not necessarily include only those traits that are genetic in origin, Alzheimer's being one such example.⁹⁶

The 'message' sent by PGD

Adrienne Asch, an ardent disability rights commentator, maintains that the selection which occurs during PGD is morally problematic because,

This one characteristic of the embryo or fetus is the basis not to continue the pregnancy or implant the embryo. That decision...concludes that one piece of information about a potential child suffices to predict whether the experience of raising that child will meet parental expectations.⁹⁷

It is claimed that destroying a 'whole' by allowing a single trait to stand in for the whole allows a disabling trait to negate everything else the person might be or become.⁹⁸ This, according to Asch's critique, expresses a discriminatory attitude not only about a disabling trait but also about those who carry it. Asch also submits that this signals an intolerance of diversity; not merely in society but in the family unit, which could ultimately harm parental attitudes towards all children.⁹⁹

Asch approaches the problem from a perspective in favour of reproductive liberty, noting that parents have the right to choose when and how many children they want. However, she points out that prenatal testing¹⁰⁰ goes the extra length of allowing prospective parents to not only determine when and how many children they wish to create but also, what *kind* of children they want.¹⁰¹

In relation to assisted reproductive technologies such as PGD and pre-natal testing, Asch notes that the underlying reason for prenatal screening and testing is the elimination of the impaired fetus.¹⁰² According to her critique,

When potential parents use these methods to select against disabling conditions in their future children, they express something negative to and about people living with those conditions. Such choices send the discriminatory message to these individuals that their lives are less worthwhile than the lives of people who do not live with disabilities.¹⁰³

Summing up the claim, Edwards noted,

The "message" that is conveyed by the practice of prenatal screening is that it is morally desirable that persons of a certain kind should not

⁹⁶ Gavaghan, above, n40 at 27

⁹⁷ Adrienne Asch "Why I haven't Changed My Mind About Prenatal Diagnosis: Reflections and Refinements" (Parens, E, & Asch, A, *Prenatal Testing and Disability Rights* (Georgetown University Press, Washington DC, 2000) at 234

⁹⁸ Stainton, above, n1

⁹⁹ Parens & Asch, above, 86. At 42

¹⁰⁰ Which I am reading to encompass PGD

¹⁰¹ Parens & Asch, above, 99 at 41

¹⁰² Erik Parens & Adrienne Asch *Prenatal testing and disability rights* (Georgetown University Press, Georgetown 2000) at 8

¹⁰³ Parens & Asch, above, n86

exist. This seems to presuppose that some human lives are less worth living than others, and this is harmful to currently living disabled people since it expresses a view that their lives should not be worth living.¹⁰⁴

Essentially, I take the claimed ‘message’ to be that those people with identity constituting traits, traits, the reduction of which viewed as morally desirable, are harmed by the practice of PGD being employed to remove individuals possessing such traits from coming into existence. The identifiable harm is the knowledge that their lives are worth less than those who do not possess these ‘disabling traits.’

4.3 Effects of this message

The ‘message’ is claimed to affect both those living with such traits being selected against and those who will be born with such disorders in the future, causing these people to *feel devalued*.¹⁰⁵ Another claimed effect is that widespread use of this technology will lead to a ‘*loss of support*’ for disabled people in society. I will analyse the latter claim first.

Loss of support

This far-reaching claim is that the use of the PGD will affect attitudes towards disabled citizens in such a way as to create a climate where genetic disability is increasingly seen as preventable. This claim is based on the premise that the use PGD will become far more widespread, such that there is a reduction in the number of people with certain conditions.¹⁰⁶ Tom Shakespeare noted that the reduction in number of people with certain disorders could cause a real effect on the lives of those living with those disorders;

As a condition becomes rarer, the impetus to discover a cure or treatment diminishes. This reinforces my wider feeling that, the genetic screening will never be total, which means the proportion of congenital impairment may be reduced, but not eliminated, which means that disabled people will be further isolated, face increasing prejudice, and the pressure to make society accessible to all will be reduced.¹⁰⁷

This fear that perceived societal changes would lead to a lessening of public support for disability rights and reduced funding into developing cures for genetic diseases relies on a ‘sweeping empirical generalisation,’¹⁰⁸ with no evidence to support such a claim. I do not believe that such speculation can be given weight when assessing the expressivist claim. One must bear in mind that there are strong reasons, based on reproductive liberty, to allow the use of PGD. Thus, one should not be overly cautious when balancing the issues at stake.

¹⁰⁴ Edwards, above, n93

¹⁰⁵ Gavaghan, above, n40 at 23

¹⁰⁶ Gavaghan, above, n40 at 22

¹⁰⁷ Tom Shakespeare “Back to the future? New genetics and disabled people” (2005) 15 (2/3) Critical Social Policy at 31 as cited *ibid*.

¹⁰⁸ Allan Buchannan “Choosing who will be Disabled: Genetic Intervention and the morality of inclusion” (1996) 13(1) Social Policy and Philosophy at 22

Buchanan further notes that even if there was valid evidence supporting the ‘loss of support’ claim, accepting that claim would forbid us to take measures to reduce disabilities of any kind.¹⁰⁹ Edwards points out that this acceptance would lead to a *reductio ad absurdum*. If one accepts that the morally desirable reduction in the incidence of a certain condition necessarily entails the reduction of people of a certain type, this objection implies that any means of reducing that type of person is objectionable.¹¹⁰

Therefore, while disabilities with a genetic origin, for example Down’s syndrome or cystic fibrosis, will be covered by the objection, this objection will also apply in cases where disability is caused in some other way, such as through accident. If the expressivist argument were accepted, it would follow that undergoing surgery to have a disability removed ‘sends a message’ to people who have the same disabling condition.¹¹¹

Thus, an unintended consequence of the ‘loss of support’ argument is that it appears to imply that it is, a) wrong to attempt to prevent any form of disability and b) wrong to attempt to ‘put right’ an existing disability. This argument must be rejected due to the absurd consequences that could follow; for example, holding that it would be wrong to treat a babies eyes at birth to prevent blindness caused by bacteria, as lowering the incidence of the disease may lead to a lack of support for blind people.¹¹²

As noted by Alan Buchanan:

If...justice sometimes requires intervening to prevent or remedy disabilities, then it also requires that we give some weight to the interest people have in avoiding disabilities, not just the interests of people who will continue to have disabilities, as the loss of support would have us do.

Gavaghan also notes that, in some instances, a reduction in the number of people suffering from a particular condition may actually *improve* the condition of a sufferer.¹¹³ Conditions such as cystic fibrosis may require a kidney dialysis or organ transplantation, which sees affected parties ‘competing’ for scarce resources. If PGD were to become so widespread as to reduce the numbers of sufferers, their chances of receiving treatment would improve due to less ‘competition’ for the resources.¹¹⁴

Edwards makes the point that we can consistently hold two views; these being that a) prenatal screening¹¹⁵ is justified, and b) disabled people should be supported, and certainly should not be abandoned on the grounds of disability. Thus, he points out that the ‘loss of support’ need not follow from the continued practice of such screening.¹¹⁶

I note that, should such evidence of a ‘loss of support’ come to light, the appropriate way of dealing with such issues is to make every effort to remove societal prejudice towards

¹⁰⁹ Buchanan, above, n112 at 22

¹¹⁰ Edwards, above, 93 at 419

¹¹¹ Edwards, above, 93 at 419

¹¹² Buchanan, above, n112 at 23

¹¹³ Gavaghan, above, n40 22

¹¹⁴ Gavaghan. C. Right Answer, Wrong Solution... at 22

¹¹⁵ Which I am reading as to include PGD

¹¹⁶ Edwards, above, n93 at 419

the disabled community. Efforts to do so are already in existence in our regulatory structures.¹¹⁷

The New Zealand Disability Strategy¹¹⁸ acknowledges that those with a long-term impairment face barriers to full participation in society.¹¹⁹ The Strategy provides a framework for removing barriers in order to promote a more inclusive society. The focus is one of ‘integration and inclusion’ of the disabled in society and addressing underlying prejudices against the disabled.

I conclude that the ‘loss of support’ claim, which does not have sufficient supporting evidence, does not outline a sufficient case for limiting the use of PGD. I now turn to the other claim advanced on behalf of the disabled society.

The claim that the ‘message’ causes one to feel disvalued

This feeling of being disvalued is often expressed in emotive statements such as:

Some of us are "too flawed" in our very DNA to exist; we are unworthy of being born.¹²⁰

In analysing this claim, first it needs to be determined who exactly it is claimed is sending this message. Therefore it is necessary to consider separately the effect of this ‘message’ depending on whom it comes from. I will consider the effects of the message on those claiming to be disvalued when the message is sent by:

- a) Potential parents;
- b) Groups of individuals in significant numbers
- b) The State (via regulation of PGD)

a) This message comes from parents

It is simple to see how a person living with a disabling trait could be aggrieved by the knowledge that, had PGD testing been available to their parents, it is likely they may not have been born, their disabling genes being a reason for them to be selected against. I do not dispute that the use of the technology does send a negative message towards people living with such disabilities. However, while acknowledging that this ‘message’ may cause such an individual considerable anguish, I do not believe that it follows that this would constitute a good reason to limit the use of PGD.

Gavaghan pointed out that many of us probably owe our very existence to the lack of choice available to our ancestors, using the example that if our great-grandparents had the option of effective contraception then many of us may never have existed.¹²¹

¹¹⁷ The New Zealand Bill of Rights Act (NZBORA) 1990 and the Human Rights Act 1990, which I will discuss in more detail later, are two laws available to deal with discrimination issues.

¹¹⁸ The New Zealand Office for Disability Issues is responsible for ensuring that the New Zealand Government gives effect to the New Zealand Disability Strategy.

¹¹⁹ New Zealand Disability Strategy (Ministry of Health, Wellington, 2001)

¹²⁰ M Saxton, “Disability Rights and Selective Abortion” in Solinger, ed. “Abortion Wars: A Half Century of Struggle” (University of California Press, 1998) 374 at 391

¹²¹ Gavaghan, above, n40 24

However, one can hardly use this as a justification for denying contraceptive measures today.

Tom Shakespeare has observed,

The role of prospective parents has largely been ignored by disabled radicals...the decision to terminate pregnancy is not one that the majority of people take lightly...there are reasons to want to prevent the birth of a child affected by impairment which do not reflect discrimination against disabled people: for example, the desire to avoid the early death or suffering of a loved child, or a feeling that a family will be unable to cope with the strain of looking after a very impaired member.¹²²

This concession from a notable supporter of the ‘disability critique’ is noteworthy in that it is recognised that reproductive autonomy is present in termination decisions, allowing parents to base their reasoning for reproductive choices on a number of reasons as they see fit. These reasons may be based on a variety of different factors that have nothing to do with expressing disvalue for disabled people. A desire to avoid bringing into the world an individual with severely limited opportunities may be due to genuine considerations taken into account by parents who do not hold a discriminatory attitude towards those in possession of such traits.¹²³ Parents may base their decision on reasons such as avoiding serious strains on a marriage or family unit, or putting additional pressure on limited resources.¹²⁴

I believe determination of this the issue requires a balancing exercise between the right of those with ‘disabling traits’ to be free from the harm caused by this message and a parent’s right to reproductive freedom.

While I accept that people with disabling traits may receive an objectionable message through the use of PGD, I do not believe that this outweighs an individual’s right to have their reproductive autonomy respected. I noted earlier that limits on reproductive autonomy might be necessary when recognising this autonomy causes harm to others; however that the harm caused by the decisions of a parent to use PGD do not sends a message harmful enough to justify limiting the right to reproductive freedom.

For example, many reproductive choices that we are free to make may send negative ‘messages’ to various individuals or groups in society. The very process in which we choose whom we wish to mate with may be based on inherent personal discriminatory criteria based on race, beauty, IQ or religious beliefs. As this discrimination occurs at a wholly private level, the liberty to undergo this discriminatory exercise is afforded to us without question through the exercise of reproductive autonomy.

As noted by Edwards, the expressivist claim:

¹²² Tom Shakespeare “Choices and Rights: Eugenics, Genetics and Disability Equality” (1998) 13(5) *Disability and Society* 665 at 672

¹²³ Buchanan, above, n1 at 31

¹²⁴ Buchanan, above, n1 at 31

...appears to require moral agents to place their obligations not to harm others above their wishes to enact their autonomous choices, and their choices to avoid avoidable harms.¹²⁵

When examining the claim that the hurtful message comes from ones parents, I do not believe the obligation not to harm others would trump reproductive liberty. Parents should be free to use this technology if they wish as it comes down to a question of reproductive choice.

It could be pointed out that this is a very ‘pro-choice’ stance to take, affording virtually unlimited reproductive autonomy to potential parents. If sufficient numbers of parents were to choose to undergo the process of PGD in order to ensure they did not have a child with a genetic abnormality, this could lead to the expressivist claim that the ‘message’ was being sent by ‘society’ in sufficient numbers to strengthen the discriminatory effects. I will now address the message sent by this group.

b) The message comes from groups of individuals in significant numbers to communicate a message of ‘disvalue.’

Although PGD is a wholly private process it might be claimed that this leads to a form of ‘private eugenics.’ This is due to the likelihood that a large majority of parents, although having the autonomy to choose in whichever way they desired, when given a choice would choose in a particular way. Obviously, in cases concerning the choice between selecting between an embryo with a disease causing genetic defect and a ‘healthy’ embryo following PGD, it could be expected that the majority would choose the ‘healthy’ embryo. Can it then be inferred that this sends a negative message to those with the particular genetic trait being selected against as to how they are valued in their particular society?

I do not believe that the mere fact that a large number of people, when offered freedom of choice, would choose the option to select the ‘healthy’ embryo can be taken as discriminatory towards people with such traits. Such a decision is inherent in human nature. A large number of people make the choice to enter into heterosexual relationships and a similarly large number of people choose not to follow the ‘Scientology’¹²⁶ belief, yet it does not follow that such individuals are discriminating against those that choose otherwise on the basis of sexual orientation or spiritual beliefs.

Restricting these groups from expressing such negative judgments by limiting the available uses of PGD would likely do little to address the issue. Gavaghan noted,

...it is likely that the more sensitive of observers will continue to *suspect* that such values exist in any event...Depriving them of that choice, at best, does no more than mask the offensive judgment or more accurately – and perhaps more significantly – one of many possible manifestations of that offensive judgment.¹²⁷

¹²⁵ Edwards, above, n93

¹²⁶ A controversial religious movement which arose mid-way through the 20th century.

¹²⁷ Gavaghan, above, n40 at 28

I conclude that, although disabled people may feel that groups of individuals as a collective devalue their identity due to the use of PGD technology, it does not follow from this that it would be a justifiable reason to limit the technology.

4.4 The need for regulation?

As outlined earlier, the concept of reproductive autonomy requires that the state should only regulate in order to avoid harm. I have concluded that neither children born as a result of a PGD procedure nor members of the disabled community are harmed through the use of PGD. Thus, it appears inconsistent with reproductive liberty that our legislators chose to regulate the use of the technology.

Regulating the technology appears to be inconsistent with other aspects of reproductive behaviour where there has not been legal recognition. For example, science has informed us that consuming alcohol while pregnant constitutes a grave harm to the foetus. We have also been informed that taking folate during pregnancy greatly increases the chances of avoiding neural tube defects. However, our legislators have so far not felt the need to regulate either of these processes. I infer that the lack of regulation in these areas reflects a recognition that a mother's right to autonomy trumps the foetus's rights not to be harmed in those situations.

However in direct contrast to PGD, where the selection process means there is no harm to a resultant child due to the non-identity conclusion, these two examples both show a situation of identifiable harm to the child. I believe that regulating PGD when there is no identifiable group harmed by use of the technology is inconsistent in comparison to the two examples I gave where there is an identifiable harm yet no regulation. I speculate that our legislators were perhaps over-awed by the ever-present 'designer baby' claims.

Considering that our legislators did choose to regulate the use of PGD, the next step is to examine whether my conclusion to the expressivist claim is the same if the 'message' is not being sent by individual parental decisions on a private level, but through the regulation imposed on the use of this technology by the state. Before I embark on an analysis of this, I will consider the regulatory framework on the use of PGD in New Zealand, and whether this regulation is capable of sending a devaluing message.

Chapter Five: The Regulation of PGD in New Zealand

5.1 The structure of New Zealand law on Assisted Reproductive Technologies

The New Zealand Government first took steps to recognise both the advantages PGD offered and the potential exploitation of the technology in June 2003. The Minister of Health approved the use of PGD in principle, subject to the National Ethics Committee on Assisted Human Reproduction (NECAHR) developing guidelines for the safe and ethical use of PGD.

During 2003/2004 NECHAR developed guidelines on the use of PGD for providers of fertility services, after consideration of the ethical issues associated with PGD. NECHAR came to the conclusion that the use of PGD as covered by the guidelines was ethically acceptable.¹²⁸ Following public consultation in late 2004, NECHAR revised the guidelines, taking into account submissions that had been received. It was noted that due to the pluralistic nature of New Zealand society, agreement on the use of PGD was never going to be possible. In March 2005, the Minister of Health approved the finalised PGD guidelines.

5.2 The HART Act

In 2004, Parliament enacted the Human Assisted Reproductive Technology Act (hereafter the HART Act 2004). The purposes¹²⁹ of the HART Act can be condensed into four main objectives. Firstly it is intended to enable the benefits of assisted reproductive technology while protecting and promoting the 'health, safety, dignity and rights of all individuals.'¹³⁰ The next two purposes¹³¹ purport to prohibit unacceptable assisted reproductive procedures and research, and certain commercial transactions relating to human reproduction. Thirdly, it is to provide a 'robust and flexible framework' to regulate and guide the performance and conduct of assisted reproductive procedures, while prohibiting procedures which do not have the continuing approval of the ethics committee.¹³² The final objective is to establish an information-keeping regime to ensure that those born from donated embryos can establish their genetic origins.¹³³

The first principle of the HART Act outlines that all persons exercising powers or functions under that Act must consider the health and well-being of children born *as a result of the performance of an assisted reproductive procedure*.¹³⁴ In relation to PGD, this principle is irrelevant to the choice made over which embryo to select. A couple could potentially choose an embryo with a genetic impairment without breaching this principle, as they would be doing everything in the interests of the particular child/children born following the procedure.¹³⁵

¹²⁸ Guidelines on Preimplantation Genetic Diagnosis. Prepared by the National Ethics Committee on Assisted Human Reproduction, March 2005

¹²⁹ Human Assisted Reproductive Technology Act 2004, s3

¹³⁰ *ibid* s3(a)

¹³¹ *ibid*, s3(b)-(c)

¹³² *ibid* s3 (d)-(e)

¹³³ *ibid* s3(f)

¹³⁴ *ibid*, s4(a)

¹³⁵ This is due to the principle only applying to children *born* as a result of the procedure, thus as those selected against at the embryo stage are never born they do not generate the protection of this principle.

Other guiding principles¹³⁶ are health safety and dignity of future generations,¹³⁷ the health and well-being of women in particular,¹³⁸ the importance of informed consent,¹³⁹ access to information about one's genetic origins,¹⁴⁰ the needs, values and beliefs of Maori people,¹⁴¹ and that different ethical, spiritual and cultural perspectives are considered and treated with respect.¹⁴²

The HART Act does not directly deal with every aspect of assisted reproductive technology, instead delegating policy and decision-making authority to separate committees.¹⁴³ PGD is not specifically mentioned in the HART Act, although the specific prohibition against selecting 'an in vitro human embryo for implantation...on the basis of the sex of the embryo'¹⁴⁴ is a direct reference to the process of sex selection following PGD.

The HART Act divides assisted reproductive technologies into three categories. Certain actions are specifically prohibited,¹⁴⁵ other acts defined as an 'assisted reproductive procedure'¹⁴⁶ are able to proceed only with the prior approval in writing of the ethics committee¹⁴⁷, and certain acts are designated to be 'established procedures,'¹⁴⁸ which may be carried out without requiring prior approval.

PGD is represented in each of these three categories. Pursuant to the HART Act,¹⁴⁹ PGD was given the status of an 'established procedure' following an Order in Council.¹⁵⁰ The uses of PGD with the status of 'established procedures,' are set out in the guidelines.¹⁵¹ The guidelines establish that PGD in conjunction with HLA tissue typing is able to proceed with ECART approval in certain circumstances, while certain uses of PGD are specifically prohibited in the Guidelines.

Advisory Committee on Assisted Reproductive Technologies (ACART)

The HART Act mandates that an advisory committee known as the Advisory Committee on Assisted Reproductive Procedures and Human Reproductive Research be set up.¹⁵² The Act also mandates certain membership requirements of the committee.¹⁵³ The Act then delegates to ACART a policy-making role with considerable scope for the creation

¹³⁶ *ibid*, s4

¹³⁷ *ibid* s4(a)-(b)

¹³⁸ *ibid* s4(e)

¹³⁹ *ibid* s4(d)

¹⁴⁰ *ibid*, s4(e)

¹⁴¹ *ibid* s4(f)

¹⁴² *ibid*s4(d)-(g)

¹⁴³ The two committee's, ACART and ECART took over the functions of the now disestablished NECAHR.

¹⁴⁴ *ibid* s11(1)(a)

¹⁴⁵ *ibid* Schedule 1

¹⁴⁶ *ibid* s5

¹⁴⁷ *ibid* s16(1)

¹⁴⁸ An 'established procedure' is defined in section 5 of the HART Act 2004 to be any procedure, treatment or application declared to be an established procedure under section 6. Section 6 allows the Governor-General, following the recommendation of the Minister after advice tendered by the advisory committee, to declare certain procedures as established procedures.

¹⁴⁹ *ibid* s6

¹⁵⁰ Human Assisted Reproductive Technology Order 2005 (SR 2005/181)

¹⁵¹ Guidelines on Preimplantation Genetic Diagnosis. Section 1.

¹⁵² *ibid* s32

¹⁵³ *ibid* s33,34.

of guidelines in relation to techniques such as PGD.¹⁵⁴ The Act provides a mechanism¹⁵⁵ by which certain procedures may be declared to be ‘established procedures’ on the basis of ACART’s recommendation.

The New Zealand Parliament has essentially given ACART the authority to determine the permissible limits on PGD within the constraints provided by the principles¹⁵⁶ of the Act.

Ethics Committee on Assisted Reproductive Technologies (ECART)

The HART Act designates¹⁵⁷ that the Minister set up ECART, a committee responsible for approving applications for assisted reproductive techniques in accordance with policy made by ACART. ECART has a mandatory requirement to act in accordance with any guidelines issued by ACART,¹⁵⁸ and may not grant an approval until it is satisfied that the activity proposed to be undertaken under the approval is consistent with relevant guidelines.¹⁵⁹ In the absence of guidelines, ECART will not approve a procedure until ACART provides direction on the issue, thus their decision-making functions are strongly restricted by the Advisory Committee.

5.3 Guidelines on Preimplantation Genetic Diagnosis

The NECAHR Guidelines established a system for the oversight of PGD in New Zealand, outlining the permissible limits of the technology.

Outside of established procedures that may be carried out without ECART oversight, it is an offence¹⁶⁰ for anybody to perform an assisted reproductive procedure¹⁶¹ without the prior approval in writing of ECART. Performance of a PGD procedure that is not within the criteria of an ‘established procedure’¹⁶² or lacks ECART approval will render any person performing it liable to a fine not exceeding \$50,000.¹⁶³ Thus, these Guidelines have indirect legal force through the HART Act, making them analogous to delegated legislation.

Section One

Section One outlines the uses of PGD that a provider may carry out without ECART approval. The Order in Council¹⁶⁴ outlining established procedures is virtually identical to this section.

¹⁵⁴ *ibid*, s35(1)

¹⁵⁵ *ibid*, s35(1)(b)(ii)

¹⁵⁶ *ibid*, s4

¹⁵⁷ *ibid*, s27

¹⁵⁸ *ibid*, s29(a)

¹⁵⁹ *ibid*, s19(2)

¹⁶⁰ *ibid*, s16(1)

¹⁶¹ *ibid*, s5. PGD clearly falls within this definition, being a procedure performed for the purpose of assisting human reproduction that involves the creation of an *in vitro* human embryo.

¹⁶² ‘Established procedures’ are set out in section 1 of the Guidelines

¹⁶³ *ibid*, s16(2)

¹⁶⁴ Human Assisted Reproductive Technology Order 2005 (SR 2005/181) Schedule. Part 2

PGD may be used routinely to detect familial single gene disorders, carry out sex selection for familial sex linked disorders, and detect familial chromosomal disorders. It can also be used to detect non-familial chromosomal disorders associated with age or infertility, (two routine procedures which I will not bring into my discussion, as they do not raise any of the ethical issues I am focusing on.)

For each of the three categories of disorder, there is a requirement that the disorder has been identified in the family/whanau. Familial single gene and familial sex-linked disorders require a 25% or greater risk of an affected pregnancy, with the additional requirement for familial sex-linked disorders that there is no specific test available for the mutation that causes the disorder.

Each of the three categories also require that there is evidence that the future individual may be *seriously impaired* as a result of the disorder. No definition of *serious impairment* is given in the HART Act or the Order in Council. The only assistance in defining this term is given in Section One of the guidelines stating:

It is the responsibility of PGD providers, in collaboration with a clinical geneticist, to determine whether a disorder is likely to be serious in the offspring.

Thus, a broad discretion is left on PGD providers and clinical geneticists in deciding whether a particular genetic impairment is likely to be *serious*. The extremely broad term appears wide enough to include susceptibility¹⁶⁵ disorders and those with a low penetrance.¹⁶⁶ The reference to ‘future individual’ may arguably imply that the scope of PGD may be broadened from testing for heritable disorders apparent at birth to include late onset conditions. Additionally, there is no requirement that the future individual *will* be seriously impaired as a result of the disorder. The use of the word *may* can arguably infer that a mere possibility or likelihood of developing a disease is adequate.

Thus it appears there is scope in the guidelines for PGD to be extended to include disorders that have the potential manifest in adulthood, where a particular genetic sequence increases the chance of one developing the disorder in contrast to the general population. However, this increased chance largely depends on environmental factors. This is a significant departure from ‘traditional PGD’ of testing for serious heritable disorders apparent at birth.¹⁶⁷

¹⁶⁵ ‘Susceptibility’ genes have been identified that increase one’s chance of developing a disorder in contrast to the general population. For example, a frameshift mutation in the NOD2 gene has been associated with susceptibility to Crohn’s disease. Crohn’s disease is an inflammatory disorder thought to result largely from environmental factors in a predisposed host. This is outlined in: Ogura Y *et al* (2001), A frameshift mutation in NOD2 associated with susceptibility to Crohn’s disease. *Nature* 411 at 603

¹⁶⁶ ‘Penetrance’ refers to the statistical likelihood that somebody with a particular mutation will develop a disease. Lung cancer is an example of low-penetrance genetic interactions. The gene *CYP1A1* has been found to activate a separate gene *GSTM1*, which detoxifies the carcinogenic hydrocarbons found in tobacco smoke. Thus, certain individuals with mutations in these genes are at a higher risk of developing lung cancer. However, this risk is greatly exacerbated through smoking. Environmental factors typically play a large role in the expression of low-penetrance genes. For an example see: Alexandrie *et al*. “Genetic susceptibility to lung cancer with special emphasis in *CYP1A1* and *GSTM1*: a study on host factors in relation to age at onset, gender and histological cancer types” (1994) 15 (9) *Carcinogenesis* at 1789

¹⁶⁷ Jeneane Snelling Preimplantation genetic diagnosis for susceptibility conditions: A new frontier or a logical extension? (2008) 16 *J Law Med* at 264

A report on the regulations submitted that it appears doubtful it was intended for such late onset and low penetrance disorders to be included in the ‘established procedures’ category.¹⁶⁸ In favour of allowing susceptibility testing is that the required standard is *seriousness*. Therefore, even though individuals predisposed to late-onset disorders may have decades of good years before the disorder manifests, the genetic disadvantage may be a justification for this selection.

Section Two

Section two outlines uses of PGD that require ECART approval before they can be carried out and details the parameters for ECART decision making. HLA tissue typing in conjunction with PGD must be submitted for approval on a case-by case basis and may only be carried out when certain criteria.¹⁶⁹

Section Three

Section three outlines prohibited actions of PGD. A PGD procedure that does not fall into the requirements of sections one or two is prohibited, as is using PGD to alter the genetic constitution of an embryo.¹⁷⁰

Section Three then goes on to prohibit PGD for, ‘social reasons, including sex selection,’ reaffirming the prohibition on choosing for an embryo on the basis of it’s sex in the HART Act.¹⁷¹ The wording of this prohibition in the Guidelines makes it clear that the ban on this use of PGD is for ‘family balancing’ purposes, through the inclusion of the term, ‘social reasons.’ The use of the non-exclusive term ‘including’ indicating that the prohibition would extend to other ‘social reasons’ not listed.

I wish to focus on the prohibition that states that PGD may not be used ‘to select embryos with a genetic impairment seen in a parent.’ The implication of this prohibition effectively prevents parents from undergoing PGD and then choosing to implant an embryo that contains the genes for a ‘genetic impairment’ in one or both of the parents. I note that this restriction does not impose a legal obligation for impaired parents to undergo a screening test for PGD, even when they may be known to carry impaired genes, thus implying that the reason for this prohibition is to prevent the *deliberate* creation of a genetically impaired child.

In my mind, this section is highly problematic and unnecessary. The initial question one grapples with is why this prohibition was included in our regulation in the first place. As stated by Fukayama one would presume:

That parents would not seek to deliberately harm their children, but rather will try to maximize their happiness.¹⁷²

¹⁶⁸ Henaghan and others *Findings from the Law Foundation Sponsored Human Genome Research Project* (Brookers Ltd, Dunedin, 2009) p17

¹⁶⁹ All which are mandatory obligations that ECART must take into consideration are satisfied.

¹⁷⁰This prohibits the implantation of a genetically modified embryo, which is already prohibited via Schedule 1, clause 8 of the HART Act 2004.

¹⁷¹ Human Assisted Reproductive Technology Act 2004, s11(1)(a)

¹⁷² F Fukayama, *Our Posthuman Future: Consequences of the Biotechnology Revolution* (New York: Faber, Strauss & Giroux, 2002) at 92

It appears that it would be a small minority of parents that would ever wish to choose for a child with a genetic impairment. However, it has already been evidenced that some parents have desired to do this.¹⁷³

This section is in conflict with reproductive autonomy by placing a major restriction on the rights of certain parents to reproduce how they desire. As I have aforementioned¹⁷⁴ reproductive autonomy is a right that can be subject to limits in accordance with ‘widely shared and clearly understood ethical principles.’¹⁷⁵ Thus, the prohibition¹⁷⁶ can be justified if it is balanced out by a strong competing interest.

I turn now to consider the strong competing interest required for such a limit on this right. At first thought one might reason that it is in the best interests of the child *not* to have a genetic impairment. However, this interest can be simply put to rest by reference to the non-identity conclusion.¹⁷⁷ For the particular child born as a result of a selection following PGD, assuming their life does not consist of such intolerable suffering that they would be better off not being born at all, they cannot suffer harm by their birth. In the controversy surrounding *Sharon Duchesneau* and *Candy McCullough*’s choice to increase their chances of having a deaf child like themselves, had they used PGD to screen their embryos, the choice would not be between selecting a ‘hearing Gauvin’ vs. a ‘non-hearing Gauvin.’ The choice would be between selecting a ‘non-hearing Gauvin’ vs. selecting a wholly different individual.¹⁷⁸

If a couple select a deaf child following a PGD screen,¹⁷⁹ the resulting child may be deaf but it is in the interests of that particular child to be born and thus, assuming deafness is not so bad that the child would be better off not being born at all, the child has benefited from the procedure.

As the prohibition cannot be justified on the grounds that it promotes the welfare of the child, one then has to search for other reasons that could justifiably limit the interests of the parents. A possible reason could be the economic benefit to society of not bringing ‘impaired’ children into the world, due to the additional cost on the public health system.

In relation to an economic justification, it appears a stretch that this could be sufficient to limit the right to reproductive autonomy, as one would expect such a situation to be extremely uncommon,¹⁸⁰ and thus unlikely to result in any more than the most minor benefit to the health system. As noted by Gavaghan when discussing a similar section in comparable UK legislation:¹⁸¹

¹⁷³ For example, the case of Sharon Duchesneau and Candy McCullough who wishes to have a baby who shared their deafness.

¹⁷⁴ See Chapter 3.1 Reproductive autonomy

¹⁷⁵ John Robertson *Children of Choice: Freedom and the New Reproductive Technologies*. (Princeton: Princeton University Press, 1994)

¹⁷⁶ Ignoring for the moment the broad, arbitrary and inconsistent wording of the prohibition

¹⁷⁷ See Chapter 3.3 Welfare of the Child. *Non-identity Conclusion*

¹⁷⁸ In accordance with the ‘zygotic principle’ outlined in Chapter 3.3. Welfare of the child. *The non-identity theory*.

¹⁷⁹ Assuming New Zealand law allowed them to do so.

¹⁸⁰ I am still working on the assumption that the majority of parents would not seek to bring a child with a genetic impairment into existence, minor ‘impariments’ such as deafness being one such example.

¹⁸¹ The comparable section in the Human Fertilisation and Embryology Act 2008 is s14(4)(9) which requires: Persons or embryos that are known to have a gene, chromosome or mitochondrion abnormality involving a significant risk that a person with the abnormality will have or develop (a) any serious physical

If the justification is primarily economic, the section looks a little like the proverbial sledgehammer, poised to pulverise the nut of a particularly rare and financially inconsequential parental choice.¹⁸²

In relation to the economic justification, consider the example of a deaf couple in New Zealand who wish to have a deaf baby. They could go about this without employing PGD, attempting to conceive naturally, which could result in either a hearing or non-hearing child. If they produced a hearing child, they might presumably wish to try again in their attempt to create their preferred non-hearing child. Assuming their intention to produce a deaf child is strong, there is no legal restriction on them producing a large number of children in order to fulfill their desire. Assume on their fourth successful birth, they are rewarded with their desired non-hearing child. Also assume they would have stopped at one child had their first birth been a deaf child, would this not result in a greater cost to the health system? If PGD had been successfully employed from the beginning,¹⁸³ from an economic perspective the public health benefit would make PGD the desirable option.

I also note that for such a couple there is no legal restriction on them choosing to keep a 'genetically impaired' foetus which showed an impairment in a pre-natal scan. Thus, it seems arbitrary and inconsistent that the same choice is not available to parents, as a facet of their reproductive autonomy, following a PGD procedure.

The next problem with this prohibition is that the wording of the Guideline appears to have implications beyond the situation of parents wishing to select for a certain disability. Consider for example a couple that underwent PGD in order to prevent a heritable condition occurring in their offspring, and were faced with the outcome that the only viable embryo/s were ones that had the particular disabling trait. It appears that it would be illegal for a provider to insert one or all of the remaining viable embryos. This implication appears nonsensical as had the couple chosen to reproduce naturally and were later faced with the same problem via a prenatal screen, there would be no legal obligation on them to abort the foetus.

This dilemma is most likely the result of an unintentional drafting oversight in the guidelines to which further clarification appears necessary. It is noticeable that although the UK has a similar prohibition on selecting for a genetic impairment,¹⁸⁴ the equivalent section avoids this 'last viable embryo' situation by the wording:

...an embryo must not be preferred to those that are known to have such an abnormality.

The word 'preferred' implies that in the absence of a viable 'healthy' embryo, an embryo with an abnormality could be implanted. Arguably the word 'select' in the New Zealand

or mental disability, (b) a serious illness, or (c) any other serious medical condition, must not be preferred to those that are known to have such an abnormality.

The section has the same controversies as the New Zealand prohibition in relation to the lack of justification to balance reproductive autonomy; however section 14(4)(9) has sufficient clarity to avoid various inconsistencies present in the New Zealand regulation.

¹⁸² Gavaghan, above, n74 at 144.

¹⁸³ Assuming the cost of such a procedure would lie on the parents and not on the public health service.

¹⁸⁴ Human Fertilisation and Embryology Act 2008, s14(4)(9)

guidelines could be used to the same effect; however given the hefty fine which can be imposed on providers acting in breach of the guidelines, it is doubtful they would be willing to take such a risk without first gaining clarification.

Sections four and five

Section four outlines an extensive list of information that providers must give to consumers prior to consenting to treatment and also makes it mandatory that counseling requirements are fulfilled. Section five sets out the procedural requirements for providers wishing to perform PGD.

5.4 The Implication of these Guidelines

The New Zealand Guidelines in combination with The Order in Council¹⁸⁵ allow, through a broad use of language, the potentially unintended consequence that a vast number of genetic disorders may be tested for using PGD as an ‘established procedure’ and therefore not subject to ECART scrutiny.

Of considerable importance to the expressivist debate is section three of the guidelines, which prohibits both sex selection and selecting for embryos with a genetic impairment seen in a parent.¹⁸⁶

It is of interest that the guidelines restrict reproductive autonomy severely in a seemingly unjustified manner. The non-identity concept does not appear to have been considered;¹⁸⁷ however it does not appear that the notion of ‘procreative beneficence’ has been adopted in the alternative, as this would entail the recognition of ‘social selection’ in order to achieve the best possible baby.¹⁸⁸ In fact such ‘social’ selection is specifically prohibited. The mix of vaguely worded criteria and arbitrary prohibitions creates confusion, not only in determining just what conditions are covered by the guidelines, but also in the ethical basis for the criteria.

Keeping in mind the considerable restrictions that these regulations place on the right of reproductive autonomy which I found to be unjustified, I will now examine whether the claim proves the regulations ‘express a discriminatory attitude towards people living with such traits.’

¹⁸⁵ Human Assisted Reproductive Technology Order 2005 (SR 2005/181)

¹⁸⁶ Guidelines 8.3

¹⁸⁷ As had it been considered, I do not believe that there would have been found sufficient justification to prohibit ‘selecting for a genetic impairment seen in a parent.’

¹⁸⁸ Savulescu gave an example of a good memory as a trait capable of leading to a ‘better life.’

Chapter Six: The effect of this regulation on the expressivist claim

6.1 Does the regulation of PGD express disvalue for people with ‘disabling’ traits?

After analysing the relevant legal framework for PGD to proceed in New Zealand, I now turn to the question of whether the state, via regulation, is expressing disvalue for disabled people.

While I did not consider that the hurt felt by the disabled community due to the use and acceptance of PGD amongst parents and societal groups was unjustified, I have come to a different conclusion when examining our legislators.¹⁸⁹

I consider that the judgment from our legislators in the form of PGD regulation, most specifically the guidelines on PGD works in such a way as to exacerbate the discrimination that members of the disabled community might already be experiencing through societal approval and usage of the technology.

To establish this, it is helpful to compare the requirement in section one of the guidelines, that ‘serious impairments’ may be screened out of existence, with the explicit prohibition¹⁹⁰ on choosing for the ‘social reason’ of sex selection. I believe this sends a clear message that while our legislators do not appear to be in approval of the concept of reproductive autonomy to the extent of allowing ‘social selection’ of traits such as sex, certain traits are considered ‘bad’ enough to allow PGD to be employed to select against them. By expressly prohibiting PGD used for ‘social’¹⁹¹ reasons, I believe this reinforces the discriminatory message sent out to those suffering from such disabling conditions that *can* be screened for.

Moreover, this section draws an arbitrary line between what disorders can and cannot be selected for. A ‘serious impairment’ can be screened out of existence, but other traits that might just fall short of this threshold cannot be. One can see that drawing a line such as this can be viewed as a value judgment between those traits.¹⁹² While I am not criticising the metaphoric ‘line’ chosen by the legislators, this difficulty inevitably comes about simply through attempts to make a distinction that includes some traits while excluding others. However, the very act of line-drawing through the regulation,

...increases the likelihood that an explicitly devaluing message will be sent about people whose conditions are listed as ‘serious enough to avoid.’¹⁹³

Interestingly, in another disability critique by Parens and Asch, they agreed that using screening tests for some conditions were reasonable.¹⁹⁴ However, when they attempted to distinguish between reasonable and unreasonable tests, the problem arose of ‘how

¹⁸⁹ Although they are not legislators, I include ACART in this definition as pursuant to the HART Act they are designated the authority to regulate in this area through promulgating guidelines.

¹⁹⁰ In both the HART Act and then reiterated in the Guidelines

¹⁹¹ Which can be taken to mean ‘non-medical’

¹⁹² Gavaghan, above, n40 at 29.

¹⁹³ Parens & Asch. The disability rights critique of prenatal testing: Reflections and recommendations. In: Parens E, Asch A. eds. *Prenatal Testing and Disability Rights*. (Washington, CA: Georgetown University Press; 2000) at 15

¹⁹⁴ An example being Tay-Sachs disease.

many and how clearly should such lines be drawn?¹⁹⁵ It was noted that drawing lines could send a hurtful message by putting some member of the disabled community on ‘the right side of the tracks and others on the wrong.’¹⁹⁶ I will consider alternatives to this line drawing in my recommendations as to how I believe PGD should be regulated.

My most pressing concern is the explicit prohibition in section three on selecting for a genetic impairment seen in a parent. As I discussed in the preceding chapter, I found this prohibition lacks any justification to outweigh the severe restriction on reproductive autonomy. Adopting the non-identity theory rules out a justification on the grounds of the welfare of the child and the economic justification that was minimal at most did not, in my opinion, come close to justifying the prohibition.

Thus, I consider it can only be reasoned that the prohibition on choosing for a genetic impairment seen in a parent metaphorically screams, ‘we do not want any more like you to be born,’ in a rather loud voice. I consider that those affected by this provision have every right to ‘feel devalued’ by the provision.

While arguably it can be pointed out that other areas of the law provide for the best interests of the needs and rights of those living with disabilities in our society,¹⁹⁷ the effect of this may be:

...society is simultaneously sending two messages to the disabled and their families. The first message says, “Since you’re here, we’re going to care for you as best we can,” but the second says, “But everyone would be better off if you were not here at all.”¹⁹⁸

Thus, for those people living with such disorders that are routinely being screened out following PGD, I consider they are hearing the message loud and clear that our legislators have collectively decided that they do not value their lives to the extent of ‘normal’ people. The restriction of PGD via these regulations for the avoidance of certain disabling traits could arguably be seen as eugenic in character.¹⁹⁹

Thus, I conclude that the way PGD is currently regulated in New Zealand results in an unjustifiable discrimination towards members of the disabled society. I will now outline the way I believe this predicament could be resolved.

¹⁹⁵ Parens & Asch, above, n86 at 45

¹⁹⁶ Parens & Asch, above, n86 at 45

¹⁹⁷ Examples being s19 of the New Zealand Bill of Rights Act 1990, which through reference to s21(h) of the Human Rights Act provides the right to freedom from discrimination on the grounds of disability, and the The New Zealand Office for Disability Issues which is responsible for ensuring that the New Zealand Government gives effect to the New Zealand Disability Strategy.

¹⁹⁸ Gavaghan, above, n40 at 26 outlined the quote as stated by H Reinders *The Future of the Disabled in a Liberal Society: An Ethical Analysis*. (Notre Dame, Ind, University of Notre Dame Press, 2000)

¹⁹⁹ Gavaghan, n40 at 31. I note he was expressing a view that regulation *in general* in this area could be thought of as ‘eugenic in character,’ without referring to the specific New Zealand regulations which I have considered.

Chapter Seven: Alternative approaches to regulation

My conclusion is that our current approach to regulation of PGD, rather than respecting the right to reproductive liberty and respecting diversity in our society, instead makes arbitrary value judgments about certain lives.

I note that in regulating PGD and similar technologies, there are three broad approaches that one can take, each of which I will outline.

1. One approach could be to ban the process altogether. This would effectively put an end to the expressivist claim. However, to do so is to ignore the many benefits of PGD. This approach is undesirable as the use of PGD to save the lives of sick siblings, prevent children being born with the dreadful Tay-sachs condition and allow a couple to reproduce free in the belief that they have decreased their chances of having a severely disabled child, are all examples where use of the technology is extremely desirable.

Germany is one country that adopts this regulatory approach.²⁰⁰

2. The second approach is the approach that New Zealand currently adopts, by allowing PGD in certain circumstances but restricting these through regulation. The UK adopts a similar approach where the Human Fertilisation and Embryology Act 1990 delegates almost complete discretion to the HFEA Authority²⁰¹ to determine the permissible limits of PGD with very few express provisions in the Act.²⁰²

The discriminatory effect of the current regulations on those with disabling traits seems an inherent problem with this particular approach to regulation. As I outlined earlier²⁰³ the process of drawing a line between what disabling traits can and cannot be screened for only serves to judge the value of lives against each other and furthers the hurt experienced by those being selected against.

3. The United States of America have adopted a *laissez-faire* approach to PGD, with decisions being left up to Health Care Practitioners, there being no regulation at federal level. This approach has been criticised by some who believe that the lack of state intervention allows for ‘consumer eugenics.’²⁰⁴ This in turn leads to concerns that in such an open market the application of PGD will be expanded beyond the scope of medical purposes and into ‘social selection.’

However, in relation to the problem I identified, adopting this approach would no longer cause discrimination to flow from the State. This would avoid the

²⁰⁰ One feels the prohibition on the technology stems from the eugenic atrocities of the Nazi party in World War Two.

²⁰¹ Although this may be subject to upcoming change due to reports that the HFEA is soon to be disestablished.

²⁰² In *R (on the application of Quintavalle) v Human Fertilisation and Embryology Authority*²⁰² the House of Lords decided that Parliament had intended to define the licensing powers in a broad way and entrust the Authority to decide whether it was ethically acceptable.

²⁰³ See chapter 6.1

²⁰⁴ Bratislav Stankovic ‘‘It’s a designer baby!’’ – Opinions on Regulation of Preimplantation Genetic Diagnosis (2005) 3 UCLA J.L & Tech 1 at 4

arguable ‘eugenic’ tag that could be placed on our State regulation. Although I note that a lack of regulation may be termed ‘consumer eugenics,’ this tag is not generally thought to be as serious as ‘eugenics’ coming from the State itself.

If New Zealand were to adopt a deregulated approach to PGD, similar to that seen in the USA, this would not signal the end of expressivist claims. 95% of people might use PGD to select for traits in such a way that some in the disabled community feel this expresses disvalue for their lives.

However, I note if this stance were to be taken, the difference would be that the discrimination would come about from ‘private’ sources. Deregulating PGD effectively removes any ‘eugenic’ tag from State action. If the State were to take a ‘neutral’ stance, allowing PGD to be used to screen for any trait, the State would be upholding the concept of reproductive autonomy and couldn’t be seen to be expressing judgments against certain fractions of our society. Thus, as I do not believe the choices made by individuals²⁰⁵ harm those with disabling traits in such a way as to justify limiting the use of PGD, there would no longer be a valid ‘expressivist’ claim that those with disabling traits are being harmed by the technology. I reiterate that due to the inherently discriminatory nature of human beings, there will always be decisions made at an individual level that affect fellow beings. However, on an individual level and even when made by a majority of individuals, the right to personal liberty allows one to make such decisions. The notion that an individual causes harm by choosing to ‘go with the majority’ cannot be a valid claim for a minority to ‘feel devalued.’ More would be required to actually ‘harm’ the interest of the minority and in the case of PGD, the imposition of State regulation satisfies this requirement.

I am aware that such suggestions are likely to lead to claims that this would be to ‘descend down slippery slopes,’ ‘practice private eugenics’ and ‘design babies.’

With regards to designing babies, I reiterate the fact that PGD is limited in its ‘designing’ function by the specific combinations of genes the parents possess. The notions of slippery slopes and eugenics are based on speculation. If our State did choose to deregulate PGD, obviously the uses of the technology could be kept under observation. Deregulating PGD is not an example of a ‘stable-door’ issue,²⁰⁶ therefore if evidence of particular problems came about,²⁰⁷ the issue could be revisited and perhaps regulated more strictly.

²⁰⁵ Which I take to include groups of individuals who form a collective

²⁰⁶ Where the consequence of the action could not easily be reversed, for example the release of GMO’s into the environment.

²⁰⁷ For example, a demographic distortion was evidenced.

Chapter Eight: Conclusion

In analysing the use of PGD, I considered the principle of reproductive autonomy and who could potentially be harmed by the technology. The non-identity conclusion confirmed that children born following PGD could not be harmed as a result of the procedure. Thus the members of society who could claim to be 'harmed' by the use of PGD are those who possess such disabling traits as are routinely selected against via PGD.

In terms of individuals who use PGD as a facet of reproductive autonomy I do not consider that PGD causes 'harm' towards those with 'disabling traits.' Harm necessarily requires more than the fact of being a minority.

However, I believe that the choice of our legislators to regulate the application of PGD does lead to 'harm' towards those with disabling traits. The arbitrary drawing of a line between serious and non-serious disorders for the avoidance of certain lives, expresses a value judgment from the state, which could arguably be considered 'eugenic' in character. The prohibition on choosing for an embryo with a genetic impairment likewise is ultimately a value judgment, effectively expressing that certain members of our society do not deserve to be born.

For those reasons I found the regulation of PGD in New Zealand to be extremely unsatisfactory by discriminating against members of our disabled community. The regulations appear to completely overlook the right to reproductive autonomy and the value of respecting diversity.

I consider that an appropriate way of remedying this situation would be a deregulation of PGD. This would avoid any discrimination coming from the State, while upholding reproductive autonomy. By adopting a neutral stance on PGD, this would effectively put to rest the potential claim that, 'New Zealand society is expressing a preference that I was not born.'

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