QUT Law Review ISSN: Online–2201-7275
Volume 18, General Issue 2 pp. 229–245 DOI: 10.5204/qutlr.v18i2.769

CHOOSING IMPAIRMENT: CONFLICTING INTERESTS

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The integration of reproductive genetic testing into clinical care presents both opportunities and challenges for parents in regards to shaping the lives of their future children. The relationship between parents and their future children has become more complex and new questions are being raised in relation to the extent of parental responsibility to future generations. This paper explores the ethical permissibility of using pre-implantation genetic diagnosis (PGD) to select for impairment, through the use of two case studies involving identity-affecting decisions. Through analysing harm using both a personal and impersonal approach, it is concluded that if a couple, or single reproducer, have a choice between an impaired and healthy embryo, and that the same number of children would result from selection, there is a moral obligation for parents to select the ones which will have an acceptable level of interest fulfilment and a normal opportunity for health.

I INTRODUCTION

The integration of genetic testing, including pre-implantation genetic diagnosis ('PGD'), into reproductive care has presented potential parents with new opportunities to influence the lives of their future children. Genetic testing has arguably made reproductive decision making and the relationship between parents and their future children more complex.[1] This raises questions about the responsibilities that parents have in the procreative process and poses new challenges for both academics and regulators.

In this paper, I initially explore the opportunities and challenges posed by assisted reproductive technologies ('ART') and the current policy situation in Australia. Genetic testing approaches have been developed with the aim of offering parents the opportunity to reduce the burden of disease and prevent the transmission of impairing genetic conditions.[2] While this is an exciting opportunity for parents, there is also significant controversy on the use of such technologies. Disability rights advocates claim, among other things, that the use of genetic testing to prevent the birth of those with disabilities correlates with a lack of respect for those living with disabilities.[3]

In addition to the issues raised when the technologies are used as intended, there are the issues associated with those who wish to use the technologies for alternative aims. This includes the use of in vitro fertilisation ('IVF') and PGD for the selection of embryos which will develop into a child with an impairment, such as deafness.[4]

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[1] John Harris, 'Rights and Reproductive Choice' in John Harris and Søren Holm (eds), *The Future of Human Reproduction* (Clarendon Press, 1998).

[2] Allen Buchanan et al, *From Chance to Choice: Genetics and Justice* (Cambridge University Press, 2000) 204.

[3] Erik Parens and Adrienne Asch, 'Disability Rights Critique of Prenatal Genetic Testing: Reflections and Recommendations' (2003) 18(3) *Issues in Law & Medicine* 297.

[4] Karen Schiavone, 'Playing the Odds or Playing God? Limiting Parental Ability to Create Disabled Children Through Preimplantation Genetic Diagnosis.' (2009) 73(1) *Albany Law Review.*

Throughout this paper, I explore the dilemma posed by potential parents deliberately seeking to ensure that their child is born with an impairment, with impairment defined as lacking part or all of a limb, or having a defective limb, organ or mechanism of the body which results in a state a rational person would want to avoid, reduces an individual's opportunity for health and limits their right to an open future.

I analyse a person-affecting harm approach by using three prominent baselines to assess whether selecting for impairment can be considered to harm the future child.[5] It is determined that in this scenario no individual is harmed due to the identity affecting nature of these decisions. Following this conclusion, an interest-based framework is discussed to explore the impact that selecting impairment may have on setting back a future child's interests. It is argued that it is outside the realm of parental autonomy to unnecessarily limit their future child's interests.

I conclude that when choosing between the same number of alternate individuals there should be a preference for those which will have an acceptable level of interest fulfilment. With an acceptable level of interest fulfilment being defined as an equal opportunity for health and normal functioning. Preference should be given to creating a better off child, in contrast to making a child better off.

This conclusion is similar to the principle of procreative beneficence outlined by Savulescu.[6] The conclusion limits the principle of procreative beneficence to same number decisions that deliberately intend to select for impairment. In contrast, Savulescu expands this to the selection of non-diseases genes and indicates that procreative beneficence may allow the selection of embryos with impairment.[7]

The following illustrative case studies will be used to provide a practical reference point for exploring each issue discussed.

Couple A both have achondroplasia (an autosomal dominant condition) and present at a fertility clinic requesting IVF and PGD. The family lives in an adaptive house, are active members of the achondroplasia community and are otherwise healthy individuals. The couple already has a child, also with achondroplasia, who was conceived naturally. The couple are seeking IVF to avoid creating a foetus with two copies of the mutated gene, which is likely to lead to stillbirth. In addition to avoiding the transfer of these embryos, the couple wishes to maximise their chances of successful IVF and would be happy to implant any other viable embryo, including transferring embryos which would develop into a child with achondroplasia. After undergoing IVF and PGD, embryos with one copy of the mutation or no detectable mutation are deemed medically viable for transfer. This is a same number decision as it is choosing between various viable embryos.

[5] Eve Garrard and Stephen Wilkinson, 'Selecting Disability and the Welfare of the Child' (2006) 89(4) *The Monist* 482.
[6] Julian Savulescu, 'Procreative beneficence: why we should select the best children' (2001) 15(5/6) *Bioethics* 413.
[7] Ibid 425.

Couple B are both deaf, one with autosomal dominant deafness (DFNA3)[8] and the other with acquired deafness, with no known fertility issues. They present at a fertility clinic requesting IVF and PGD. The couple are active within the Deaf community and live in an area well adapted to the Deaf community, including the presence of specialised schools. Even though there would be a 50 per cent chance of having a deaf child naturally, the couple seeks to use IVF and PGD to increase their chances of having a child who is deaf like them. They only want an embryo to be transferred if it is deemed likely to result in a deaf child, they do not wish to have a hearing embryo transferred. The couple have indicated that when the child is born they do not intend to treat the deafness with a cochlear implant if it is recommended. This is a same number decision as it is choosing between various viable embryos.

II ASSISTED REPRODUCTION: OPPORTUNITIES AND CHALLENGES

Many parents have a strong and natural desire to want to shape the lives of their children and to give them the best possible start to life.[9] Parents have significant power to influence the development of their child including through education, social and sporting activities, diet and healthcare.[10] The opportunity to shape their children is being widened by access to genetic technologies such as prenatal testing and PGD.

Genetic carrier testing for couples thinking of having children is now widely available in the prenatal and preconception setting. Access and utilisation of this testing is likely to increase significantly in the near future with the announcement of $500 million funding in the 2018 federal budget for the public funding of preconception carrier testing.[11] Preconception carrier testing gives potential parents a vast array of information about their disease susceptibilities and what genetic conditions they may pass on to their children. With the rise in carrier testing, there is likely to be an increase in those seeking PGD. PGD is a technology first implemented in the 1990's which identifies mutations in the pre-implantation embryo that will predispose the future child to specific genetic conditions.[12] The rationale for PGD is to enable a commissioning couple to use the information gained through carrier testing to make informed reproductive decisions. Primarily, this results in only implanting those embryos which are not likely to give rise to a child who will be born with a genetic condition. However, very little scholarship exists, except on specific case studies such as deafness, on the use of this technology to select *for* a particular genetic condition.

While PGD offers a range of possibilities for avoiding debilitating impairments and disability, there are controversies surrounding its use. Those who argue from the perspective of disability rights and advocacy have posed strong opposition to the use of genetic technologies to prevent genetic disease and disability.[13] These academics claim that attempting to eliminate various diseases and disabilities through the use of reproductive

[8] Martijn H Kemperman, Lies H Hoefsloot and Cor WRJ Cremers, 'Hearing Loss and Connexin 26' (2002) 95(4) *Journal of the Royal Society of Medicine* 171.
[9] Buchanan et al, above n 2, 91.
[10] Bonnie Steinbock, 'The Art of Medicine: Designer Babies: Choosing our Children's Genes' (2008) 372(9646) *The Lancet* 1294.
[11] Sophie Scott, *Budget 2018: Mackenzie Casella's Story Inspires a $500m Investment in Genetics* Australian Broadcasting Comission <http://www.abc.net.au/news/2018-05-09/budget-genetic-testing-initiative-is-mackenzie-casellas-legacy/9742198>.
[12] Tarek El-Toukhy, 'PGD Facts and Figures' in Tarek El-Toukhy and Peter Braude (eds), *Preimplantation Genetic Diagnosis in Clinical Practice* (Springer London, 2014) 133.
[13] Parens and Asch, above n 3.

genetic tests devalues the lives of those living with such conditions.[14] This is based on the idea that disability forms a unique part of an individual's identity and that the prevention of such conditions is making a claim about the value of their life.[15] The expressivist objection arises from the fear that increased availability of testing may lead to deepening social pressure to avoid genetic disease, and further prejudice against those living with disabilities.[16] McMahon emphasises that the use of technologies to select against disability negatively impacts human diversity and legitimises discrimination.[17] Along with decreasing acceptance, some believe that there will be declining support for those living with disabilities.[18] Buchannan emphasises that, while this perception may exist, there is no evidence to support the claim that this is a consequence of genetic testing.[19] He also highlights the fact that, even if this was to be true, it would not mean that the aim of reducing disability is wrong as they are discrete issues.[20]

A *The Dilemma*

While parents often seek to ensure the highest levels of health and opportunity for their children, there have been some rare occasions in which parents have sought to deliberately ensure that their child is born with some form of impairment. The most widely publicised case of selecting for disability involved Sharon Duchesneau and Candy McCullough, a deaf lesbian couple from the United States ('US'), who selected a deaf sperm donor to ensure that their child had a hearing impairment.[21] This event spurred much public and academic debate on the permissibility of selecting for disability. As a result of this case, it was felt that the wrongness of selecting for a disability was sufficient for prohibiting it through the *Human Fertilisation and Embryology Act 2008* (UK) in the United Kingdom.[22] While this example does not utilise PGD, it presents a classic example of parents seeking ART for the purpose of conceiving a child with an impairment.

Using PGD to select for impairment is a controversial application of the technology. While rare, there have been notable examples of this practice taking place. This is most likely when parents have an impairment themselves, such as deafness or achondroplasia, and hope that their child can also have the same impairment.[23] In a 2006 survey of US PGD clinics, 3 per cent indicated that they had provided PGD to allow parents to select for disability.[24]

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[14] British Medical Association, *Human Genetics: Choice and Responsibility* (Oxford University Press, 1998) 12.
[15] S. Edwards, 'Disability, Identity and the "Expressivist objection"' (2004) 30(4) *Journal of Medical Ethics* 418; Jackie Leach Scully, '"Choosing Disability", Symbolic Law, and the Media'(2011) 11(3) *Medical Law International* 197.
[16] Felicity Kate Boardman, 'The Expressivist Objection to Prenatal Testing: The Experiences of Families Living with Genetic Disease' (2014) 107 *Social Science & Medicine* 18; Janet Malek, 'Deciding Against Disability: Does the Use of Reproductive Genetic Technologies Express Disvalue for People with Disabilities?' (2010) 36(4) *Journal of Medical Ethics* 217.
[17] Jeff McMahan, 'The Morality of Screening for Disability' (2004) 10(1) *Reproductive BioMedicine* 129.
[18] Tony Fitzpatrick, 'Before the Cradle: New Genetics, Biopolicy and Regulated Eugenics' (2001) 30(4) *Journal of Social Policy* 589.
[19] Allen Buchanan, 'Choosing Who Will Be Disabled: Genetic Intervention and the Morality of Inclusion' (1996) 13(2) *Social Philosophy and Policy* 18, 21.
[20] Ibid.
[21] Julian Savulescu, 'Deaf Lesbians, "Designer Disability," and the Future of Medicine' (2002) 325(7367) *British Medical Journal* 771.
[22] Scully, above n 13.
[23] Schiavone, above n 4; Jackie Leach Scully, 'Disability and Genetics in the Era of Genomic Medicine' (2008) 9(10) *Nature Reviews Genetics* 797.
[24] Susannah Baruch, David Kaufman and Kathy L Hudson, 'Genetic Testing of Embryos: Practices and Perspectives of US in vitro Fertilization Clinics' (2008) 89(5) *Fertility and Sterility* 1053.

An understandable intuition regarding such applications of ART is that this application is inappropriate. Yet to date, there have not been any convincing normative arguments that specifically demonstrate why this use of PGD is wrong.

B *Australian Guidelines and Legislation*

While the ethical issues surrounding the use of PGD for the selection of impairment need to be considered, it is also important to assess the regulatory landscape. The use of PGD in Australia is primarily governed by the National Health and Medical Research Council's ('NHMRC') *Ethical Guidelines on the Use of Assisted Reproductive Technology in Clinical Practice and Research*.[25] While these guidelines are not legally binding, a key aspect of clinical licensing for IVF is that they demonstrate compliance with the NHMRC guidelines. [26] In some states, specific legislation has been enacted to further regulate the use of ART.

It is clear from the guidelines that within Australia the interests of the child or future child should be considered of great importance, even in comparison to the interests of those accessing ART. The language of the NHMRC guidelines emphasise the need to consider the 'interests and welfare of the person who may be born' in the use of reproductive technologies including PGD.[27] In regards to PGD, the guidelines indicate that the technology may be used to avoid serious genetic conditions, improve the effectiveness of ART, or to select for tissue compatibility. In Section 8.15.2, the guidelines also specifically restrict the use of PGD indicating that it 'may not be used to preferentially select in favour of a genetic condition, disease or abnormality that would severely limit the quality of life of the person who would be born'.[28] This is in line with the guidelines' focus on the interests of the child over that of the parents. This also emphasises that interests-based assessments are utilised in policy, thus making it an appropriate mechanism to explore harm in the context PGD and impairment. With the increase in access to these technologies facilitated by a boost in government funding, regulatory bodies are likely to be faced with an increased number of cases that question or challenge the current guidelines. This is likely to include questions around whether it is permissible to implant embryos that are known to have a genetic mutation which will cause, or likely cause, an impairment.

The current NHMRC guidelines can be applied to the case studies detailed in the introduction and provide a useful starting point for assessing the acceptability of these decisions. It is important to note that, in the most recent revision, the NHMRC provides broad criteria on how to assess whether a condition may severely limit the quality of life of a future child by emphasising that each should be assessed on a case by case basis. In Case A, the potential parents are accessing PGD for the accepted use of preventing the transmission of a lethal combination of mutations. When left with a combination of both single (carrier) mutation and no mutation viable embryos, it is likely that the interests of the future child will be considered. If the condition is not deemed to have the potential to have a negative impact on the child then the parents would be free to select any of the remaining viable embryos. As the

[25] National Health and Medical Research Council, *Ethical Guidelines on the Use of Assisted Reproductive Technology in Clinical Practice and Research* (Australian Government, 2017).
[26] Ibid.
[27] Ibid 75.
[28] Ibid 73.

NHMRC guidelines explicitly prohibit the use of PGD to select for a genetic defect, the parents in Case B would not be allowed to use PGD to select an embryo that has a high chance of resulting in a deaf child.

In addition to the NHMRC guidelines on the use of PGD, a number of states have relevant legislation that further governs the implementation of PGD. In Victoria, the *Assisted Reproductive Treatment Act 2008* (Vic) s 28(2)(b) permits the use of PGD to prevent a genetic abnormality in the embryo.[29] If individuals wish to use PGD other than for this purpose they must make an application to the Victorian Patient Review Panel. Similar legislation exists in South Australia and Western Australia, with each state allowing the use of PGD for the prevention of serious genetic conditions, without defining how the seriousness of a condition should be determined.[30] In Western Australia, all those seeking to use PGD must apply for review by the Reproductive Technology Council. From a regulatory perspective, Australia is focused on promoting the interests of the future child, even if this limits parental autonomy.

III REPRODUCTIVE AUTONOMY

Autonomy is one of the most critical concepts in philosophy and bioethics. In its most basic form, autonomy is the ability of an individual to live their own life in line with their own principles and values. For an individual to be considered autonomous, they must have the ability to make decisions and to act freely on those decisions.[31] However, it is critical to note that the right to self-determination is strongest when our decisions have minimal impact on others. As the impact of our decisions on others grows, we can no longer rely solely on the principle of autonomy to govern our actions. Links to others are particularly pertinent in the reproductive context as procreative decisions have a significant impact on the future child.

As 'few decisions we make are more significant than the decision to reproduce'[32] autonomy is critical in the reproductive context. Reproductive autonomy means being able to make informed choices on current and future pregnancies. This includes the 'freedom not to reproduce and the freedom to reproduce when, with whom and by what means' one chooses.[33] Making informed decisions has become more complex in the genomic era, as it is possible to gather an ever-growing amount of information on which conditions an individual may be at risk of transmitting to a future child.[34]

Regardless of the decisions made, this increasing access to technology and information arguably influences the freedoms and responsibilities of prospective parents to decide whether to transmit a hereditary condition to their children.[35] How this information is used can often be a cause of controversy and is closely linked with the issue of selecting for impairment using PGD. Williams highlights the fact that new technologies have a major

[29] *Assisted Reproductive Treatment Act 2008* (Vic) s 28(2)(b).
[30] *Human Reproductive Technology Act 1991* (WA) s 14(2b).
[31] In this paper the concept of autonomy will be limited to decision making, as is regularly the case in bioethics literature. This is on contrast to the broader conception of autonomy found in philosophy where it is a considered as a property of persons and linked with self-rule. Gerald Dworkin, *The Theory and Practice of Autonomy* (Cambridge Univeristy Press, 1988).
[32] Aaron Ridley, *Beginning Bioethics* (St Martin's Press, 1998)
[33] John A Robertson, 'Procreative Liberty and the Control of Conception, Pregnancy, and Childbirth' (1983) 69(3) *Virginia Law Review* 405
[34] Harris, above n 1.
[35] Buchanan et al, above n 2, 204.

impact on the status of the foetus and women, with the technology beginning to further complicate maternal-foetal conflict.[36] Clarkeburn fears that the expansion of reproductive genetic tests, including PGD, will result in a limitation of reproductive freedom by imposing new duties on parents.[37] If parental autonomy was the only consideration in this matter, future parents would be able to use this information in whichever way they saw fit. However, others, such as Garcia et al, argue that all the reproductive information gathered by potential parents should be used primarily for the benefit of the future child.[38] This suggests that the interests of the future child should be considered when making reproductive decisions.[39] This emphasises a conflict that can arise between the interests of the parents and the future child and it is critical to explore how these conflicts can be managed and whether there are situations in which parental autonomy should be limited.

IV PERSON-AFFECTING HARM APPROACH

Many obligations that individuals have to others arise from a duty to not inflict harm. There are both person-affecting and impersonal views of harm. In a person-affecting view of harm, to harm someone is defined is an act or omission that makes that individual worse off than they would have been. An impersonal view of harm is one which focuses on overall good among individuals, rather than in relation to a specific individual.

In the case of PGD, parents are not exercising a choice to make an individual better or worse off. Instead, they are choosing between potential people. These decisions are known as identity-affecting decisions. This means that each decision made would result in a different individual or individuals coming into existence, rather than changing the outcome or future of an isolated individual.[40]

A *Three Prominent Baselines*

Using the three prominent baselines approach, or personal approach to harm, I will demonstrate that no individual is harmed by selecting for impairment. Harm, as defined by Feinberg, is the 'thwarting, setting back or defeating of interests'.[41] This definition of harm relies on an individual being made worse off than they were or they would have been in some alternate world or future.

When determining whether an individual has been harmed using a person-affecting approach, an individual's welfare is compared to three prominent welfare baselines. Jonas terms these three baselines as temporal, counterfactual and duty-based.[42] Using these prominent

[36] Clare Williams, 'Dilemmas in Fetal Medicine: Premature Application of Technology or Responding to Women's Choice?' (2006) 28(1) *Sociology of Health & Illness* 1.
[37] Henriikka Clarkeburn, 'Parental Duties and Untreatable Genetic Conditions' (2000) 26(5) *Journal of Medical Ethics* 400.
[38] Elisa García, Danielle RM Timmermans and Evert van Leeuwen, 'Parental Duties and Prenatal Screening: Does an Offer of Prenatal Screening Lead Women to Believe that they are Morally Compelled to Test?' (2012) 28(6) *Midwifery* e837.
[39] While it is critical to consider the interests of the future child when making reproductive decisions there are other issues that also need to be considered. These include the increasing moral status of the foetus through gestation.
[40] Derek Parfit, *Reasons and Persons* (Clarendon Press, 1987).
[41] Joel Feinberg, *Harm to Others: The Moral Limits of the Criminal Law* (Oxford University Press, 1987).
[42] Monique Jonas, 'Assessing Baselines for Identifying Harm: Tricky Cases and Childhood' (2015) *Res Publica* 1.

baselines, Garrard and Wilkinson argue that no harm comes to an individual by selecting for disability using PGD.[43] They support this by addressing each baseline as laid out below.

Temporal baseline is the welfare state an individual had before an act occurred. Using the temporal baselines involves assessing an individual's welfare before and after an act occurred, for example, before and after the selection of an embryo that will develop into a child with an impairment. To address this baseline we must ask 'is the child worse off than they were before implantation?' No. As life is considered to have greater value than non-existence, it would be difficult to assert that the child could be worse off than they were before implantation. Non-existence can be considered to have a neutral welfare level and as long as the future child's life is worth living, by living they will have some positive welfare value.

Counterfactual baseline is the welfare state an individual would have had, had the act not occurred. Is the child worse off than they could have been in the relevant possible world? The answer to this question is more complex.[44] At face value, the answer would be also be no. This is because impairment is the only possible future for that particular embryo, so transfer cannot be considered to make that individual worse off than they would have been. It means that in an alternate future, it is likely that a different embryo would be chosen that would result in the non-existence of the impaired individual. However, this baseline would require an impairment to be treated at birth as a decision to not treat, which would mean that the individual is harmed as they are worse off without treatment than in an alternate world with treatment.

Duty-based baseline is the welfare state an individual ought to have. Is the child worse off than it ought to be? To answer this question Garrard and Wilkinson use a positive welfare approach arguing that a child 'ought to have a minimally decent existence'.[45] In other words, a life worth living. Again, they argue that any worthwhile life will have a positive welfare value in comparison to a neutral value for non-existence. They also argue that no arbitrary 'minimum welfare level' can be defined that all children ought to achieve as this may not be attainable for all individuals.[46] While this may be the case for those with serious impairments, I argue that every child ought to have a normal opportunity for health and the possibility of an open future uninhibited by any reasonably controllable impairment or disadvantage. Normal opportunity is considered by Daniels to be the normal range of goals and life plans that one could expect to decide between within society.[47] While in many cases the freedom from impairment cannot be guaranteed, in the case of PGD the deliberate transfer of embryos that will give rise to children with more limited life plans is something that can be avoided.

Using these prominent baselines, it can be determined if an act or decision causes harm by making an individual worse off than they were, worse off than they could have been, or worse off than they should have been. This demonstrates that if a person-affecting approach to assessing harm is adopted, no individual is harmed by selecting to transfer an embryo which will develop into a child with an impairment. While this may be the case, other approaches to assessing harm, such as an impersonal approach to harm may result in a different conclusion.

[43] Garrard and Wilkinson, above n 5.
[44] Ibid.
[45] Ibid.
[46] Ibid.
[47] Norman Daniels, *Just Health Care* (Cambridge University Press, 1985).

V AN INTEREST BASED APPROACH

Complexities with reproductive autonomy arise when the interests of the parents and future child conflict. Harris argues that individuals should have the 'right to control their own role in procreation unless the state has a compelling reason for denying them that control'.[48] As discussed above, the primacy of autonomy is significantly reduced when making decisions that will shape the lives of others, such as future children.[49] This links strongly to Mill's harm principle which states that an individual's freedom can be limited when it causes illegitimate harm to others.[50] Like Mill, Camporesi argues that while reproductive freedom is a fundamental right, the state has the ability to intervene when there is a 'direct danger to other citizens'.[51] She emphasises that this cannot be based merely on differences of opinion but instead must rely on a normative assessment on what is ethically permissible.

As reproductive decisions have such a significant impact on the future child, reproductive freedom can be limited to the extent that it protects the interests of the future child, including avoiding unnecessary harm. While in the context of PGD we are only talking about the interests of potential children, Stramondo outlines how embryos can in this situation be considered similarly to newborns and that their conditional future interests are of importance if they are expected to survive to the point where these interests can be satisfied.[52] While the mother does not have an unconditional obligation to ensure the healthy birth of the child (if this was the case abortion and alcohol consumption during pregnancy would be prohibited), parental responsibility to the potential child does exist. Garcia et al argue that this obligation to the potential child arises from the intention to conceive and carry a child to term.[53] In instances where the mother's bodily integrity is concerned, such as if a foetus is diagnosed with a severe genetic condition that would require termination or foetal surgery to 'treat' it, it would not be morally sound to compel the mother to undergo these interventions.[54]This is because these interventions carry physical risk to the mother and could have a negative impact on her physical wellbeing. The mother also has the right to bodily integrity. However, in cases in which the mother's bodily integrity or physical safety is not at risk, the interests of the future child become more important. Buchanan et al support this view, arguing that the more serious the harm to be prevented, and the less serious the risks to the mother and future child, the less important a woman's reproductive autonomy becomes[55]. Ultimately, as the risk/benefit ratio of avoiding harm changes, so too does a mother's obligation to prevent harm.

In the case of parents wishing to select for an impairment, they are ultimately serving their own interests rather than that of the future child. While in some instances it is acceptable for parents and individuals to make decisions that serve their own interests, these interests must be balanced against the interests of others. Sandel highlights the fact that parenting should be based on unconditional love and that genetic selection has the potential to negatively impact

[48] Harris, above n 1.
[49] Buchanan et al, above n 2.
[50] John Stuart Mill, *On Liberty* (Ticknor and Fields, 1863).
[51] Silvia Camporesi, 'Choosing Deafness with Preimplantation Genetic Diagnosis: An Ethical Way to Carry on a Cultural Bloodline?' (2010) 19(01) *Cambridge Quarterly of Healthcare Ethics* 86.
[52] Joseph Stramondo, 'Disabled by Design: Justifying and Limiting Parental Authority to Choose Future Children with Pre-Implantation Genetic Diagnosis' (2017) 27(4) *Kennedy Institute of Ethics Journal* 475
[53] García, Timmermans and van Leeuwen, above n 37.
[54] Buchanan et al, above n 2, 241.
[55] Ibid.

on this.[56] It can be demonstrated that by selecting for impairment parents are seeking to serve their own interests by reasoning such as 'wanting a child like themselves' or by thinking that caring for a child with their same impairment would be easier or communication would be more effective.[57] As a result, it must be questioned whether it is appropriate for a future child to have their own autonomy limited for the purpose of making their parents' lives easier in caring for them. The interests of parents must be contrasted with the future child's interests, including their future autonomy.

B *Interests of a Future Child*

A future child's interests can be analysed using an approach articulated by Daniels. Daniels asserts that all individuals should have a normal opportunity range and that healthcare efforts are critically important in the maternal and child contexts as this sets the terms under which the individuals will develop.[58] In other words, every child should have a normal opportunity for health, to pursue their own life plans, and be a full participating member of society. This requires having normal functioning and being free from preventable genetic disease. Having an impairment that significantly limits functionality will impact on an individual's decisions and life plans, which may include career options, reproduction, living arrangements and education. This limitation on life plans is likely to impede individual autonomy as it reduces the number of options available to an individual below the normal range. This was argued by Feinburg who believed that every child has a 'right to an open future' and deliberately selecting for an impairment limits this.[59] Daniels places great importance on ensuring the equitable distribution of disease risk, which would include the avoidance of deliberately selecting for an impairment which reduced normal functioning. Daniels argues that there is a 'social obligation to protect fair equality of opportunity'.[60] As a result, individuals need to refrain from acts that impede equality of opportunity and act in a way that promotes equality. This clearly precludes the use of healthcare resources in a way that promotes inequality. By being born with an impairment the child will have their future autonomy and life plans limited. As argued above when the harm avoidable is significant enough, and the risks to the mothers' interests minimal, then the balance between the parents' autonomy and the child's interests shifts in favour of the child.

C *Obstacles in Assessing Interest*

While this may seem a simple enough approach, there are inherent difficulties in assessing the interest of a future child. Daniels model is criticised by disability rights advocates and is countered by a social model. Supporters of the social model argue that disability stems from society's failure to recognise and accommodate the needs of individuals with an impairment. Koch believes that physical difference has no negative impact on an individual or their interests and that the issue lies only in society's discriminatory reaction to difference.[61] Oliver uses this to argue that disability is a social construct which can be eliminated with adaptations to the built environment.[62] Barker and Wilson support this view, as they

[56] Michael J Sandel, *The Case Against Perfection: Ethics in the Age of Genetic Engineering* (Belknap Press of Harvard University Press, 2007).
[57] Schiavone, above n 4.
[58] Daniels, above n 46, 75.
[59] Joel Feinberg, *Harm to Others: The Moral Limits of the Criminal Law* (Oxford University Press, 1987).
[60] Daniels, above n 46, 78.
[61] Tom Koch, 'Disability and Difference: Balancing Social and Physical Constructions' (2001) 27(6) *Journal of Medical Ethics.*
[62] Michael Oliver, *Understanding Disability: From Theory to Practice* (MacMillian 1996) 32.

emphasise that a focus on the functional aspects of disability diminishes the importance of the reported quality of life of those living with disabilities.[63] It is recognised that, in terms of quality of life and life satisfaction, key variables in the assessment of whether life is worth living, those with impairment rate similarly to those without an impairment.[64] If the social model of disability was to be adopted in this paper, there would be limited grounds to argue against the permissibility of selecting for disability as any negative consequences of the condition are deemed to be social.

However, proponents of a social conception of disability often ignore the physical aspects. Even with no social prejudice, many would argue that those with physical and mental disability would still experience life differently to a 'typical' person. This is not to say that disability is intrinsically bad, however social change will never take away the fatigue or pain experienced by those with disabilities such as achondroplasia. Individuals are also likely to have restrictions on their life plans as well as often reductions in quality and quantity of life.[65]

The social model focuses on the disabled person's perception of their own life. However, this approach is obscure as selecting against disability prior to conception means that the disabled person would never come into being and have the opportunity to comment on their own life. When faced with the discussion regarding the avoidance of disability through genetic intervention, many of those with disabilities respond with claims by saying things such as 'I am very glad to be alive'[66], or that their lives are worthwhile. While this is a valid claim, there is a difference between respecting the lives and value of those living with disability and seeking to avoid disability in a future child.[67] Instead, an interests-based judgement is being made which compares the potential interest fulfilment of a future disabled individual to a future non-disabled individual. In comparing the medical and social models of disability, it is important to recognise that both believe in remedying the inequality that arises from disability.

In this paper the term impairment is used instead of disability. Impairment here is seen in a medical context and aims to minimise the influence of normative assessment. Proponents of the social model agree that impairment exists with Morris saying that you 'can't deny the destressing nature of the body's experience'.[68] This approach recognises that some effects of impairment are impossible to remove through social change, such as pain and discomfort.[69] Criticising this term, Asch asserts that impairment is not a good predictor of future happiness, with it being no more effective in predicting this than other factors, such as gender and socio-economic status.[70] However, this is too strong a claim as there will be impairments that have

[63] Matthew J Barker and Robert A Wilson, 'Well-being, Disability and Choosing Children' (2018) *Mind* (online).
[64]Ibid.
[65] J Malek and J Daar, 'The Case for a Parental Duty to Use Preimplantation Genetic Diagnosis for Medical Benefit' (2012) 12(4) *American Journal of Bioethics.*
[66] Sheila Black, 'Passing My Disability on to My Children', (2016) *The New York Times* (online), 7 September 2016 <http://www.nytimes.com/2016/09/07/opinion/passing-my-disability-on-to-my-children.html?_r=1>.
[67] Ridley, above n 31.
[68] Jenny Morris, 'Impairment and Disability: Constructing an Ethics of Care That Promotes Human Rights' (2001) 16(4) *Hypatia* 1, 9.
[69] Tom Shakespeare, *Disability Rights and Wrongs* (Routledge, 2006)
[70] Erik Parens and Adrienne Asch (eds), *Prenatal Testing and Disability Rights* (Georgetown University Press, 2000).

a negative impact on an individual, even without societal judgments, including impairments that cause pain and discomfort.[71] These limitations are a restriction on the individuals' autonomy and should not be unnecessarily imposed on a future child through the selection for an impairment. Achondroplasia and deafness involve a defective organ or system within the body and that they have features that rational individuals would want to avoid.

D *Procreative Beneficence*

It is widely accepted that most parents have their child's or future child's best interests at heart when making decisions that will impact on their lives. Savulescu and Kahane claim that most people would agree that 'there is a moral defect in parents who intend to conceive a child but are indifferent to whether their child will have the potential for a good life'.[72] This translates to significant social pressure for parents to make decisions with the interests of their child or future child in mind. For example, waiting to start a family until financially stable, not conceiving during periods of illness, such as rubella, and refraining from drinking alcohol while pregnant. While it cannot be said that these decisions would be better or worse for any particular child, it is accepted that overall it is better to maximise a future child's wellbeing. In line with this, Savulescu and Kahene argue that:

> …if reproducers have decided to have a child, and selection is possible, then they have a significant moral reason to select the child, of the possible children they could have, whose life can be expected to go best, or at least not worse than any of the others[73]

In the context of genetic selection and PGD, this would mean that parents have an obligation to select the 'best' embryo for transfer. However, that view has been criticised for requiring too much of parents and for supporting genetic enhancement as this view requires the parents to not only pick a healthy embryo, but to pick the 'best'.[74] The conclusion reached in this paper is similar to that claim and has the same implications for enhancement.

A more extreme approach is the selection against disability view, which is based on the notion that the subject of choice is the presence of a disability rather than the potential for a good life. This can be extended to the extreme with a constraint on reproduction which would suggest that it is not permissible to knowingly have a disabled child.[75] That approach would restrict reproduction in every case where an embryo was known to carry a disability, regardless of the possibility that the future child could have a life worth living. Procreative beneficence does not have this restriction, only in rare cases where the life of a future child was not predicted to be worth living, would there be some moral reason to avoid procreation.

E *The Same Number Quality Claim*

As the person-affecting approach to harm falls short in explaining why selecting for impairment may be wrong,[76] we can instead look to other conceptions of harm. While

[71] SD Edwards, 'The Impairment/Disability Distinction: A Response to Shakespeare' (2008) 34(1) *Journal of Medical Ethics*.
[72] Julian Savulescu and Guy Kahane, 'The Moral Obligation to Create Children with the Best Chance of the Best Life' (2009) 23(5) *Bioethics* 274.
[73] Ibid 279.
[74] Tom Buller and Stephanie Bauer, 'Balancing Procreative Autonomy and Parental Responsibility.' (2011) 20(2) *Cambridge Quarterly of Healthcare Ethics* 268.
[75] Savulescu and Kahane, above n 71, 285.
[76] It also appears to compel human enhancement which is discussed further below.

selecting for impairment cannot be considered wrong through a person-affecting approach, Parfit's same number quality claim can help to explain why this situation is considered morally questionable through an impersonal approach to harm. This claim states that:

> If in either of two possible outcomes the same number of people would ever live, it would be worse if those who live are worse off, or have a lower quality of life, than those who would have lived.[77]

Garrard and Wilkinson use what they term the 'Moon-Mars' example to explore this principle.[78] In their example, the 'World President' has the choice to establish a colony on either Mars or the Moon. This is an identity-affecting decision, as different people will create the colonies and will be born into them. In the short term, both colonies will be roughly equal in quality. However in the long term, the Mars colony will experience significant degradation and reduction in quality of life. In applying the same number quality claim to this example, the President should choose to establish the colony on the Moon as it has greater long term welfare rating. This is an example of an impersonal approach to harm as it is based on overall welfare rather than on the welfare of a specific individual. McMahan emphasises in his Encompassing Account that while person-affecting acts of harm take primacy over impersonal harm, in instances where the effect of an act is only impersonally harmful, that fact alone provides reason to prevent it.[79] This claim supports adopting an impersonal and interest-based approach to harm in this paper.

The Moon-Mars example is analogous with selecting for impairment, as it involves decisions regarding the long-term outcomes of the same number of individuals. In both Cases A and B, the parents are selecting between embryos which are likely to give rise to a child with an impairment and those which are not. In these instances, the same number of children will result (embryo splitting aside), although they will be different children. Using Parfit's same number quality claim, parents should select the embryos that would have the highest levels of welfare. This claim is an alternate iteration of procreative beneficence, except that the same number quality claim is restricted to same number decisions. This would preclude the selection of embryos with an impairment in situations where other 'healthy' embryos were available to be selected.

F *Implications for Enhancement*

While the same number quality claim offers a justification as to why it is not permissible for parents to select for impairment if unimpaired embryos are available, similar arguments have been criticised for the implications they have for enhancement. This principle would require potential parents not only to select an unimpaired embryo, but also to select of 'the best' embryo, as this is the one with the best chance at the highest welfare. Some argue this offers support for parents seeking to enhance the genetic makeup of their future child; a practice which has its own ethical, social and practical implications.[80] Enhancement is a significant issue in bioethics and it is beyond the scope of this paper to provide a robust treatment of the

[77] Parfit, above n 42, 360.
[78] Garrard and Wilkinson, above n 5.
[79] Jeff McMahan, 'Wrongful Life: Paradoxes in the Morality of Causing People to Exist' in John Harris (ed), *Bioethics* (Oxford University Press, 2001).
[80] Julian Savulescu et al, 'Behavioural Genetics: Why Eugenic Selection is Preferable to Enhancement' (2006) 23(2) *Journal of Applied Philosophy* 157.

issue. However, there is a clear distinction between selection and enhancement.[81] I contend that enhancement is the conceptual opposite of harm, in that it is person-affecting and requires someone to be made better off than that person would have been or could have been. In the instance of selecting between embryos, there is no act to enhance. Instead, there is merely selection between possible lives.

While the full scope of the enhancement issue cannot be resolved here, it is useful to highlight that if the selection of the best embryo is to be considered enhancing, there are practical limitations which can effectively negate the issue of enhancement in the clinic. When utilising genetic testing, such as PGD, a decision has to be made by the clinician or laboratory in regards to what mutations will be analysed. In other words, to find a specific mutation you must look for it.[82] While PGD can be used to test for a vast array of conditions, the mutation panel is specific to individuals utilising the technology and their associated risk factors. For example, in a couple who are carriers for cystic fibrosis their embryos will be tested for specific mutations known to cause cystic fibrosis, but it is unlikely to also be tested for the mutations causing achondroplasia that would be tested for in Case A.[83] This means that in a practical sense, if only disease causing mutations are assessed during PGD there is not sufficient information available to support enhancement decisions. So in Case A, the mutations for achondroplasia will be analysed, but information regarding other traits such as intelligence or physical strength or endurance would not be available to the parents or clinicians when selecting between embryos. Thus, the issues raised by the compulsion to enhance do not translate to practical applications of PGD.

VI WHY IT IS WRONG TO SELECT FOR IMPAIRMENT: IMPLICATIONS FOR CASES A AND B

Throughout this paper the following argument has been outlined:

Premise One: having an impairment is defined as lacking part or all of a limb, or having a defective limb, organ or mechanism of the body which results in a state a rational person would want to avoid, reduces an individual's opportunity for health and limits their right to an open future.

Premise Two: When choosing between the same number of alternate individuals, there should be a preference for those that will have an acceptable level of interest fulfilment; with an acceptable level of interest fulfilment being defined as an equal opportunity for health and normal functioning. Preference should be given to creating a better off child, in contrast to making a child better off.

Therefore, if a couple, or single reproducer, have a choice between an impaired and healthy embryo, and that the same number of children would result from selection, there is a moral obligation for parents to select the ones which will have an acceptable level of interest fulfilment and a normal opportunity for health.

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[81] Ibid.

[82] Søren Holm, 'Ethical Issues in Pre-Implantation Diagnosis' in John Harris and Søren Holm (eds), *The Future of Human Reproduction* (Clarendon Press, 1998).

[83] It is interesting to note that emerging sequencing approaches such as whole genome sequencing may put pressure on this presumption. This approach is not yet routinely used in PGD, and a consideration of emerging technologies is beyond the scope of this paper.

To assess the implications this argument would have on parental responsibility and decision making in the use of PGD, it can be applied to the illustrative case studies. In line with Premise One, the conditions that feature in each of the two case studies can be considered as impairments as each condition involves a defective organ or system that would restrict an individual's life plans. Once this is accepted, then Premise Two above can be considered. The principle enunciated in this premise both combines and restricts the same number quality claim and principle of procreative beneficence. This modified principle requires a potential parent to select the better off child in same number decisions, but does not extend to require a choice that would be considered enhancement.

G *Case A*

Case A, which involves a couple with achondroplasia, is similar to many that would occur at IVF clinics. In this situation, couple A are seeking to use PGD to avoid the distress of maintaining a pregnancy and having a stillborn child as a result of a double dominant mutation for this condition. Using PGD also allows them to avoid the anxiety of undergoing prenatal testing and making decisions regarding abortion; a widely permissible use of the technology. After undergoing IVF and PGD, couple A has embryos that will develop into both children of normal stature and those with achondroplasia. When the above argument is applied to Case A, the parents would be morally required to select one of the embryos with no detectable mutation for implantation as those would have the best chance at the highest levels of welfare. In this instance, it will be an embryo free from the mutation causing achondroplasia as this condition impacts on an individual's long term health and is associated with pain and fatigue.

H *Case B*

When the above argument is applied to Case B, the couple in this scenario should not select an embryo that would develop into a deaf child if other, unimpaired embryos were available for implantation. This is because those embryos that would develop into children with deafness are likely to have a lower overall level of welfare than those with normal hearing. This would be due to limitations in life plans, such as career choices, the impact on development of social connections and physical risks posed by not being able to hear. This presents a plausible approach for demonstrating why selecting for impairment is wrong. Case B is distinct from Case A in that the couple is seeking to use IVF and PGD for the sole purpose of selecting for impairment. I believe that this adds an additional degree of wrongness to these cases.

I *Degrees of Wrongness*

While it has been argued that in all cases the transfer of embryos likely to develop into a child with an impairment should be avoided, I contend that these decisions are not equally wrong. Case B involves potential parents accessing IVF and PGD for the sole purpose of selecting for a child with an impairment. This adds a degree of wrongness which is not present in the other cases.

The presence of compound decisions, rather than single decisions, can change the way ethical permissibility is assessed. When responding to a critique of their argument that no harm results from selecting for disability, Garrard and Wilkinson assert that compound decisions, which are made up of several smaller decisions, can have each step of the decision assessed

for moral permissibility.[84] They compare this to the compound decisions of buying a train ticket with the intention to carry out a terrorist attack. While the purchase of the ticket may not in itself be wrong, the broader aim is. While they do not consider selecting for disability, I believe that the decision to utilise IVF and PGD to select for disability is a compound decision. In this case the potential parents are making the decision to access IVF and PGD and coupling this with the intention to have a child with a disability. The two decisions are therefore: (i) to access IVF and PGD; and (ii) to select an embryo with an impairment. The first act of accessing IVF and PGD is not wrong. It is instead made wrong by the intention to use it to have a child with an impairment.

This principle can be applied to Case B. In Case B, the parents' desire and decision to have a child is not wrong and even their desire to access IVF would not be wrong. However, their decision is made wrong by the intention to use this technology for the sole purpose of having a child with an impairment and their further decision to not treat the resulting impairment. This can be contrasted with Case A where the couple accesses PGD to ensure the best outcome for the pregnancy and future child and are left only with an option of implanting an embryo with known disease-causing mutations and it is assumed that once this child is born they will treat the child for any symptoms for the condition. It is the compounding of the unsound decisions in Case B that I believe adds an additional degree of wrongness making it the least ethically permissible.

VII CONCLUSION

The integration of reproductive genetic testing into clinical care presents both opportunities and challenges to parents in regards to shaping the lives of their future children. The relationship between parents and their future children has become more complex and new questions are being raised in relation to the extent of parental responsibility to future generations. Robust ethical analysis and public consideration of these issues have not kept pace with the integration of these new technologies. This was demonstrated by the case of Sharon Duchesneau and Candy McCullough seeking donor sperm for the purpose of ensuing their child was born deaf. This sparked the need for a normative assessment of the issue of selecting for impairments, rather than against them.

This paper explored the ethical permissibility of using PGD to select for impairment, through the lens of two case studies. Through analysing the harm principle, as well as interest-based approaches, the complexity of identity-affecting decisions and nonexistence were explored. Throughout this paper, it was asserted that having an impairment, defined as lacking part or all of a limb, or having a defective limb, organ or mechanism of the body which results in a state a rational person would want to avoid, reduces an individual's opportunity for health and limits their right to an open future. In addition, when choosing between the same number of alternate individuals, there should be a preference for those which will have an acceptable level of interest fulfilment; with an acceptable level of interest fulfilment being defined as an equal opportunity for health and normal functioning. Preference should be given to creating a better off child, in contrast to making a child better off. Therefore, if a couple, or single reproducer, have a choice between an impaired and healthy embryo, and that the same number of children would result from selection, there is a moral obligation for parents to select the ones which will have an acceptable level of interest fulfilment and a normal opportunity for health.

[84] Garrard and Wilkinson, above n 5.

When applied to the illustrative case studies, these principles would require the parents in Case A and B to select embryos that do not have a detectible disease-causing mutation. While this paper provides a normative argument against the moral permissibility of the selecting for impairment using PGD, further work is needed to assess whether this moral obligation should be enforced through regulation or whether potential parents should retain the ability to decide what type of children they will have, even if these decisions are known to be morally wrong.

The limitations of most scholarship on this topic, including this paper, is that, at its heart, the topic rests on assessment of when we should endow an person or future person with interests and rights worthy of protection. There are pros and cons to all approaches with every formulation leading to some erroneous conclusions. For example, indicating that an embryo has interests worthy of protection without qualification would lead to a complete rejection of abortion. However, indicating that future individuals should have no interests until they are born alive would mean that no 'harm;' could be caused to a foetus. This paper attempts to assess the interests of a future individual from an interest-based approach focusing on impairment rather than a social conception of disability. A framework based closely on the same number quality claim provides an impersonal approach to assessing the permissibility of selecting for impairment through the use of PGD.