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PREIMPLANTATION GENETIC TESTING: THE CONFLICT BETWEEN REPRODUCTIVE AUTONOMY AND DISABILITY RIGHTS.

With the UK, Ireland, and Portugal as Case Studies.

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i. ABSTRACT

Preimplantation Genetic Testing allows parents who are at risk of passing on a serious genetic disability or illness to avoid implanting embryos with genetic abnormalities, when going through IVF. In the UK and Portugal, this is publicly funded and limited to 'serious' genetic abnormalities only, whereas in Ireland there are no national regulations. At first glance, selecting against genetic abnormalities is a justifiable aim in the name of public health and avoidance of human suffering. In addition to this, reproductive autonomy is an important bioethical principle and control over one's private and family life is commonly recognised as essential for human flourishing within a liberal society. However, if we do not remember our history we may be doomed to repeat it. Objectively harmful eugenic policies of the 20th century advocated for the eradication of disability in order to improve the strength of humankind. This traumatic history continues to create fear amongst the disability community for the return of stigmatisation, discrimination and reduced funding for services. However, the reality is that raising a child with a disability correlates with economic, social and mental strains. Should we therefore set limits on an individual's ability to avoid these strains, in order to protect human diversity and the rights of persons with disabilities? If we truly respect reproductive autonomy and the value of disability in our communities then why is it considered immoral to deliberately select an embryo with the gene for deafness? Whilst the majority of disability is attributed to non-genetic factors and therefore the eradication of disability is impossible, grave damage can still be done to our tolerance for human variation and the inherent human dignity regardless of one's genetic constitution.

Word Count – 29863

ii. TABLE OF ABBREVIATIONS

1990 Act	Human Fertilisation and Embryology Act 1990 (UK)
2008 Act	Human Embryology and Fertilisation Act 2008 (UK)
CRPD	Convention on the Rights of Persons with Disabilities
DNA	Deoxyribonucleic Acid
ECHR	European Convention on Human Rights
ECtHR	European Court of Human Rights
ESHRE	Ethics and Law of the European Society of Human Reproduction and Embryology
EU	European Union
FISH	Fluorescent In Situ Hybridisation
HFEA	Human Fertilisation and Embryology Authority
HPRA	Health Products Regulatory Authority
HSE	Health Service Executive (Ireland)
IVF	In-Vitro Fertilisation
NHS	National Health Service (UK)
PCR	Polymerase Chain Reaction
PGD	Preimplantation Genetic Diagnosis
PGT	Preimplantation Genetic Testing
PGT-A	Preimplantation Genetic Testing for Aneuploidy
PGT-M	Preimplantation Genetic Testing for Monogenic Diseases
PGT-SR	Preimplantation Genetic Testing for chromosome Structural Rearrangements
PWD	Persons with Disabilities / Person with a Disability
RNA	Ribonucleic Acid
UDHR	Universal Declaration of Human Rights
UK	United Kingdom
UN	United Nations

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1 INTRODUCTION

1.1 Research Questions and Importance of the Topic

Since the discovery and introduction of PGT, debates have emerged concerning the impact that avoiding the birth of babies with genetic disabilities through PGT and IVF grounded on the right to reproductive autonomy will have on the rights and interests of people living with a disability. Much of the academic commentary on the disability critique is based on the 'expressivist objection' to PGT, arguing that it sends a message to the disability community that their lives are less valuable and should be eradicated where possible. This thesis will explore the expressivist objection, and goes further by exploring the future impacts this can have on the social and environmental barriers that already exist and whether routinisation of PGT will work to expand the bracket of those considered to have a disability.

This thesis aims to provide new insights into the respect for reproductive autonomy for which PGT is rooted in. By exploring the push factors for decisions on undergoing PGT to avoid birth with a genetic disability, this thesis questions whether such decisions are truly autonomous, or are made relative to the unfortunate hardship experienced with raising a child with a disability. In doing so, this paper aims to provoke considerations on whether the social attitudes and environmental barriers work to form the necessary coercion that make PGT practices eugenic.

Existing scholarship has explored arguments for invoking the harm limitation on reproductive autonomy in relation to PGT, in order to prevent harm to the interests of the embryo as a future child or to the family and greater society - who will bear the responsibility of caring for such children. This infers a moral responsibility to use PGT where there is a known risk of having a child with a serious genetic disability, and argues that deliberately selecting embryos that will increase the risk of a child having a certain disability is inherently immoral and should be prohibited. This thesis provides scepticism into whether the latter outlook highlights a hypocrisy in both respect for reproductive autonomy and the inherent value and dignity of PWD.

Whilst commentary on this topic has been made relative to the absence of regulation and a fear for commodification of healthy babies, or a scepticism of regulations in a given jurisdiction, this thesis is unique in its employment of three jurisdictional case studies. The purpose of these

case studies is to highlight that answers to calls for regulation do not always address the issue effectively and that uniformity across jurisdictions is important to deal with reproductive tourism. The UK is considered quite lenient in its regulatory approach, contrasting with Portugal that has been considered more robust, and finally Ireland that has failed to implement any regulatory controls on the practice of PGT. Therefore, these case studies provide effective illustration of theoretical circumstances for the ethical and rights based issues explored.
Finally, this thesis delves into the uncertainty that regulations will address the issues presented, and aims to deal with the implications for the fate of human dignity being dependent on one's genetic constitution and the fate of tolerance for human difference.

1.2 Limitations

PGT can have functions other than the purpose of avoiding genetic disability. These include sex selection, saviour siblings or even to identify a genetic abnormality that is resulting in prolonged infertility or frequent miscarriages. It is not the task of this thesis to analyse these functions, as we focus on the implications for the disability community and our respect for human dignity and difference. In addition to this, when we discuss the use of PGT as a method of screening out disability in embryos, this can often be comparable to methods of prenatal screening and subsequent termination. This alternative approach to avoiding the birth of a child with a disability will not be addressed in this thesis, nor will there be a critical discussion on the right to life of the unborn. Due to practical constraints in consideration of the word count, an analysis of the legal or moral personhood attributed to the embryo is a limitation of this thesis. This would include discussions on the weight of considerations on the interests of the embryo as a future child and when this embryo would be afforded human dignity, which are referred to but not elaborated on.

1.3 Outline

The overall structure of the thesis takes the form of six chapters, inclusive of this introduction and the ultimate concluding observations. Chapter 2 takes the first opportunity to provide answers to the when, why, and how PGT is used in medical practices today. This chapter will also outline the regulations and accessibility of PGT in our three case studies. Genetic counselling is also introduced here, informing the reader on the principles and importance of

providing information to prospective parents on the risks and benefits associated with PGT and raising a child with a disability. The purpose of Chapter 2 is to effectively set the scene on the background information that is necessary in order to comprehensively follow the theoretical analysis on the rights and issues at play.

Chapter 3 provides the historical importance of the eugenics movement, with a focus on its traumatic impact on the disability community. In doing this, this chapter serves to illustrate how eugenic thinking developed and to compare the end-goals with the possible result of new genetic technologies.

In Chapter 4, the importance and legal footing of reproductive autonomy is established, as well as the justifiable limitations under the harm principle. The notion of a responsibility to introduce the healthiest children possible into the world is established here, and we address the issue of 'selecting for disability' whereby reproductive autonomy is prohibited in order to select an embryo with, for example, deafness. This chapter therefore allows us to set up the contradictions to respecting unlimited reproductive autonomy that PGT purports to uphold.

Penultimate to our concluding observations, Chapter 5 is where the disability critique of PGT is presented and analysed. This chapter discusses the advances in the international framework on disability rights from a medical model to the capabilities approach that focuses on addressing the social and environmental barriers to PWD. From this, we question what it is to be disabled and how this is relative to a certain context, time, and community. Ultimately, the purpose of this chapter is to outline the threats widespread embryo selection can have on the rights and interests of the disability community. This includes; stigma and discrimination, stereotypes and unfortunate realities of raising a child with a disability, future impacts on funding, accessibility, and services. Finally, the overarching threat to respect for human diversity and human dignity at the hands of individual acts and the possibility of it amounting to a destruction of tolerance within our global community will be explored.

2 PGT BACKGROUND AND REGULATIONS IN UK, IRELAND & PORTUGAL

Pre-implantation genetic testing ("**PGT**") is essentially the processes whereby embryos are tested for genetic abnormalities. PGT is carried out on embryos before being implanted for the

purpose of in vitro fertilisation ("**IVF**"), a well-known method of medically assisted reproduction.[1] PGT allows couples to go 'from chance to choice'[2] in order to achieve the successful pregnancy of a 'healthy' baby, which can be viewed as an undeniable feat for reproductive autonomy and reprogenetic science. The term 'reprogenetics' is the combination of reproductive technology and genetic scientific methods, and therefore is a useful term we will use to capture the performance of IVF and PGT for the purposes of creating a 'healthy' child.[3]

Prospective parents who are at risk of passing on a serious genetic abnormality allowing their future child to develop a serious disability or disease, or where the parents carry a genetic anomaly that is causing persistent miscarriage or infertility can turn to PGT as a source of real hope to fulfilling what can be considered essential to human flourishing – the choice to have a child and found a family.[4] This chapter will provide at the outset the relevant background knowledge of the PGT process, necessary to follow comprehensively the central arguments that will develop throughout this thesis. Secondly, this chapter provides an overview of the accessibility, procedure and regulations where applicable to our case studies; the UK, Ireland and Portugal. Finally, the principles and importance of genetic counselling in the PGT process will be illustrated in this chapter. This is necessary to provide background information to complement the arguments made both for and against the ethics and morality of embryo selection following PGT.

2.1 Methods of PGT

There are three main methods for testing the genetic makeup of embryos, depending on the situation. Often academic literature, publications and legislation refers to preimplantation genetic 'diagnosis' as opposed to 'testing', which is usually referring to preimplantation genetic testing for monogenic diseases ("**PGT-M**") which indicate within embryos; "recessive single-gene disorders (e.g. cystic fibrosis), dominant single-gene disorders (e.g. Huntington's

[1] JPM Geraedts and GMWR De Wert, 'Preimplantation Genetic Diagnosis' [2009] 76(4) Clinical Genetics 315, 315

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

[3] Robert Coco, 'Reprogenetics: Preimplnatational Genetics Diagnosis' [2014] 37(1) Genetics and Molecular Biology' 271, at p271

[4] Snead O. Carter, *What it Means to be Human: The Case for the Body in Public Bioethics* (Harvard University Press 2020), at p145

Disease), sex-linked disorders (e.g. Duchenne's muscular dystrophy), chromosomal disorders (e.g. translocation) or HLA matching (e.g. saviour siblings).[5] The term 'PGT' is an umbrella terms including two other types of genetic testing as well. Where a person capable of pregnancy has struggled with previous miscarriages, or previous cycles of IVF have failed, this may be due to a genetic abnormality in the number of chromosomes normally incompatible with life, or resulting in a birth with a chromosomal disorder such as Down Syndrome. In this situation, they can avail of preimplantation genetic testing for aneuploidy ("**PGT-A**").[6] Lastly, PGT for chromosome structural rearrangements ("**PGT-SR**") can be performed alongside PGT-A when hereditary chromosomal abnormalities are at risk due to one or both parents have a balanced chromosome structural rearrangement, or prospective parents who already had a child or pregnancy with a chromosome rearrangement.[7] PGT-A and PGT-SR are often considered to raise far less ethical concerns when compared to PGT-M. Therefore, academic commentary, empirical studies and policy debates often concern PGT-M, and therefore similarly will form the basis of most of the arguments and analysis of this thesis when discussing tensions between reproductive autonomy and the impact of PGT on the disability community.

The process involves the removal of one or more cells from embryos generated by IVF and analysing the DNA of those cells. Following these tests on what could be up to 10 embryos, only the embryos with the 'desired genetic profile' will be implanted into the woman's uterus.[8] Embryos can be obtained in conjunction with an intracytoplasmic sperm injection in conjunction with IVF, which helps to fertilise the egg if needed and removes the cells around the embryo and increase the accuracy of the genetic diagnosis.[9]

There are two options for performing a biopsy on the cells. First, a single cell may be removed from the embryo 3 days following IVF, and this is known as a 'single blastomere biopsy.' Alternatively, a fertilised egg may be cultured for 5 or 6 days until what is known as a

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[5] L M Pastore and Others, 'Patients' Preimplantation Genetic Testing Decision-Making Experience: An Opinion on Related Psychological Frameworks' [2019] 4 Human Reproduction Open 1, at p1

[6] Gena Shepherd, 'PGT-A, PGT-M, and PGT-SR: What do all these Acronyms Mean and Why do they Keep Changing?'(*ORM Genomics,* 20 September 2018) < https://ormgenomics.com/2018/09/20/pgt-what-does-it-all-mean/> last accessed 21 July 2022

[7] Ibid.

[8] David S. King, 'Preimplantation genetic diagnosis and the 'new' eugenics' [1999] 25 Journal of Medical Ethics 176

[9] Dagan Wells, 'Advances in preimplantation genetic diagnosis' [2004] 115 European Journal of Obstetrics & Gynaecology and Reproductive Biology 97

'blastocyst' has developed, and approximately 5 cells are then removed a biopsied.[10] Genetic analysis is then performed by fluorescent in situ hybridisation ("**FISH**") for cytogenetic diagnosis (which concerns chromosomal abnormalities and sex diagnosis in cases of X-linked diseases) or polymerase chain reaction ("**PCR**") for molecular diagnosis (which sequences a patient's DNA or RNA for potential future diseases).[11] The FISH process has been developed significantly and its sensitivity expanded since its first use in 1969, and is used to localise DNA sequences on chromosomes.[12] The procedure allows for a clinical diagnosis of chromosomal abnormalities including deletions, duplications and translocations in the DNA double-helix structure.[13] Some examples of chromosomal abnormalities that can be commonly diagnosed in embryos and are the most commonly seen in new born babies are Down syndrome, trisomy 18, trisomy 13, Turner Syndrome, Klinefelter syndrome and triple X syndrome.[14]

FISH can also be used with PGT in order to demonstrate the presence of X-linked diseases. X-linked diseases are understood as conditions caused by mutations on a single gene in the X chromosome. Females have two X chromosomes, whilst males have one Y and one X chromosome, meaning that mutated genes on the X chromosome will cause the disease in males. Because of this, if a member of the prospective parents carries the X-linked disease, the DNA of the biopsied cell during FISH can be examined to determine the sex of the embryo, and then only female embryos will be implanted.[15] Examples of X-linked chromosomes often sought to be prevented through PGT are haemophilia, colour blindness, Duchenne muscular dystrophy, Vitamin D resistant ricks, Charcot-Marie tooth disease, Alport syndrome and Fabry

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[10] G. Kokkali and Others, 'Blastocyst biopsy versus cleavage stage biopsy and blastocyst transfer for preimplantation genetic diagnosis of B-thalassaemia: a pilot study' [2007] 22(5) Human Reproduction 1443, 1443

[11] Claire Basille and Others, 'Preimplantation genetic diagnosis: State of the Art' [2009] 145 European Journal of Obstetrics & Gynaecology and Reproductive Biology 9, 9

[12] Clare O'Connor, 'Cytogeneticists can now go "FISH-ing" for chromosomal abnormalities, which are deletions and duplications that can cause disease. How exactly does FISH work?' [2009] 1 Nature Education 171

[13] Ibid.

[14] Appendix F, Chromosomal Abnormalities 'Understanding Genetics: A New York, Mid-Atlantic Guide for Patients and Health Professionals' (Genetic Alliance, 8 July 2009) <https://www.ncbi.nlm.nih.gov/books/NBK115545/> last accessed 18 March 2020

[15] S. J. Fasouliotis and J.G. Schenker, 'Preimplantation genetic diagnosis principles and ethics' [1998] 13(8) European Society for Human Reproduction and Embryology 2238

disease.[16] Another form of preimplantation genetic diagnosis is performed by a PCR test when concerning single gene molecular disorders, which amplifies the DNA sequences of the biopsied cell to determine the presence of a known mutation and / or indirect markers of allelic segregation on the chromosome.[17] Common single gene abnormalities that PCR can be used to detect include cystic fibrosis, Tay-Sachs disease, spinal muscular atrophy, sickle-cell disease/anaemia, Marfan syndrome, Huntington disease and beta thalassemia.[18]

After testing is carried out on the embryos, the final embryo selection phase occurs, whereby only unaffected embryos will be transferred into the uterus for the purposes of the IVF procedure in order to develop into a pregnancy.[19] This identification and selection is made by the medical practitioner, and is where the controversy and ethical concerns surrounding PGT jumpstarts.

2.2 Access to PGT – Why and Who?

The decision by prospective parents to undergo PGT can often be juxtaposed to the commonly more daunting and traumatic experience of conceiving a pregnancy, having prenatal genetic screening and terminating a pregnancy on the basis of such results. [20] PGT also avoids issues relating to the right to life of the unborn foetus being stronger in some jurisdictions than in others, which may in turn lead to reproductive tourism or generally barriers to this route. In contrast to prenatal screening, pre-implantation genetic diagnosis allows women to have a pregnancy without risk of having a child born with a particular genetic disorder.[21] It has been argued that because discarding embryos is within the routine nature of the IVF operation, and the general agreement that an embryo does not carry near the same weight of moral or legal personhood as a foetus (albeit with a foetus not being granted moral personhood in most liberal

[16] Marina Basta and Ashish M. Pandya 'Genetics, X-Linked Inheritance' (NCBI, 2022) <https://www.ncbi.nlm.nih.gov/books/NBK557383/> last accessed 18 March 2022

[17] Basille and Others, supra n11

[18] Alan Thornhill and Karen Snow, 'Molecular Diagnostics in Preimplantation Genetic Diagnosis' (2002) 4(1) The Journal of Molecular Diagnostics <https://jmdjournal.org/retrieve/pii/S1525157810606769> last accessed 18 March 2022

[19] Baille and Others, supra n11

[20] King, supra n8, 179

[21] King, supra n8, at p176

societies with a strong recognition of reproductive autonomy), then there are no tangible rejections to selecting embryos on basis of its genotype.[22]

Concerns for the impact that routinisation of and unfettered access to PGT would have on the community of persons with disabilities, including biases, discrimination and eugenic attitudes, caused various jurisdictions to introduce restrictions on who and when someone can access PGT.[23] Any regulations of PGT and other genetic testing technology have to be flexible enough to be effective in coping with the rapid developments that come with emerging technologies.[24]

It is necessary to mention that PGT can in theory be used for purposes other than the avoidance of genetic disease and disability, but also could detect the presence of genes associated with characteristics such as eye colour or an ability to sing (this would be non-medical genetic embryo selection), or HLA-typing to create 'saviour siblings' so as to facilitate a transplantation for another child with a life-threatening condition, and finally for sex-selection. These situations are largely considered problematic by consensus for jurisdictions that have regulated for PGT and limit its use to the prevention of serious genetic disabilities and diseases. Whilst the limitation on what is 'serious' or the nature of the conditions that are permissible to test for vary across the case studies as we will discuss next, usually factors such as the severity of the disorder, the age of onset of the disorder and the probability that the genotype will actually come to fruition in the phenotype.[25]

For the purposes of this thesis, I will be comparing access to PGT for IVF in the UK, Ireland and Portugal, both in terms of the nature of disabilities allowed to be screened for, who has access to these tests, and whether the services are publicly funded or privately accessible only.

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[22] Ibid.

[23] Ibid., at p178

[24] Eva C A Asscher, 'The regulation of preimplantation genetic diagnosis (PGT) in the Netherlands and the UK: a comparative study of the regulatory frameworks and outcomes for PGT' [2008] 3(4) Clinical Ethics 176, 176

[25] Guido de Wert, 'Ethics and the Future. Preimplantation Genetic Testing: Normative Reflections' in Joyce Harper (ed) *Preimplantation Genetic Diagnosis* (2nd Edn, Cambridge University Press 2009), at p264

2.3 Regulation of PGT - Case Studies

2.3.1 The United Kingdom

PGT was first developed in the UK in 1990, and has a reputation for being quite liberal and permissive in its approach to regulating PGT, as opined by Asscher[26] and Braude.[27] The Human Fertilisation and Embryology Act introduced in 1990,[28] although not specifically regulating genetic selection methods, did establish the Human Fertilisation and Embryology Authority ("**HFEA**"). This is a semi-independent body that has the authority to set the parameters for what treatments may be licensed and has the responsibility for policy guidelines and regulations involving embryos. [29]

In 2009, amendments to the 1990 Act set out in the Human Embryology and Fertilisation Act 2008[30] came into force, following growing concerns that widespread unregulated use of PGT in IVF could spread eugenic messages that babies with any sort of disability should be avoided where possible. The 2008 Act denoted useful criteria to guide the HFEA when deciding whether a certain clinic is licensed to perform PGT to diagnose a particular genetic predisposition.[31] The intention of these new criteria was stated by Lord Darzi; "that [PGT] should be undertaken only on the grounds of avoiding serious disease."[32] Schedule 2 1ZA(2) expands on the authority's responsibility; that it should be "satisfied that there is a significant risk that a person with the abnormality will have or develop a serious physical or mental disability, a serious illness or any other serious medical condition."[33] The 2008 Act also clarified that embryo selection on the grounds of sex will not be authorised, unless it is for the purposes of avoiding a serious X-linked disease. However, we are still left with the challenge of determining what genetically linked conditions are 'serious' enough to allow them to be

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[26] Ibid.

[27] Peter Braude, 'Pre-Implantation Genetic Diagnosis: Safely Born but Not Designed' in Sheila A.M McLean and Sarah Elliston (eds) *Regulating Pre-Implantation Genetic Diagnosis: A Comparative and Theoretical Analysis* (Taylor & Francis Group 2012), at p5

[28] Human Fertilisation and Embryology Act 1990 (United Kingdom)

[29] Ibid. at p177

[30] Human Fertilisation and Embryology Act 2008 (United Kingdom)

[31] Emily Jackson, 'Statutory regulation of PGT in the UK: unintended consequences and future challenges' in Sheila A.M McLean and Sarah Elliston (eds), *Regulating Pre-Implantation Genetic Diagnosis: A Comparative and Theoretical Analysis* (Taylor & Francis Group 2012), at p71

[32] Ibid., at p78

[33] Human Fertilisation and Embryology Act 2008, Schedule 2, 1ZA (2)

screened out without controversy. Notably, the parameters of what constitutes 'serious' was not debated in the House of Lords or defined in the 2008 Act[34] and therefore the decision on the perceived risk of passing on a genetic abnormality or a chromosomal rearrangement is prescribed by the medical practitioners in the IVF clinics, as long as the concerned monogenic condition is included on the HFEA authorised list.[35] Whilst the seriousness of the disorder was initially to be circumscribed according to the HFEA list based on what the authority considered serious and ethical to test for and avoid, it was later reconsidered that the seriousness of a condition cannot be objectively determined based, and therefore seriousness is to be determined by the clinical physician in practice following discussions and negotiation processes with the patient. The new genetic abnormalities that are then permitted for testing are updated on the HFEA website list, which in 2018 had over 400 conditions and has increased to include over 1300 monogenic conditions at present,[36] some which are treatable, late-onset or carry uncertainty whether the child born will ever in their life be affected by the genetic abnormality.[37]

The NHS Commissioning Board in the UK produced a policy listing the circumstances in which PGT will be routinely commissioned by the national health system.[38] IVF is available to heterosexual couples, single females and homosexual female couples. In order to avail of three publicly-funded cycles the couple must; be at risk of having a serious genetic condition, have been referred to the PGT clinic by an NHS Clinic Genetics Service, have a risk of conceiving a pregnancy affected by a serious genetic condition of 10% or more, and have received genetic counselling from a clinical geneticist or a registered genetic counsellor.

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[34] Human Fertilisation and Embryology Act 2008

[35] 'Embryo Testing: Testing For More Than One Condition At A Time' (Hfea.gov.uk, 2022) <https://www.hfea.gov.uk/media/1500/embryo-testing-testing-for-more-than-one-condition-at-a-time.pdf> last accessed 5 August 2022

[36] 'PGT-M Conditions | HFEA' (*Hfea.gov.uk*, 2022) <https://www.hfea.gov.uk/pgt-m-conditions/?page=1> last accessed 5 August 2022

[37] Thomas Lemke and Jonas Rüppel, 'Social Dimensions of Preimplantation Genetic Diagnosis: A Literature Review' [2018] 38(1) New Genetics and Society 80, at p84

[38] NHS Commissioning Board Clinical Reference Group for Genetics, *Clinical Commissioning Policy: Pre-implantation Genetic Diagnosis (PGT)*, NHSCB/E01/P/a, (2013) <https://www.england.nhs.uk/wp-content/uploads/2013/04/e01-p-a.pdf> last accessed 12 June 2022, at p7

It could be argued, on review of the above criteria, that the UK's approach to providing routine PGT access to couples is not as liberal as stated by Asscher.[39] However, it could be rebutted that the fact that decisions on what constitutes 'seriousness' ultimately rests on negotiations between doctor and patient reduces the rigidity of the regulations in practice.

2.3.2 Ireland

Ireland is a stark contrasting jurisdiction with the UK for the purposes of PGT and IVF access, in the sense that there is almost a total lack of national legislation in its regard. The 'Assisted Human Reproduction Bill'[40] was presented in 2017, which would provide PGT regulation, and although there have been persistent calls for action and implementation on this, the coinciding Act is yet to be established at present. The Quality and Safety of Human Tissues and Cells Regulation 2006,[41] does not regulate PGT, but does provide some governance on the use of gametes and embryos.[42] The Health Products Regulatory Authority ("**HPRA**"), under the 2006 Regulation,[43] is empowered with regulating medicines, medical devices and other health products in Ireland, and to date has licensed approximately 5 clinics across Ireland to carry out embryo biopsy for PGT, of which the genetic analysis is carried out by a private global genetics laboratory called Reprogenetics UK.[44] Therefore, IVF is not provided through the national health system (the Health Service Executive ("**HSE**")) as opposed to the UK, or publicly funded as in Portugal. Instead, a couple can only avail of IVF through a private specialist or clinic, which is no doubt costly and creates a large barrier to accessing these services.[45]

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[39] Asscher, supra n24

[40] Assisted Human Reproduction Bill 2017

[41] S.I. No. 158/2006 – European Communities (Quality and Safety of Human Tissues and Cells) Regulations 2006

[42] Dáil Debate, 12 March 2019 'Assisted Human Reproduction Legislation' (per Minister for Health Simon Harris) <https://www.oireachtas.ie/en/debates/question/2019-03-12/259/> last accessed 18 March 2022

[43] Quality and Safety of Human Tissues and Cells Regulation, supra n41

[44] World first for Irish IVF clinic with successful PGT pregnancy for a fatal inherited disease (Springboard Communications, 2022) <https://springboardcommunications.ie/world-first-for-irish-ivf-clinic-with-successful-PGT-pregnancy-for-a-fatal-inherited-disease/> last accessed 18 March 2022.

[45] 'Fertility Treatments and Assisted Human Reproduction in Ireland' (*Citizens Information*, 19 June 2020) <https://www.citizensinformation.ie/en/birth_family_relationships/before_your_baby_is_born/fertility_treatments_and_dahr.html> last accessed 7 July 2022

In October 2017, the Irish government approved the drafting of the 'Assisted Human Reproduction Bill 2017'[46] which expressly proposes for statutory regulation of PGT for embryos.[47] In 2019, the government further stated that they were committed to publicly funding infertility services, including IVF.[48] Part 5 of the 2017 Bill sets out the circumstances for which PGT can be permitted, stating that "PGT shall be permitted in cases where there is a significant risk of a child being born with a serious genetic disease that is included in the list to be established and maintained by the Regulatory Authority,"[49] and all other purposes are therefore prohibited. As this Bill is not yet enacted, there is no list of diseases available, however Head 29 states that 'genetic disease' for the purposes of the bill is a hereditary disease which must be coupled with a high risk of the person with the disease having a "short life expectancy, serious physical or mental disability or illness and poor treatability."[50]

Therefore, in contemplation of the above – whilst there are some plans for future regulation and commissioned provision of PGT and IVF services – the current absence has left these practices open to be regulated by the private sphere. Clinics licensed by the HPRA offer these services to couples that can afford them firstly, and then will ascertain whether the couple pose a risk of passing on life-limiting or serious genetic disorders and thereby carry out PGT and only implant unaffected embryos in the uterus. This lacuna in public provision and control over PGT and IVF creates a risk of deterring the poorer amongst the Irish population from accessing such services, and may result in wealthier persons being able to have multiple healthy babies thus resulting in a sort of genetic underclass or entrenchment of disability or genetic abnormality being associated with poverty.[51] This fear is consistent with the fact that those who

[46] Assisted Human Reproduction Bill 2017 (Ireland)

[47] Dail Debate, supra n42

[48] Lynn Enright, 'Infertility treatment: When will free IVF be introduced in Ireland?' (Irish Times, 16 January 2021) <https://www.irishtimes.com/life-and-style/health-family/infertility-treatment-when-will-free-ivf-be-introduced-in-ireland-1.4451397 >last accessed 18 March 2022.

[49]Irish Department of Health, *The General Scheme of the Assisted Human Reproduction Bill,* at Part 5: Head 30 < https://assets.gov.ie/19004/d250693cb05d44e2b2c45d7cf26614d3.pdf> last accessed 10 July 2022

[50] Ibid., at Part 5: Head 29

[51] Dorothy E. Roberts, 'Race, Gender and Genetic Technologies: A New Reproductive Dystopia?' [2009] 34(4) The University of Chicago Press 783, at p784

avail of medically assisted reproductive technologies are disproportionately wealthy and white.[52]

2.3.3 Portugal

Finally, this section will present Portugal's national legislation and government initiatives on access and provision of PGT and IVF services. Medically-assisted reproduction has been treated as a major issue in recent years and has led to structural reforms in the Portuguese health sector.[53] 'Fertility Clinics Abroad' described Portugal as the country having one of the most progressive and patient-friendly IVF legislation in Europe.[54] The Medically Assisted Reproduction Law introduced in 2006,[55] and updated in 2021[56] regulates reproductive technologies and monitoring of costs and quality of these services.[57] The first three IVF cycles are publicly funded by the state health services, and is open to female patients between the ages of 18 and 40, and males between 18 and 60 and is available for heterosexual couples, single women and homosexual female couples.[58]

Chapter 5 of the updated 2021 statutory instrument concerns PGT.[59] Article 28(2) states that PGT must be carried out "under the guidance of a responsible specialist doctor" and can only be applied for serious genetic diseases recognised by the National Council for Medically Assisted Procreation, and therefore having scientific recognition that PGT will diagnose, treat or prevent such diseases.[60] In terms of who can access such treatment, article 29 states that couples or a single woman from a family with genetic abnormalities that cause "early death or serious illness, when there is a high risk of transmission to their offspring."[61] In addition to

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[52] Charlene Galarneau, 'Many "Ways of Looking": Physician Refusal of Embryo Transfer' *Center for Bioethics, Harvard Medical School* (Boston, 1 June 2019) <https://bioethics.hms.harvard.edu/journal/mdrefusal-embryo-transfer> last accessed 2 June 2022

[53] Susana Silva and Henrique Barros, 'Perspectives on access to in vitro fertilization in Portugal' [2012] 46(2) Rev Saúde Pública 344, at p345

[54] Dorothy Walas, 'IVF Portugal' (*Fertility Clinics Abroad,* last updated 10 February 2022) <https://www.fertilityclinicsabroad.com/ivf-abroad/ivf-portugal/> last accessed 18 March 2022

[55] Medically Assisted Reproduction Law No.32/2006 of July 2006 (Portugal)

[56] Medically Assisted Reproduction Law No.90/2021 of December 16 (Portugal)

[57] Silva and Barros, supra n53, at p345

[58] Walas, supra n54

[59] Medically Assisted Reproduction Law, supra n56, Part V

[60] Ibid., Art 28(2)

[61] Ibid., Art 29(1)

this, it is clarified that the genetic disabilities deemed applicable for PGT purposes are determined by current good practices both nationally and internationally, and are reviewed periodically by the National Council for Medically Assisted Procreation.[62] A deliberation of what constitutes an illness as being 'serious' enough to be considered morally acceptable to have people select against embryos with that trait is a continuously controversial and contested aspect of the PGT process, and the absence of a legal definition in Portugal has led to the CNPMA interpreting it as genetic diseases that cause significant suffering and / or premature death.[63] This varies slightly to the UK definition which incorporates considerations on the treatability, but in any event the genetic abnormalities are deliberated by the CNPMA periodically.

The Portuguese approach to regulating PGT can be considered progressive in the sense that it is one of the few jurisdictions with specific statutory requirements relating to the application of preimplantation genetic testing. These provisions and the responsibilities of the National Council for Medically Assisted Procreation in establishing a set of applicable genetic abnormalities which are periodically reviewed, as well as case-by-case deliberations for other situations, could be considered as a strict and limited accessibility dynamic. This can be seen by the stated periodic review of applicable genetic diseases, with article 7 qualifying that PGT techniques are prohibited and considered unethical for multifactorial diseases where the predictive value of genetic testing is low, or for diseases with genetically complex makeup.[64]

2.4 Genetic Counselling

Genetic counselling is a fundamental step in the PGT and IVF process. Like any general human rights framework, bioethical principles focus largely on the core respect for patient autonomy and informed consent, and genetic counselling plays a huge role for ensuring this in order for PGT testing to be carried out in an ethical manner. This includes counselling related to IVF

[62] Ibid., Art 29(2)
[63] National Council for Medically Assisted Procreation, 'Resolution on Pre-implantation Genetic Testing' (November, 2021) <https://www.cnpma.org.pt/profissionais/Documents/CNPMA%20DeliberacaoPGT_2021.pdf> last accessed 7 August 2022
[64] Ibid., Art 7(5)

treatment and also genetic counselling.[65] In the next chapter we will discuss the historical background that eugenics plays in the bioethical and human rights fields today at more length, but the transition away from the medical paternalism relationship between doctor and patient is a key feature to mark the repulsion of eugenic practices that paternalism gave way to and a move towards women's reproductive rights through feminist and liberal movements in the 1960s and 70s.[66]

Academic commentary frequently endorses the definition for genetic counselling provided by the American Society of Human Genetics which is as follows:

> A communication process which deals with the human problems associated with the occurrence, or risk of occurrence, of a genetic disorder in a family. It involves an attempt to help the individual or family; comprehend the medical facts about a disorder, appreciate the way in which heredity contributes to the disorder and to the risk of recurrence, understand the options for dealing with the risk of recurrence, choose the course of action which seems most appropriate for them and make the best possible adjustment to the disorder in an affected family member.[67]

Any autonomous decision by a patient must be done when they are fully informed, and therefore genetic counselling must be communicated to a patient in a manner that ensures they know what they are consenting to and the associated risks and benefits. A focus on the principle of non-directiveness is important, so that the prospective parent doesn't feel as though they are being coerced or manipulated into making a certain decision. Lashwood states that non-directive counselling means the trained professional communicates both the medical facts about the genetic impairment as well as the perception of risk that the parent will pass on the gene associated with a certain impairment. Non-biased information on the predicted impact

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[65] Filipa Carvalho and Others, 'ESHRE PGT Consortium Good Practice Recommendations for the Organisation of PGT' [2020] 2020(3) Human Reproduction Open 1, at p5

[66] Shachar Zuckerman, 'The Emergence of the "Genetic Counselling" Profession as a Counteraction to Past Eugenic Concepts and Practices' [2021] 35 Bioethics 528

[67] Alison Lashwood, 'Genetic Counselling' in Joyce Harper (ed) *Preimplantation Genetic Diagnosis* (Cambridge University Press 2009), at p86 citing the American Society of Human Genetics Ad Hoc Committee on Genetic Counselling 1975

that the disorder could have on the future child and the family should be communicated so that prospective parents can carefully consider their options.[68]

Genetic counselling can operate as a useful tool to counteract biases and stigma attached to disability in order to prevent eugenic outcomes that will be discuss in the next chapter. There are many arguments that it is the genetic counselling step within the entire IVF process where the negative social construction of disability is embedded, by a purely medical approach to disability and a discussion of the impact that a disability will have without any actual experience of disability on behalf of professional counsellors, often coming from a biased able-bodied position.[69] Rubeis and Steger remind us of the importance of information regarding a genetic disability not being purely medical in approach and contrasted with a perfectly healthy genetic constitution, but that sound and evidence-based information is used to inform prospective parents of the predicted quality of life attached to the concerned impairment.[70] The ESHRE Consortium for PGT endorses the necessity of non-directiveness in genetic counselling and the requirement that it is performed by an appropriately qualified professional in order to consider PGT offered in accordance with best practice.[71]

3 EUGENICS & 'NEO EUGENICS'

The term eugenics is attached to notions of vehement malpractice, based on racist and classist views rooted in immature science that ultimately led to the Holocaust - and should therefore have the same 'never again' reaction.[72] However, we must inform ourselves of the roots and path along which the eugenics movement grew. First, it is worth expanding on the definition of eugenics and where this came from. Francis Galton first coined the *term* eugenics, directly

[68] Ibid., at p85
[69] Zuckerman, supra n66, at p538
[70] Giovanni Rubeis and Florian Steger, 'A burden from birth? Non-invasive prenatal testing and the stigmatisation of people with disabilities' [2018] 33 Bioethics 91, at p97
[71] Lashwood, supra n67, at p85
[72] Adam Rutherford, 'A cautionary history of eugenics' [2021] 373(6562) American Association for the Advancement of Science 1419

translated from Ancient Greek meaning 'well born.'[73] Interestingly, Galton was a cousin of the renowned scientist Charles Darwin, whom theorised natural selection and that a strong genetic makeup passed on through heredity leads to, what Herbert Spencer labelled, 'survival of the fittest' among mankind. [74] So-called 'Mendelian laws,' deriving from Gregor Mendel, scientifically inferred that genetic determinism meant certain psychological traits and social behaviours were governed by heredity.[75] Perhaps more commonly associated with Germany's *Rassenhygeine*,[76] these emerging classifications of individuals as 'fit' or 'unfit' led to eugenic policies being established in US, Canada, Britain and Scandinavia towards the end of the 19th Century, and really blossoming when this century turned.[77] The label of 'unfit' did not only apply to persons with physical and mental disabilities, but was extended to cover race, ethnicity, country of origin and poverty.[78] However, for our purposes we will analyse the application and implications of eugenic policies concerning disability. Those with a disability were seen as diminishing the quality of the human race by passing on their 'undesirable' traits generation by generation and thus allegedly reducing productivity in society, whilst at the same time consuming precious resources.[79] This combination exacerbated social stigma towards PWD. The growth of eugenic thinking led to drastically ableist views, such as Binding and Hoche's statement that PWD "were 'useless eaters' whose 'ballast lives' could be tossed overboard to better balance the economic ship of state."[80]

In this chapter, we will outline the historical development that led to such strong support for eugenic policies that ultimately became state sanctioned. It is then important to underline that although in hindsight eugenic practices can easily be deemed deeply bigoted, that it was supported by progressive liberal thinkers and feminists as opposed to being cast as fascist and far-right. After establishing the reaction to eugenics after WWII ending and the promise to

[73] Thomas F. Cargill, 'Eugenics in High School History: Failure to Confront the Past' [2020] 25(1) Independent Review 5, at p7
[74] Ibid.
[75] Mark P. Mostert, 'Useless Eaters: Disability as Genocidal Marker in Nazi Germany' [2002] 26 The Journal of Special Education 155, at p158
[76] Lene Koch, 'The Meaning of Eugenics: Reflections on the Government of Genetic Knowledge in the Past and the Present' [2004] 17 Science in Context 315, at p
[77] Daniel J Kevles, 'Eugenics and human rights' [1999] 319 British Medical Journal 435, at p435
[78] Cargill, supra n73, at p5
[79] Mostert, supra n75, at p157
[80] Ibid.

never let such harrowing denial of human dignity occur again, we will compare and contrast eugenics with the new genetic and reprogenetic practices today. Finally, we will prompt questions and concerns for whether PGT can be considered eugenic in practice.

3.1 From the Responsible Citizen to State Coercion

Objectively harmful, government-mandated practices such as sterilisation laws and state-sanctioned killings and abortions are famed eugenic practices from the early 20th century. However, more socially acceptable practices helped to pave the way for support on more extreme eugenic policies nationally, and then internationally. The US is said to be the inspiration for the Nazi movement to develop political means for their racist ends. During the 1920s, eugenic laws were enacted in 24 states in the US,[81] and the infamous case of *Buck v Bell,* from which the commonly restated enunciation 'three generations of imbeciles are enough'[82] was announced by Justice Oliver Wendell Holmes, ramped up the constitutional authority for more states to introduce forced sterilisation policies for those considered mentally unfit and thereby less worthy of life. Such 'imbeciles' were targeted and controls were introduced so that 'society can prevent those who are manifestly unfit from continuing their kind.'[83] Previous to this, feelings of intolerance and ignorance towards PWD were spread across societies through gentler actions considered as 'positive eugenics' such as 'Fitter Family' competitions in US state fairs,[84] as well as state incentives through proposals in the UK for family allowances that would be proportional to parental income so that those in the upper classes would be in a better position to have more children.[85]

Another method of 'positive eugenics' was infiltrated through marriage laws, prohibiting those with disabilities from getting married – these existed in North America from as early as the

[81] Kevles, supra n77, at p435
[82] *Buck v Bell* [1927] 274 U.S. 200, 47 SC 584
[83] Henry Friedlander, *The Origins of Nazi Genocide: From Euthanasia to the Final Solution* (Chapel Hill, N.C.: The University of North Carolina Press 1995), at p8
[84] Kevles, supra n77, at p436
[85] 'The Eugenics Movement | Rare Books & Manuscripts' (*Adelaide.edu.au*, 2022) <https://www.adelaide.edu.au/library/special/exhibitions/significant-life-fisher/eugenics/> last accessed 7 May 2022.

1880s[86] and were introduced as part of the Nuremberg laws in Germany.[87] Therefore, it is important to highlight how these practices grew to be acceptable and desired across different sects of society with diverse interests and backgrounds, but common in their reduction of human beings as permissible to construct and destruct for economic or social purposes.[88] Early Scandinavian methods focused on the underlying message that seeking to avoid transmission of heredity disease through reproduction was a necessary duty in order to be a responsible citizen.[89] Therefore, sterilisation laws were considered 'voluntary' requiring consent of the citizen, save for 'extreme cases' - reserved for individuals deemed antisocial (such as prostitutes or people with mental disabilities).[90] We must of course bear in mind how these 'antisocial' diagnoses were abused and extended to include even those considered merely 'promiscuous.'[91] Sterilisation laws similar to those implemented across the US, were one of the first official acts introduced by the Nazi party in 1933, which made PWD such as deafness and blindness vulnerable to sterilisation. [92]

Another illustration of the toxic state eugenic practices is seen in the evolution from 'voluntary euthanasia' to involuntary killing. The often-recited phrase of the 'right to die' was manipulated under the growing ideology that the life of PWD was of a lesser value, and a parasite on family and societal resources. Intolerance manifested itself so that the right to die could be requested by third parties, such as family members, so as to cease the suffering of the 'life unworthy of life,' hiding behind the allegation that euthanasia is the merciful act.[93] A survey carried out by a director of an asylum for disabled persons showed that a large number of parents expressed a 'positive' attitude towards the killing of their children.[94] This clearly reflects the impact of more conservative eugenic policies and messages being spread through

[86] Harriet S. Meyer, 'Keeping America Sane: Psychiatry and Eugenics in the United States and Canada, 1880-1940' [1998] 279(6) Journal of the American Medical Association 477
[87] Mostert, supra n75, at p161
[88] Sheila Faith Weiss, *The Nazi Symbiosis: Human Genetics and Politics in the Third Reich* (University of Chicago Press 2010), at Ch1 p34
[89] Koch, supra n76 at p320
[90] Ibid.
[91] Jean-Jacques Amy and Sam Rowlands, 'Legalised non-consensual sterilisation – eugenics put into practice before 1945, and the aftermath. Part 1: USA, Japan, Canada and Mexico' [2018] 23(2) The European Journal of Contraception & Reproductive Health Care 121, at p125
[92] Mostert, supra n4, at p161
[93] Ibid., at p159
[94] Ibid.

societies internationally led to an ultimate acceptance of official state sterilisation and killings of thousands of PWD, even by family members and nurses with close relationships with these persons.

3.2 Eugenics: A Progressive Movement?

As aforementioned, the dark history associated with eugenics is often linked with far-right political ideals, such as that of the Nazi Regime in Germany. However, eugenic beliefs and policies should not be historically cast aside as radically conservative or fascist regimes that wouldn't stand today. Eugenics, as stated by Davenport, was 'the science of the improvement of the human race by better breeding.'[95] Although we can now look back and criticise the widespread genetic determinism as being immature science manipulated for racist, homophobic and ableist ends, at the time eugenics was deemed as settled science and often people who questioned it were outcasted and labelled as 'deniers.'[96] We will come back to this dismissal of the eugenics of the 20th Century as being based on 'bad' science as leverage for distancing new scientific technologies and practices later in the chapter.

Following on from this, eugenic policies are not confined to the history of far-right political parties, but were also put forward by progressive parties of the time. Koch underlines that these progressive parties in regions such as Scandinavia were voted in by 'comfortable majorities' and supported by groups in society that identified as socialists and feminists.[97] This is important to underline to draw out the accusation of democratic illegitimacy. The political school of thought, named 'Social Darwinism', applied genetic determinism to enhance social ends, which was largely supported by liberals and social democrats due to its promising aims of reducing costs and improving productivity amongst members of society.[98]

Feminist interests were founded on the basis that women were seen to be essential to 'better breeding.' Therefore, eugenic science and policies could enhance women's rights and

[95] Friedlander, supra n83, at p4
[96] Cargill, supra n73, at p5
[97] Koch, supra n76, at p324
[98] Ibid., at p325

important that a 'fitter' human race would be more open to improving equality for women and giving more opportunities for reproductive autonomy.[99]

3.3 Hitler's Rassenhygeine and the 'Never Again' Promise

Thus far, this chapter has established the narrative on the growth of eugenic thinking over time. From mere popular theories on the correlation between characteristics and social issues, stemming out to stronger political guidance and policies, and ultimately growing support across the world as a common goal to strengthen the human race. The means to reach such a goal being to minimise the number of PWD, amongst other 'undesirable' groups deemed to be genetically determinate, such as criminals and poor people in our societies.[100] The superiority of the Aryan race was becoming an increasingly popular attitude across northern Europe at this time.[101] As aforementioned, eugenics then really 'hit its nadir'[102] during Nazi rule in Germany under the *Rassenhygeine* programme, forming part of the Nuremburg laws.[103] Patients in care institutions suffering with mental and physical disabilities lost their rights, including children.[104] Such radical segregation, sterilisation and deliberate killing of those deemed 'unworthy' of life led to the 'unprecedented horrors of the Holocaust.'[105] The Holocaust, coupled with the conclusion of the second world war, is arguably the most significant event for human rights action. After the destruction and blatant denial of humanity through the Nazi's *Rassenhygeine* policies, the world was forced by shock to turn their attention to a new age of recognising a minimum standard of fundamental human rights for all human beings equally, and a commitment to upholding these. There was a distinguished promise made amongst the

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[99] Esther Rosario, 'Feminism' (*The Eugenics Archives*, 2013) <http://eugenicsarchive.ca/discover/tree/52336b0a5c2ec50000000049> last accessed 5 May 2022.
[100] Kevles, supra n77, at p435
[101] Adam Hochman, 'Of Vikings and Nazis: Norwegian contributions to the rise and fall of the idea of a superior Aryan race' [2015] 54 Studies in History and Philosophy of Science Part C: Studies in History and Philosophy of Biological and Biomedical Sciences 84, at p84
[102] Bonnie Rochman, *The Gene Machine: How Genetic Technologies Are Changing the Way We Have Kids – and the Kids We Have* (Scientific American / Farrar, Straus and Giroux 2017), at p61
[103] Frank Stahnisch, 'Racial Hygiene and Nazism' (*The Eugenics Archives,* 2014) <https://eugenicsarchive.ca/discover/encyclopedia/545134d251854fef65000001> last accessed May 10, 2022
[104] Ibid.
[105] Ibid.

states that formed the United Nations that 'never again' would such horrors be permissible under international law.[106]

After this longstanding tragic treatment of PWD during Nazi rule, eugenic theories and practices began to be seen in a new, sinister light.[107] Genetic scientists began to turn their back on the tabooed label of eugenics, and instead turned eugenics research departments into ones focusing on genetic science and their thinking toward newer technologies such as preimplantation genetic diagnosis.[108] Therefore, it is necessary to bear in mind the means and ends of the old eugenic policies, and why they were eventually abandoned when we begin to consider the ethical standing of the new genetic technologies and critically analyse the distinctions between new genetic practices and the traditional eugenic practices.

3.4 Defining 'New Genetics' – Distinct from the old Eugenics?

Scientists and members of society in general who are in favour of enjoying the benefits of scientific development and the application of new genetic technologies to human beings, are quick to ensure the distinction between the new genetic era and the horrid Eugenic era is made clear.[109] Two common assertions are that the old eugenics is based on state coercion whereas today's practices are voluntary, and the second being that old eugenics is based on immature and unsound science whereas today we know more about genetics and can be correctly applied with more confident scientific knowledge. These assertions will be analysed and challenged, thus blurring the lines between old and new genetic practices.

3.4.1 Voluntary vs Involuntary

It has been presented above how the eugenic policies that enforced sterilisation and euthanasia of persons with disability became increasingly harsh and were made into direct legal orders by the state. However, this is not entirely true as many states implemented only voluntary eugenic policies and whilst these had significant impacts on public opinion & therefore action, they

[106] Eric Brown, 'The Dilemmas of German Bioethics' [2004] 5 The New Atlantis 37, at p38
[107] Susan Bachrach, Ph.D, 'In the Name of Public Health – Nazi Racial Hygeine' [2004] 351(5) The New England Journal of Medicine 417, at p419
[108] Rutherford, supra n72, at p1419
[109] Robert Sparrow, 'A Not-So-New Eugenics: Harris and Savulescu on Human Enhancement' [2011] 41(1) The Hastings Center Report 32, at p32

were still technically voluntary. At the same time, some policies existed that were technically 'voluntary policies' rather that state dictated rigid laws, and some eugenic practices were rigid legal obligations. Fuelled by propaganda and bigoted intolerance, a message was bestowed on communities that one must do what is right for society and rid the human race of those who are draining it of its resources without paying anything back – aka the 'useless eaters.'[110] Huxley summarises this theory simply, stating that by encouraging birth rates among the fit, and sterilising the unfit, would lead to the improvement of mental abilities among future generations and lead to 'responsible citizenship.' If we turn to look at the new genetic era, it can be argued that the same global ends are being advocated to be met through a similar individualised duty of a 'responsible' person or parent-to-be. Advocates of the application of new genetic technologies through processes such as PGT or prenatal testing often state not only that the use of these technologies are a feat for humanity and a positive development to eradicate harmful diseases and disability, but that parents should feel morally obligated to undergo such testing.[111] This falls under the theory that to choose not to avail of PGT or to undergo testing and insist that an 'unfit' embryo is implanted, is doing harm to the future child. This discussion of harm to a future child is arguably manifestly intangible – as it implies a harm is being committed without an actual victim of harm, as selecting for an unfit embryo or avoiding testing altogether is bringing about a situation where a *different* child will exist, it is not that the same child is now being detrimentally harmed – different embryos result in different possible pregnancies and subsequently entirely different children.[112] This is known as the 'non-identity problem'[113] and will be discussed later when discussing reproductive autonomy and genetic 'disenhancement.'[114] However, the sentiment that you would be harming your child by not undergoing PGT when going through IVF implies a sense of *de facto* involuntariness, where a social pressure based on new norms of genetic perfection make parents feel that choosing to not undergo PGT would be irresponsible and out of the ordinary.[115]

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[110] Mostert, supra n75
[111] Sparrow, supra n109, at p32
[112] Martin Harvey, 'Reproductive Autonomy Rights and Genetic Disenhancement: Sidestepping the Argument from Backhanded Benefit' [2004] 21(2) Journal of Applied Philosophy 125, at p127
[113] Ibid.
[114] Ibid., at p125
[115] Heather Draper and Ruth Chadwick, 'Beware! Preimplantation Genetic Diagnosis May Solve Some Old Problems but it Also Raises New Ones' [1999] 25(2) 114, at p117

Therefore, although the traditional eugenics was harmfully enforced through state coercion and as support grew voluntariness declined, it can be argued that new eugenics still involves a sort of involuntariness albeit manipulated to appear that such 'moral obligation' is for individual interests of individual parents rather than for communal social ends.[116] Still, the end result may appear that both involve a sort of coercion, whether that be state or social.

3.4.2 Unsound vs Sound Scientific Basis

A UK study based on interviews with scientists saw strong attempts to highlight that new genetics is based on legitimate science and its end goals are beneficial for individuals, whereas eugenics was based on a sort of 'pseudo-science' and its ends were vested in hatred and were dangerous for humanity.[117]

The discovery of DNA's double-helix structure by Watson and Crick in 1953 was monumental for genetic science and puzzled scientists for decades – a large time after the eugenic era.[118] In 1990, the Human Genome Project began, and was concluded only in 2003 when the mapping of the sequence of the entire human genome was achieved.[119] This was a great feat in the name of genetic scientific development, and implied the use of genetic technologies would be based on more personalised and predictive genetic knowledge in order to identify various illnesses, diseases and disabilities.[120] On the back of such leaps in scientific exploration, there are frequent efforts amongst geneticists to communicate that genetic science of today is 'value-free,'[121] whilst eugenics was not objective but rather based on backward science manipulated for propagandic purposes.

It would be unfruitful to deny that advances in genetic information have made it clear the lacuna that existed in scientific knowledge for centuries, which eugenic advocates relied on to the detriment of PWD. At the same time, we must contextualise the phenomenon that history repeats itself, and that we think we know everything until someone comes along and dispoves

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[116] Sparrow, supra n109, at p32

[117] Alan Petersen, 'Is the New Genetics Eugenic?: Interpreting the Past, Envisioning the Future' [2007] 60(1) New Formations 79, at p83

[118] Aisling de Paor, *Genetics, Disability and the Law: Towards and EU Legal Framework* (Cambridge University Press 2017) at p15

[119] Ibid., at p29

[120] Petersen, supra n117, at p79

[121] Ibid., at p82

it. This is exactly James Stuart Mill's theory, that freedom of expression in a democratic society allows us to constantly express our theories and learn from one another and that after deliberation over time, truth will reveal itself.[122] Therefore, how can we say with 100% authority that the science of today won't be undermined and disproven fifty or one hundred years down the line? Even the mere possibility of this eventuality should make clear the necessity of risk-managing the wider application of genetic technologies for public use and their impact on our disability community.

3.5 Can we classify PGT as a 'Neo Eugenic' practice?

Going back to the argument that new genetics are beneficial for the individual and based on 'value-free' science[123] – it could be said that the theory advocating for new genetics and the application of genetic technologies is often backed up by asserting human rights such as the right to reproductive autonomy and the right to private life and family life. Whilst it would be reductive and cynical to say that the invocation of individual rights are based on self-interest alone, it may have some relevance when considering the impact of the cumulative effect of morally justifiable individual acts of reproductive autonomy on the disability community. A contemplation of the impact on wider society, marginalised groups or future generations is not always a prime consideration when making personal decisions or exercising our individual human rights. And should it be up to the individual? Or is it at this stage where the state should step in to regulate reproductive autonomy in order to protect collective interests?

Before we can take a disability rights approach to possible regulations and restrictions on access to PGT during the IVF process, we must first employ a philosophical analysis on whether PGT can be labelled as eugenic, and therefore being placed under the 'Neo Eugenics' umbrella term when operating in the contemporary environment of newer scientific and technological advances and discoveries.

We have already taken some time to discuss eugenics of the 19th and early 20th century. If we break down in a simplified manner the effects of eugenic policies on PWD, the result was that less disabled persons existed – whether that be from killing existing PWD, or sterilising human

[122] Irene M. Ten Cate, 'Speech, Truth and Freedom: An Examination of John Stuart Mill's and Justice Oliver Wendell Holmes's Free Speech Defenses' [2010] 22(35) Yale Journal of Law and the Humanities 35, at p38

[123] Petersen, supra n117, at p82

beings who are at risk of producing offspring that carry disabilities. The basic end goal was genetic improvement of human beings over generations.[124] The by-product of these processes was that as the numbers of PWD decreased, discrimination and intolerance towards PWD still living increased. Comparing and contrasting this to the application of genetic technologies amidst the scientific discoveries and inventions by geneticists today, whilst the vehement mal-intent and pure bigotry may be absent, we can argue the by-products of these practices could be the same. Although framed as a feat for our global healthcare and beneficial for parental reproductive autonomy and control and predictability of private and family life, the result of genetic technologies such as prenatal testing and PGT are that less PWD are brought into existence – albeit not via involuntary euthanasia (although euthanasia is becoming increasingly decriminalised with the inclusion of 'assisted dying with dignity' legislation being implemented across the globe which raises some similar ethical issues for the disability community).[125] The harm to the disability community expressed through eugenic practices is not just that less PWD will exist, as we are aware that disabilities can develop throughout life due to external circumstances. However, the position known as the 'expressivist argument' illustrates the eugenic consequences of an unregulated widespread use of PGT, that is when prospective parents choose, through an assertion of their reproductive autonomy, to undergo PGT in order to avoid birthing a baby with a genetic abnormality, it is 'expressing' a personal and / or societal view that PWD are 'worse' or 'less worthy of existence.'[126]

The purpose of this chapter is to illustrate the dangerous practices, rooted in science that is historically asserted as undisputable, that led to eugenic movements across the world. 'Health is wealth' is a common phrase amongst human beings to gain perspective on daily troubles, and everyone has a right to health as a fundamental human right protected under the UN International Covenant on Economic, Social and Cultural Rights.[127] It cannot be undermined that an upstanding level of public health is a sound political means in order to achieve the ends

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[124] Robert A. Wilson, 'Eugenics: positive vs negative' (*The Eugenics Archives*, 2013) <https://eugenicsarchive.ca/discover/connections/5233c3ac5c2ec50000000086> last accessed 26 July 2022

[125] 'New Eugenics: UN Disability Expert Warns Against 'Ableism' In Medical Practice' (*UNOHCHR*, 2020) <https://www.ohchr.org/en/press-releases/2020/02/new-eugenics-un-disability-expert-warns-against-ableism-medical-practice> accessed 26 May 2022.

[126] Christopher Gyngell and Thomas Douglas, 'Selecting Against Disability: The Liberal Eugenic Challenge and the Argument from Cognitive Diversity' [2018] 35(2) Journal of Applied Philosophy 319, at p321

[127] International Covenant on Economic, Social and Cultural Rights (1966) 993 UNTS 3, Article 12

that is a productive workforce, thereby resulting in a stimulated economy and a well-functioning society overall.[128] However, given the traumatic history of eugenics associated with disability, the reconciliation between these means and ends must be done with very careful consideration and awareness of the dark history.

4 REPRODUCTIVE AUTONOMY

Medically assisted reproduction, and the invention and availability of reproductive technologies such as IVF and PGT have long been said to be very important in assisting prospective parents to realise their right to 'procreative liberty' or 'reproductive autonomy.'[129] In this chapter, when referring to prospective parents and those who bear the right to reproductive autonomy this shall include women, heterosexual couples, homosexual male couples using a surrogate, non-binary and transgender individuals capable of pregnancy. Reproductive autonomy has been increasingly recognised globally as essential to human dignity, or according to prominent scholars on reproductive autonomy such as Robertson – as essential to human flourishing.[130] This right was traditionally protected as a negative right, thereby being something the state shall not interfere with, as opposed to actively ensuring something is being guaranteed, such as the right to education.[131] This has led to the availability of contraception and abortion services, and on the basis that infertility should not disqualify individuals from the same opportunities to reproduce borne from the same procreative moral desires as those who are fertile; to have a child that is genetically linked, medically assisted reproductive methods has become another necessary method of ensuring reproductive autonomy for all.[132] Over time, a positive aspect of reproductive autonomy has developed whereby states actively ensure this right is granted through public funding of medically assisted reproduction for those who are infertile or are suffering to have a successful birth of a healthy

[128] Mark L Flear and Others, 'European Law and New Health Technologies: The Research Agenda' in Mark L. Flear and Others (eds) *European Law and New Health Technologies* (Oxford University Press 2013), at p1
[129] Krisin Zeiler, 'Reproductive Autonomous Choice – A Cherished Illusion? Autonomy Examined in the Context of Preimplantation Genetic Diagnosis' [2004] 7 Medicine, Health Care and Philosophy 175, at p175
[130] Carter, supra n4, at p145
[131] John A. Robertson, *Children of Choice: Freedom and the New Reproductive Technologies* (Princeton University Press 1994), at p29
[132] Ibid., at p 32

child, as is the case in the UK and Portugal - but not Ireland. According to Zeiler, reproductive autonomy or 'procreative liberty' can be said to be a branch under the right to individual autonomy of human beings generally and coming into existence when operating within the realm of reproductive medicine and functioning.[133] Reproductive autonomy is traditionally understood as being exercised when prospective parents and women make individual decisions whether to have children or not, and if so, when and how many.

In this chapter, we will first set out the development of international recognition of reproductive autonomy as a human right, and the applicable recognition of it in our case studies. Then, we will address what has come into question over the years as genomic science advances and genetic technologies become available, which is whether a decision on the 'qualities of future offspring,'[134] should also be protected as being within the realm of reproductive autonomy. This is where the use of PGT as an act of reproductive autonomy comes into the relevance of this thesis, and allows us to see both the conflict and the harmony between reproductive autonomy and the rights of PWD interplaying and causing ethical dilemmas. From this, we will discuss when the 'presumptive priority' of reproductive autonomy, as Robertson puts it, can be rebutted in accordance with the 'harm principle' where it is shown that the effects of PGT are producing such harm onto others that justifies limiting the exercise of reproductive autonomy.[135] This will entail an exploration into the type of harm being alleged to be perpetrated, and the viability of the embryo as a future child being a victim of such harm that should be prevented against. There are two converging schools of thought that arise when addressing the harm limitation, which is the principle of procreative beneficence introduced by Savulescu,[136] stating that we have a moral obligation to introduce the healthiest children possible into the world and not harm future children by causing them avoidable suffering, and the non-identity problem introduced by Parfit,[137] stating that there cannot be any harm to a future child by virtue of embryo selection, because the alternative selection of different embryos results in entirely different children and thereby there is no identifiable victim to the harm that the principle of procreative beneficence is alleging. In this chapter we will take the

[133] Zeiler, supra n129, at p175
[134] Harvey, supra n112, at p126
[135] Robertson, *Children of Choice: Freedom and the New Reproductive Technologies,* supra n131, at p16
[136] Savulescu, supra n178
[137] Derek Parfit, *Reasons and Persons* (Oxford University Press 1986)

opportunity to introduce the controversial situation where parents want to undergo PGT and select embryos with a certain genetic predisposition so that they increase their chances of having a child with a certain disability – known as selecting for disability or genetic 'disenhancement'[138] - in order to illustrate the different theories on PGT and the prevention of harm to a future child. The purpose of this chapter is to introduce the importance of reproductive autonomy in our society and understand the desires of parents and the medical profession to prevent suffering and harm to prospective children of IVF, and to set the scene on how genetic disability is framed and situated within the limits of reproductive autonomy and the selection of embryos after PGT testing is performed.

4.1 Historical Progression of the Recognition of Reproductive Autonomy

"The right to reproduce is deeply embedded in the history of human rights discourse."[139] The historical background and context to the growing recognition of a right to reproductive autonomy is important in relation to PGT, because it illustrates the movement away from medical paternalism which was prominent during the time period where eugenic practices operated. In accordance with the global retrospective abhorrence at the denial of rights during Nazi rule and eugenic practices during the 1930s and 40s, a shift in focus onto individual autonomy as being fundamental to respecting the inherent dignity of all human beings was translated into the reproductive medical and bioethical field generally by increasing patient decision making and informed consent.[140] It is these principles of informed consent and autonomy that advocates of new genetics practices have 'allied' with in order to differentiate from what was harmful eugenic practice.[141]

Although we mentioned in Chapter 2 on eugenics how the feminist movement initially allied with the eugenics movement, this fell away as different surges of feminist sects emerged. For eugenic feminists, control over reproduction in the form of birth control was seen as means to

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[138] Harvey, supra n112, at p126

[139] Tom Campbell and Laura Cabrera, 'The Weak Moral Basis for Strong PGT Regulation' in Sheila A.M. McLean and Sarah Elliston (eds) *Regulating Pre-Implantation Genetic Diagnosis: A Comparative and Theoretical Analysis* (Taylor and Francis Group 2012), at p23

[140] Paul Steven Miller, and Rebecca Leah Levine, 'Avoiding Genetic Genocide: Understanding Good Intentions and Eugenics in the Complex Dialogue between the Medical and Disability Communities' [2013] 15(2) Genetics in Medicine 95, at p98

[141] Koch, supra n76, at p315

enable healthier women to pursue employment and education and other social rights, they also advocated for involuntary birth control of unfit women, thereby not endorsing reproductive autonomy for all. This does not bear the same resemblance to the movement of women's rights in liberal democracies today, according to Kevles, stating that our notion of reproductive autonomy has 'transformed moral sensibilities about eugenics, so that we recoil at the majority's ruling in Buck v Bell.'[142] Generally, as stated in Chapter 2 also, after the atrocities of WWII and a sheer neglect of human rights, the Kantian notion of having autonomy and choice in relation to how a person organises and lives their life as being the highest manifestation of human freedom and the essence of the importance of humans as deserving of respect has become a more widely accepted human rights standard and ideal compass.[143]

4.2 International and Regional Provisions of Reproductive Autonomy

Reproductive autonomy or procreative liberty are not expressly referred to in the core human rights instruments relevant to this thesis and its case studies, such as the UDHR or the ECHR. This may make invocation of a fundamental right difficult in practice, however such reproductive rights are arguably customary rights now, deriving from the constellation of freedoms that are already recognised in international human rights instruments such as autonomy of human beings, bodily integrity and the right to a private life and a family life.

A handbook on reproductive rights published in 2014, jointly by the UN Populations Fund, the Danish Institute for Human Rights and the UN Office of the High Commissioner for Human Rights, establishes the reproductive rights are based on a recognition of couples and individuals rights, referring to UN General Recommendations on both marriage and family relations[144] as well as women's rights,[145] to 'decide freely and responsibly the number, spacing and timing of

[142] Kevles, supra n77, at p438
[143] Campbell and Cabrera, supra n139, at p26
[144] UN Committee on the Elimination of Discrimination Against Women, General Recommendation No. 21 on Equality in Marriage and Family Relations (13th Session, 1994)
[145] UN Committee on the Elimination of Discrimination Against Women, General Recommendation No 24 on Article 12 of the Convention (Women and Health) (20th Session, 1999)

their children and to have the information and means to do so.'[146] The World Health Organisation, in the same year, endorsed this same understanding of reproductive rights.[147]

Reproductive autonomy as a human right is still contested globally and its recognition is inconsistent in practice. As aforementioned, Zeiler interprets reproductive autonomy as being protected under the already widely-recognised right to individual autonomy, which is commonly protected in Western liberal societies and is a core principle of modern bioethics.[148] Individual autonomy in relation to decision-making is also a recognised principle under Article 3(1) of the CRPD.[149] The Universal Declaration on Bioethics and Human Rights also highlights the importance of respecting the autonomy of others in bioethics, and protects the 'autonomy of persons to make decisions' under Article 5.[150] The UN Working Group concerning discrimination against women and girls made an important reminder in their 2017 position paper, of the recognition of the right of a woman or girl to make autonomous decisions about her body and reproductive functions, as a core of the basic rights of equality, privacy and bodily integrity.[151]

In the European context, for which is relevant to our case studies, the European Court of Human Rights ("**ECtHR**") has long placed the right to reproductive autonomy as being protected under the umbrella of Article 8 of the European Convention on Human Rights ("**ECHR**").[152] Article 8 recognises that 'everyone has the right to respect for his private and family life, his home and

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[146] 'Reproductive Rights are Human Rights: A Handbook for National Human Rights Institutions' HR/PUB/14/6 (UN Population Fund, The Danish Institute for Human Rights and the UN Office of the High Commissioner for Human Rights, 2014) at p19 <https://www.unfpa.org/sites/default/files/pub-pdf/NHRIHandbook.pdf> last accessed 10 July 2022

[147] 'Framework for Ensuring Human Rights in the Provision of Contraceptive Information and Services' (World Health Organisation, 2014) at p1 <https://apps.who.int/iris/bitstream/handle/10665/133327/9789241507745_eng.pdf> last accessed 10 July 2022

[148] Zeiler, supra n129 at p175

[149] CRPD, supra n238, Article 3(1)

[150] Universal Declaration on Bioethics and Human Rights (adopted by acclamation 19 October 2005 UNESCO 33rd General Conference), Article 5

[151] Working Group on the Issue of Discrimination Against Women in Law and Practice, 'Women's Autonomy, Equality and Reproductive Health in International Human Rights: Between Recognition, Backlash and Regressive Trends' (UN Human Rights Special Procedures, October 2017), at p1 <https://www.ohchr.org/sites/default/files/Documents/Issues/Women/WG/WomensAutonomyEqualityReproductiveHealth.pdf> last accessed 10 July 2022

[152] Council of Europe, Convention for the Protection of Human Rights and Fundamental Freedoms (European Convention on Human Rights, as amended) (ECHR) 1950, Article 8

his correspondence,'[153] and the ECtHR has used this provision in case law to protect a plethora of rights and leading to the decriminalisation of abortion in many member states, the availability of contraception and overall strengthening the existence of reproductive autonomy as a fundamental right, albeit in accordance with the margin of appreciation doctrine.[154] Therefore, although the ECtHR has recognised reproductive autonomy within the scope of Article 8, the lack of consensus on, for example the moral status of a foetus and by extension the criminalisation of abortion, means that reproductive autonomy is not an unlimited or uncontested fundamental right across Europe.[155] This makes an argument rooted in reproductive autonomy as a human right for the advocacy of PGT not straightforward in practice.

4.3 Quantity vs Quality

As set out in the introduction, reproductive autonomy is traditionally understood as a woman or prospective parent's right to determine if and when to create future offspring, and the number of children.[156] However, PGT and embryo selection is concerning the genetic makeup of a prospective child, and we must address whether reproductive autonomy does and should include a right of control over the quality of a future child. Following Robertson's allegation of a right to procreative liberty that is broad in scope and strong in qualification, any restriction on the dynamics of reproduction are usually widely criticised within liberal, progressive and feminist sects of society because such decisions relating to reproduction and family are seen to be integral to the dignity and personal identity.[157] This broad scope can be interpreted to include the quality of prospective children. Harvey follows this, asserting that the employment of embryo selection and reprogenetics generally are necessary tools for exercising reproductive autonomy, stating that the 'apparently unlimited right to reproductive autonomy' includes both the control over the qualities of future children, and not just the quantity.[158] The ESHRE Task Force purports to support this, in stating that reproductive autonomy includes the freedom to

[153] Ibid.
[154] Olivia Coral Daniels, 'Reconciling Reproductive Rights: Eugenic Abortion and the Home Birth Disputes at the European Court of Human Rights' [2022] 71 Duke Law Journal 1605, at p1611
[155] Ibid., at p1613
[156] UNFPA Reproductive Rights Handbook, supra n146, at p19
[157] Johnathon Glover, *Choosing Children: Genes, Disability and Design* (Oxford University Press 2008), at p38
[158] Harvey, supra n112, at p126

decide about the health of possible future children.[159] This is where genetic technologies become of relevance in addition to medically assisted reproduction, as they interfere with the genotype and possible phenotype of future children, helping determine and alter the quality of the prospective child.[160]

There is deliberation on the extent to which control exerted through the use of PGT should be considered to be a necessary aspect of someone exercising reproductive autonomy, and therefore something not to be interfered with or unjustly limited through by regulations. Ethical concerns over allowing individuals to control the genetic quality of future offspring can be out of fear of making a sort of commodity out of the human embryo, the notion that children could become 'engineered to satisfy parents.'[161] This concern is deepened when we consider the possibility of accessing of PGT and IVF through the private sector, as is the case in Ireland where regulations and public funding are absent,[162] thereby risking the development of a 'genetic underclass'[163] applying to those individuals who cannot afford to ensure their children have the healthiest genotype possible. Another perhaps 'naturalist' position condemns interfering with the 'natural' outcomes of reproduction – with the scholar and priest Fr. Germain Kopaczynski taking 'PGT' to represent an dual acronym also standing for 'Playing God Disorder.'[164] These views are consistent with the criticism that if we are not careful, the use of PGT can seriously risk what it means to be disabled and lead to a reduction in tolerance for human difference.

Considering the basis for a reproductive autonomy inclusive of a control over quality, the reasons that a woman or a couple decide to undergo PGT and IVF allow us to understand that choices by prospective parents to undergo PGT are often not made lightly or 'on a whim', but with a great deal of consideration of the time, resources, and personal distress and risks

[159] ESHRE Task Force 2014, supra n214 at p1611

[160] Shachar Zuckerman, 'The emergence of the "genetic counselling" profession as a counteraction to past eugenic concepts and practices' [2021] 35(6) Bioethics, at p537, at p538

[161] Robertson, *Children of Choice: Freedom and the New Reproductive Technologies,* supra n131, at p160

[162] Springboard Communications, supra n44

[163] Aisling de Paor and Peter Blanck, 'Precision Medicine and Advancing Genetic Technologies – Disability and Human Rights Perspectives' [2016] 5(3) Laws 36, at p43

[164] Germain Kopaczynski, 'Preimplantation Genetic Diagnosis "Playing God Disorder"' [2002] 27(5) Ethics and Medics 1, at p3

associated.[165] A 2004 study on two British IVF clinics provide useful empirical data to support the commonality of PGT patients for reasons of a risk and fear of passing a serious genetic disorder onto a future child, or a genetic anomaly that is causing miscarriage or infertility.[166] It was also expressed by some patients that PGT was chosen by prospective parents on the basis that the alternative would mean procreation would be avoided, not possible, or would have to face the often more traumatic experience of selective abortion.[167] Therefore PGT and concern over the genetic quality of embryos for implantation can be seen in some cases as crucial in order to procreate, and any restriction in this sense would interfere with a woman or couple's right to procreative liberty.

Following on from this, looking at PGT in accordance with the serious concerns explained in the previous paragraph forms a strong argument in favour of undergoing PGT and the subsequent selection of healthy embryos, and thereby a choice concerning the quality of future offspring as a justifiable and reasonable exercise of reproductive autonomy.[168] Campbell and Cabrera accept such a conclusion, emphasising the inherent human desire of parents to avoid the suffering of their children where possible, and the rational acceptance that parents should have a right to make such assurances, and even be assisted through genetic technologies such as PGT.[169] But how do we measure suffering, and how do we predict the risk of actual suffering? For some, this is the avoidance of a 'serious' inheritable genetic disorder or disability. But an agreement on the 'seriousness' threshold of such genetic abnormalities is difficult and some say impossible. Stephen Hsu, cofounder of Genomic Prediction, a private company that now provides PGT and IVF across six continents, follows this prediction that the controversy concerning PGT will ease over time and become the norm.[170] This should be considered when we think of what disabilities are to be covered, and ask where will we draw the line as reprogenetics lose any sort of taboo and the idea of what is unhealthy or undesirable

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[165] Celia Roberts and Sarah Franklin, 'Experiencing New Forms of Genetic Choice: Findings From an Ethnographic Study of Preimplantation Genetic Diagnosis" [2004] 7(4) Human Fertility 285, at p291

[166] Ibid., at p287

[167] Ibid., at p288

[168] De Wert, in Joyce Harper (ed) *Preimplantation Genetic* supra n25, at p271

[169] Campbell and Cabrera, supra n139, at p24

[170] Rachael Pells, 'Genetic Screening Now Lets Parents Pick The Healthiest Embryos' (*Wired*, 2022) <https://www.wired.com/story/genetic-screening-ivf-healthiest-embryos/> accessed 10 July 2022 citing Stephen Hsu, personal communication

becomes under the umbrella of 'serious.' Is it perceivable that this would have a knock-on effect of broadening societal understanding of what it means to be disabled, or what it means to be a human deserving of respect and recognition of equal value of all persons?

As Glover reminds us, all human beings carry recessive mutations, and if we stray into the zone of unrestricted reproductive autonomy over the quality of future children, a decrease in stigma and a possible increase in a consumer-like demand for healthy children may result in the 'the clear white line between healthy and unhealthy' becoming a 'grey smear,' according to Savulescu.[171] Therefore, we may reach a point where it is agreed that control over the quality of children is, albeit a valid concern and in the ethical interests of many future parents, it should not be construed as an unlimited right that should not be interfered with, and should be limited where the concerned action would be exercising a preventable and serious harm. But a harm onto whom? And how do we measure such a harm? In the next section we will address two of the main debates on the prevention and harm and suffering in future offspring. However, it must be noted that harm may also be alleged to be exercised onto an interest third party, being the disability community, as a consequence of social outcomes at risk from the 'cumulative effect of otherwise acceptable individual choices.'[172] This will be addressed after we explore what can first be considered acceptable individual choices and what genetic fate is harmful enough to limit parental autonomy.

4.4 The Harm Limitation

Like many rights, reproductive autonomy, although often said to be broad in scope and strong in assertiveness, can be limited in order to prevent harm to others. John Stuart Mill effectively sets out the rationale for the limitation on rights, such as liberty and autonomy generally, and when to employ a balancing act with the rights of others or as a collective interest for the common good. Mill states that '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.'[173] Robertson follows this harm limitation understanding, but maintains that procreative liberty should take 'presumptive priority' or 'primacy' in these situations,[174] and that any harm being

[171] Glover, supra n157, at p7 quoting Julian Savulescu as a personal communication
[172] Campbell and Cabrera, supra n139, at p21
[173] John Stuart Mill, *On Liberty* (Longman, Roberts & Green 1869)
[174] Robertson, *Children of Choice: Freedom and the New Reproductive Technologies,* supra n131, at p16

alleged must be of a serious degree in order to justify a limitation on what is considered inherent to 'personal identity, meaning and dignity.'[175] Thereby, in order to argue in favour of a stronger regulation or limitation on access to PGT or the process of embryo selection, the standard of proof generated in accordance with Robertson and other 'bioliberal' perspectives, such as Savulescu and Harris, is quite a high one.[176]

It is necessary to unpack what sort of 'harm' is threatening to limit reproductive autonomy here, and who is this harm being perpetrated onto? It is often said that there is a duty where an act will affect a child, that their interests must be taken into consideration and therefore that PGT should be regulated in a fashion that protects the interests of the future child and avoids any harm being perpetrated against them.[177] This has become known as 'procreative beneficence,' as termed by Savulescu.[178] An extension of such a responsibility to prevent harm to future children crops up when discussing the situation where parents want to undergo PGT and select embryos with a certain genetic predisposition so that they increase their chances of having a child with a certain disability, such as deafness or dwarfism being the most common examples. In this situation, some would advocate that to intentionally give a child a disability is immoral and that embryo selection in this manner should be prohibited, whereas others argue that a non-ableist approach to PGT and a true protection of reproductive autonomy shall allow for genetic 'disenhancement' as it has been termed.[179] We will discuss both of these phenomena in this section, and critically analyse if and where embryo selection through PGT shall limit reproductive autonomy in accordance with preventing harm to future children, where it is alleged to be obligatory to be carried out in order to protect future children, or where it shall be limited or more carefully considered in order to prevent harms to the rights and interests of PWD. Finally, we will discuss the responsibilities and guidelines of medical practitioners in PGT and embryo selection, and where they are required to act in order to uphold reproductive autonomy, or refuse to implant embryos in the interest of harming a future child and whether this is ethically and morally permissible.

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[175] Deirdre Madden, *Medicine, Ethics and the Law in Ireland* (2nd Edn, Bloomsbury Professional 2011), at p115
[176] Campbell and Cabrera, supra n139, at p20
[177] De Wert in Joyce Harper (ed) *Preimplantation Genetic Diagnosis,* supra n25, at p263
[178] Julian Savulescu, 'Procreative Beneficence: Why We Should Select the Best Children' [2001] 15(5/6) Bioethics 413, at p413
[179] Harvey, supra n112, at p125

4.4.1 Parental Irresponsibility & Procreative Beneficence

There is a school of thought amongst this ethical and moral debate in favour of PGT and the selection of healthy embryos in the name of a 'duty of procreative beneficence.'[180] This theory essentially makes the assertion that to avoid PGT testing where there is a known risk of passing on a 'serious' genetic, or to make efforts and plans to increase your chance of having a child with a disability, goes against a moral responsibility as parents to act in the best interests of their future child to have a good life, and a duty towards the 'human enhancement' of future generations.[181] It is a common understanding that PGT is used and advocated for on the basis that it represents a global feat for parental desires to have healthy children, and to avoid suffering amongst future generations thus also alleviating public health system pressure. As aforementioned, those who decide to undergo PGT have often been through a series of exhausting and sometimes traumatic trials and tribulations in the attempt to have a healthy child, or any child at all. Therefore, as we have stated, PGT can be interpreted as a necessary method in order to realise an individual's right to reproductive autonomy.

Whilst beneficence and non-maleficence are fundamental principle of bioethics that medical professionals must uphold, [182] scholars, scientists and medical practitioners infer the purposes of genetic technologies as creating a public, utilitarian moral duty onto prospective parents to use such technology that is available to them to ensure they do all that is necessary to bring about the creation of the healthiest children possible into our world. Whilst this is not legal duty, these views being phrased as a duty in order to be a responsible parent and member of society can risk informing genetic counselling protocol and to medical practitioners encouraging being directive in their advice to patients making such decisions. Harris presents one of the scholarly fields of debate on the ethical and moral responsibility that exists socially that rests upon parents and medical practitioners to enhance the quality of life of future generations by making use of genetic technology to avoid inheritable diseases and disability in

[180] Savulescu, supra n178

[181] Sparrow, supra n109, at p32

[182] Natália Oliva Teles, 'Diagnóstico Genético Pré-Implantação: Aspetos Técnicos e Considerações Éticas' [2011] 24 Acta Médica Portuguesa 987, at p988

children.[183] He attempts to differentiate between the desire to have healthy children and the eugenic desire to eradicate disability, by explaining that:

> If children are wanted, it is better to have healthy children than to have disabled children where these are alternatives, and it is better to have children with disabilities than to have no children at all.[184]

Therefore, this position posits not to claim that a child with a disability is a harmed life in and of itself, but that where the parents have knowingly played a part in the increased risk of having a child with a disability, they have perpetrated a harm, according to those who take this view. It is worth contextualising this argument amongst reproductive choices and actions generally, taking for example a woman who makes a decision whether to smoke or consume alcohol during her pregnancy, according to medical research and advice that to avoid such substances may result in birth defects or certain impairments to the child. This woman is not having her actions monitored every day, and in choosing to smoke or drink alcohol may in fact be in direct causation to why a child is born with a disability, yet is not subject to the same 'license to procreate'[185] as a prospective parent undergoing IVF and considering PGT. The difference in this situation, as Dr Verlinsky states, is that 'if we make a diagnostic tool, the purpose is to avoid disease.'[186] Therefore, where such cutting-edge technology and science are available here, it is negligible and irresponsible for parents to not take advantage, and this infers that a woman or couple's reproductive autonomy and parental interests shall not be paramount in this situation, in order to curtail bringing children into existence that will suffer. Another school of thought falling under the duty of 'procreative beneficence' is known as the 'transhumanist' approach or theory, and this is where things become more radical, and arguably smell much more like eugenics. Transhumanists advocate for the use of reprogenetic tools such as PGT in order to interfere with the aspects and characteristics of the human individual that are

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[183] John Harris, *Enhancing Evolution: The Ethical Case for Making Better People* (Princeton University Press 2007)
[184] Ibid., at p87
[185] De Wert in Joyce Harper (ed) *Preimplantation Genetic Diagnosis,* supra n25, at p263
[186] Vincent Barry, *Bioethics in a Cultural Context: Philosophy, Religion, History, Politics* (Cengage Learning 2011), at p245

influenced by genetics in order to improve the human genome of our species over time, as Cambpell and Cabrera stated, 'transcend the human condition as we know it.'[187] An approach to PGT following this way of thinking would be more likely to move away from private morality considerations toward public regulation requirements.[188]

In practice, it is not hard to understand the moral underpinnings behind advocating that parents act in the best interests of their child, and therefore that prospective parents make decisions of a responsible nature in order to bring about the birth of a child that will have the best chance at a flourished and happy life. This alleged moral and ethical obligation to select the best child when given such an option is based off the aforementioned human desire to avoid the suffering of children by parents as well as the bioethical principles of beneficence and non-maleficence. There is a clear issue when attaching the genetic makeup of an embryo being predisposed to a genetic disability and the assumption that the life that will come into existence will be full of suffering and will be a harmful existence. To have medical practitioners, genetic counsellors or prospective parents 'gazing into five day old cells like crystal balls and seeking enlightenment about what may happen over a lifetime'[189] seems to ignore societal and environmental factors and may even touch on eugenic notions of genetic determinism. Whilst there is merit in the bare claim that it would be harmful to deliberately fight for the selection and implantation of an embryo that will develop a genetic impairment leading to the birth of a child that will suffer immense pain and have a life expectancy of a couple of years is harmful, and even wrong, this is unlikely to be the choice of prospective parents who are going through IVF in the hope of having and raising a child.

Following the rationale behind the principle of procreative beneficence, and the attempt to move such beliefs and statements away from accusations of ableism and a devaluation of the lives of PWD, it has been argued that one can still respect the inherent value and dignity of a PWD whilst also advocating for PGT to decrease genetic disability, because of a desire to avoid human suffering in future generations. Such suffering when attached to disability cannot be predicted based on genotype alone, and arguably ignores the environmental and social factors.

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[187] Cambell and Cabrera, supra n139, at p21

[188] Ibid., at p22

[189] Andrew Joseph, 'A Baby With a Disease Gene or No Baby at All: Genetic Testing of Embryos Creates an Ethical Morass' *Stat News* (23 October 2017) < https://www.statnews.com/2017/10/23/ivf-embryo-genetic-testing/> last accessed 12 July 2022

Therefore, this obstacle has been crossed by arguing that to avoid genetic disability or anomalies generally as an obligation is permissible so as to increase the chances of flourishing for that child's life, and thereby selection of embryos must be based on which will have the maximum chances of a good life.[190] Savulescu however states that this outlook does not ignore social or environmental barriers to human flourishing of a PWD, but rather states that the assumption of decreased flourishing is evaluated on the basis of the way our society is constructed and relative to the environment that the child will be born into.[191] But why do we stop here, at genetic disability, when there is the opportunity through IVF to enhance human flourishing and decrease suffering associated with other genetic characteristics in the context of how they operate in our current society? Glover explores this, enquiring into the possibility of parental responsibility to increase the chances of 'the good life' for their children and removing obstacles to having a flourished life, then would not eliminating genetic predisposition to shyness or laziness help someone flourish within the constructs of our current society?[192] So much of our self is genetically determined to a certain extent, and society can be said to create an easier path to success or at least less obstacles for a certain type of person. For example, taking your chronotype which is the genetically predisposed way in which out body naturally indicates that it needs sleep at a certain time, influencing our peak brain performance, the way we eat and the way we exercise. The majority of people fit within the chronotype that performs best within the standardised workday times of 9 to 5. Can it be said there that 'night owls' should be avoided where there is a choice between another embryo with a preferable chronotype as it will increase their human flourishing? This is an extreme example, however, referring back to Hsu's prediction that over time the controversy and hesitancy towards PGT will decrease, [193] and thereby PGT may allow for the entrenchment of what is considered a serious genetic abnormality relative to increasing the good life for future generations and minimising suffering. For Glover, although there are cases of genetic disability where the issues they represent for a person and the suffering experienced are relatively uncontroversial, there

[190] Janet Malek and Judith Daar, 'The Case for a Parental Duty to Use Preimplantation Genetic Diagnosis for Medical Benefit' [2012] 12(4) The American Journal of Bioethics 3, at p10
[191] Julian Savulescu, 'In Defence of Procreative Beneficence' [2007] 33(5) Journal of Medical Ethics 284, at p285
[192] Glover, supra n157, at p75
[193] Pells, supra n170

remains difficulty in dealing with less extreme cases where 'the impact on human flourishing is not so obvious.'[194] For Scully, ideas on disability are fluid, and even when we consider the lived experiences of PWD, they are always relative to a particular community, context and time which is always changing over time, and we must bear this in mind when we consider what is normal or abnormal or disabled.[195] Therefore, even if we are to accept the existence of a moral obligation on the part of the parents and / or the medical profession to take such steps to enhance the possibility of flourishing and thereby prevent harm to the future child as a necessary limitation to reproductive autonomy, finding where to draw this line and what may be necessary to enhance flourishing and the degree of suffering necessary to render a life harmful is difficult to agree upon.

4.4.2 Selecting For Disability & The Non-Identity Problem

The Non-Identity Problem operates to rebut the arguments in an attempt to limit reproductive autonomy on the basis of Robertson's harm limitation in order to act in the best interests of the child, by stating that there cannot be any harm unless there is an identifiable victim of such harm, for which the PGT process does not present. We will turn to one of the most controversial aspects of embryo selection in order to illustrate the Non-Identity Problem, when a couple want to use PGT to select and implant embryos that carry a certain genetic abnormality, known as selecting for disability or genetic 'disenhancement.'[196] This is usually the desire of parents that, either one or both, carry a certain genetically inheritable disability that they would like their future children to also carry – perhaps due to what they perceive as necessity as they feel they will only be sufficient parents able to love and care for a child with the same capabilities as their own. The most commonly referred to examples of this situation are genetic predispositions to deafness and dwarfism, often considered to be essential to an individual's identity and a culture that is sacred to their inherent personality and sense of self.[197] Although

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[194] Glover, supra n157 at p10

[195] Jackie Leach Scully and Teresa Blankmeyer, 'Russia's CRISPR "Deaf Babies": The Next Genome Editing Frontier?' (*Center for Genetics and Society,* 7 September 2019) < https://www.geneticsandsociety.org/biopolitical-times/russias-crispr-deaf-babies-next-genome-editing-frontier> last accessed 15 July 2022

[196] Harvey, supra n112, at p126

[197] Jackie Leach Scully, 'Choosing Disability, Symbolic Law, and the Media' [2011] 11 Medical Law International 197

recognising their genetic anomaly as not the norm per se, but that remains an embodiment 'well within the boundaries of normal human variation.'[198] However, PGT is often performed for the purposes of avoiding these genetic abnormalities and therefore are considered 'serious' enough genetic disabilities in this context, with the UK going further to update the 1990 Act in order to prohibit implanting affected embryos in order to prevent such situations of genetic 'disenhancement.'[199]

According to the aforementioned principle of procreative beneficence and the alleged moral obligation to be a responsible parent when making choices concerning genetic testing, to avoid undergoing PGT when you have the knowledge of passing on a genetic disability, or deliberately giving a child a disability through embryo selection would be an undeniable harm and should be prohibited under any acceptable regulation of PGT. However, the Non-Identity Problem can be used to argue against the existence of such harm, by arguing against the existence of any verifiable victim. The Non-Identity Problem is essentially the reframing of how we think about embryos their fate as a future child. A major reason why discarding 'unfit' or genetically abnormal embryos during IVF after PGT is considered less problematic and unethical that prenatal screening, is because discarding embryos is an already inevitable part of the IVF process.[200] The embryo does not have the same moral status as the foetus, in terms of the controversial protection of the life of the 'unborn' because of the decreased probability of resulting in a full term pregnancy and therefore birth of a child.[201] Parfit famously introduced this theory into the ethical debate on embryo selection, stating that the birth of a child with a disability or genetic abnormality through IVF cannot be said to be harmed by this action alone, because to select a different healthier embryo would not be enhancing the genotype of the child, but rather selecting for the creation of an entirely different child. Therefore, for the same reasons that it is argued discarding an embryo is not discriminating against disabled persons or

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[198] Katie Hasson, 'Illness or identity? A Disability Rights Scholar Comments on the Plan to Use CRISPR to Prevent Deafness' (*Center for Genetics and Society,* 9 October 2019) <https://www.geneticsandsociety.org/biopolitical-times/illness-or-identity-disability-rights-scholar-comments-plan-use-crispr-prevent> last accessed 14 July 2022

[199] 2008 Act, supra n30, s 14(4)(9)

[200] King, supra n8 at p176

[201] Bartha M. Knoppers, Sylvia Bordet & Rosario M. Isasi, 'Preimplantation Genetic Diagnosis: An Overview of Socio-Ethical and Legal Considerations' [2006] 7 Annual Review of Genomics and Human Genetics 201, at p203

infringing our commitment to respecting human diversity and difference, it is also said that by choosing not to undergo PGT or to select an embryo with a predisposition to a disability, is not harming that child – because without selecting that embryo, the child would simply not exist.[202] The implications of the Non-Identity Problem to juxtapose claims of limiting reproductive autonomy in order to prevent harm to a future child based on the principle of procreative beneficence can be usefully illustrated through the ethical morass that is genetic 'disenhancement.' To illustrate the ethical issues that arise in this scenario, we turn to employ the famous case of Sharon Duchesneau and Candy McCullough, an American deaf couple.[203] These women knew in light of their lived experiences and capabilities, they would be better parents to a deaf child. They could provide a supportive, relatable and loving environment and even lived nearby the first liberal arts college for deaf persons.[204] More importantly, they did not view deafness as a harmful disability that should be avoided, but rather a 'special blessing' that runs in their family, as they already had a daughter that was deaf. Deafness had become part of their cultural identity that they express through the unique method of sign language, a feeling that is shared by most members of the deaf community.[205] Of course there exists the counterargument that a child that isn't deaf can still engage in the culture and learn sign language, and not be deprived the 'world of sound.' However, being of the opinion that reproductive autonomy should be a private unfettered matter and on the understanding that they were acting with moral intentions, in 2002 the couple sought to have a child through IVF with a sperm donor who was affected by the same form of hereditary deafness, thus increasing their chances of having a deaf child although not actually undergoing PGT.[206] Duchesneau and McCullough were met with extreme criticism, labelling them as being extremely selfish for intentionally giving a child a disability.[207] This supported the 'mainstream opinion' by both

[202] Harvey, supra n112, at p125
[203] Clarissa Becerra, 'Selecting for Disability' (*The Eugenics Archives,* 2015) <http://eugenicsarchive.ca/discover/tree/55542acc35ae9d9e7f000063> last accessed 28 May 2022
[204] Ibid.
[205] M Spriggs, 'Lesbian Couple Create a Child Who Is Deaf Like Them' [2002] 28(5) Journal of Medical Ethics 283, at p283
[206] Thomas Lemke and Jonas Rüppel, 'Social Dimensions of Preimplantation Genetic Diagnosis: A Literature Review' [2018] 38(1) New Genetics and Society 80, at p98
[207] Ibid.

medical experts and the public, that by selecting for disability after PGT is performed, through what can be termed genetic 'disenhancement,'[208] is exercising a harm on the future child. Another compelling example that can be used to argue in favour of genetic 'disenhancement' is when a dwarf couple want to have a dwarf child. Where both parents have the achondroplasia gene, there is a 50% chance that their child will have dwarfism.[209] However, there is an equal 50% chance that their child will either by of normal height or have a different strain of dwarfism that is fatal.[210] Therefore, couples wanting to avoid a fatal mutation and equally wanting a child with dwarfism, may turn to PGT and subsequent IVF to ensure they have 'a little one.'[211] Such couples desire raising a child they can relate to and support adequately, perhaps in a home that is built solely to cater for their height – e.g. lower chairs, lower cabinets in kitchens, lower sinks and toilets in bathrooms, and the fear that a child of normal height would not 'look up' to their parents both physically and metaphorically as parental figures, and that they may experience a sort of reversed discrimination in school for having dwarf parents while they were average height.[212] However, Stramondo reminds us that it is not that such desires to select for disability are based on what is most convenient for the parents, but rather that it is what they believe will improve that child's well-being in accordance with the opportunities and accommodations they can provide.[213] Some scholars contend that the argument for selecting embryos to ensure a child with achondroplasia is more 'morally acceptable' than that of deafness, because it is seen as having a lesser detrimental impact on the child's life, and even referred to as more of an 'inconvenience' than a disability. It is usually for this particular reason – not seeing deafness, dwarfism, etc. as a disability but as a culture owed to the variance of the human race that prospective parents will turn to PGT for these purposes.[214] However, there are

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[208] Harvey, supra n112 at p125
[209] Rochman, supra n102, at p59
[210] Ibid.
[211] Darshak M. Sanghavi, M.D., 'Wanting Babies Like Themselves, Some Parents Choose Genetic Defects' *The New York Times* (New York, 5 December 2006) <https://www.nytimes.com/2006/12/05/health/05essa.html> last accessed 29 May 2022
[212] Dena S. Davis, *Genetic Dilemmas: Reproductive Technology, Parental Choices and Children's Futures* (2nd Edn, Oxford University Press 2010) at p63
[213] 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, at p488
[214] Guido De Wert and Others, 'ESHRE Task Force on Ethics and Law 22: Preimplantation Genetic Diagnosis' [2014] 29(8) Human Reproduction 1610, at p1614

still medical complications and daily strains that come with growing up and living with dwarfism.[215] It remains that disabilities such as deafness and dwarfism are considered 'serious' disabilities by many experts and policymakers, including those in the European Society of Human Genetics,[216] as they consider any circumstances in which the child's opportunities are narrowed – whether that be in terms of future careers, marriage and family making or cultural and social activities – would be exercising a harm that should be avoided where possible.[217] Therefore, especially within the medical and bioethics field, there are compelling arguments maintaining that where there is a decision to be made between selecting an embryo that is unaffected and one that is affected, it would be doing harm to not prioritise the healthy embryo for implantation.[218] Davis underlines the simplified counterclaim that without the actions of such prospective parents, the child 'could not have existed otherwise than in [their] suboptimal state.'[219] And this suboptimal state operates within our assumptions on how their disability will operate within the society we have constructed and interact with the community and environment they belong to. These assumptions hinder a proper consideration and respect for the fact that 'a child can have social success, and live a rewarding life, with a disability.'[220] Whether a different child would exist or the parents are rigid in their determination to only have a child with a certain genotype or refuse PGT due to personal reasons, either way it would mean that a child simply exists or does not exist, and the Non-Identity Problem can support an argument that an objective assumption of parental irresponsibility based on genetic disenhancement can be deemed irrelevant, as there is no real identifiable victim to which harm is being perpetrated.

According to the non-identity problem's assessment of the harm limitation on reproductive autonomy, in order to show that a harm has been caused by selecting for disability, one would have to show that the child's life is so difficult and full of suffering that they would be 'better

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[215] Ibid.

[216] Dorothy C. Wertz and Bartha Maria Knoppers, 'Serious Genetic Disorders: Can or Should They Be Defined?' [2002] 108 American Journal of Medical Genetics 29, at p32

[217] Davis, supra n212, at p63

[218] ESHRE Task Force 2014, supra n214
, at p1614

[219] Davis, supra n212, at p45

[220] Caroline Lyster, 'Reproductive Technologies' (*The Eugenics Archives,* 2014) <http://eugenicsarchive.ca/database/documents/535eedf67095aa0000000254> last accessed 16 July 2022

off dead.'[221] These children being considered a 'burden from birth'[222] is in line with Robertson's description of a harm exercised through unlimited reproductive autonomy when it results in a 'wrongful life.'[223] Stromondo attests that this is a low bar for prospective parents wanting to select for a certain disability to meet, and that thereby we must move away from the concept of harm as a limitation when discussing embryo selection altogether, and towards the concept of reasonable accommodation by parents for a good short at life's opportunities. We will discuss the full implications of this in the next chapter, and how this creates issues when such high standards for a quality of a full life are only made in the context of disability.

4.4.3 Medical Practitioners Refusal to Implant

In consideration of the ethical dilemma concerning the selection of embryos affected by a gene associated with a certain disability or illness, there exists a bioethical controversy of whether medical practitioners of IVF have a responsibility or duty of care to refuse to implant genetically 'unfit' embryos,[224] at least at the very basis of embryos that are affected by a 'very serious' genetic anomaly that will negatively impact the prospective child's quality of life? This is supported by the notion that such physicians have a responsibility to 'do no harm', a fundamental bioethical principle that dates back to the Hippocratic Oath.[225]

As we mentioned in Chapter 1, King states in an article dating back to 1999, that it was often the case in IVF clinics that decisions over which embryos to implant are often controlled by medical expertise alone, in contrast to genetic counselling in relation to the decision to terminate a pregnancy after prenatal screening, where the couple would decide in accordance with genetic counselling sessions.[226] It has been stated that genetic counselling is an extremely important and often legally required step in advance of giving consent or requesting to undergo

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[221] Bonnie Steinbock and Ron McClamrock, 'When is Birth Unfair to the Child?' [1994] 24(6) Hastings Center Report 15

[222] Giovanni Rubeis and Florian Steger, 'A burden from birth? Non-invasive prenatal testing and the stigmatisation of people with disabilities' [2018] 33 Bioethics 91

[223] Bonnie Steinbock, 'Wrongful Life and Procreative Decisions' in Melinda A. Roberts and David T. Wasserman (eds) *Harming Future Persons: Ethics, Genetics and the Nonidentity Problem* 35 International Library of Ethics, Law and the New Medicine (Springer 2009) at p158

[224] Galarneau, supra n52

[225] Rachel Hajar, M.D., 'The Physician's Oath: Historical Perspectives' [2017] 18(4) Heart Views: The Official Journal of the Gulf Heart Association' 154, at p156

[226] King, supra n8, at p180

PGT or not, depending on the genetic predisposition at risk and whether it qualified for testing. However, it is after the test results are presented that the decision appears to be shifted over to the medical experts to discard all affected embryos. One limitation of an analysis of this practice is that we don't know the exact facts and figures of physicians that may refuse to implant in our jurisdictional case studies & reasons they may have – but we have seen that UK legislation has expressly prohibited the implantation of embryos affected with genetic predisposition to a serious genetic disease or disability.

In 2007, the Task Force on Ethics and Law of the European Society of Human Reproduction and Embryology ("**ESHRE**") announced their position against selecting for disability through IVF, adding that a 'fertility specialist should refuse' on the basis of a 'risk of serious harm to the *future* child.'[227] In 2014, the ESHRE Task Force published another report stating that using PGT to select for disability, specifically to ensure prospective parents have a child with the same disability as them, is ethically unacceptable.[228] Referring back to our example of selecting an embryo affected by achondroplasia, Dr Stephane Viville in France was the first doctor to use PGT for eliminating dwarfism for couples, and specifically made the reservation that he would refuse to implant affected embryos even where the couples so desired.[229] It could be argued that examples such as dwarfism and deafness are the strongest in favour of selecting for disability or as not being considered a harmful outcome after choosing not to undergo PGT at all, as these disabilities are the most common traits that patients seek,[230] and are more readily accepted as less serious disabilities that can give way to a life with reasonable accommodations and opportunities.[231] This is in contrast to more serious disabilities where the future child has a disability that is so painful or debilitating that their quality of life is diminished or their life

[227] G. Pennings and Others, 'ESHRE Task Force on Ethics and Law 13: The Welfare of the Child in Medically Assisted Reproduction' [2007] 22(1) Human Reproduction 2585, at p2588
[228] ESHRE Task Force 2014, supra n214 at p1610
[229] Harvey, supra n112, at p60
[230] Judith Daar, 'A clash at the petri dish: transferring embryos with known genetic anomalies' [2018] 5(2) Journal of Law and the Biosciences 219, at p233
[231] 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, at p488

expectancy so reduced, such as a single year in total agony as Harman proposes, that it cannot be seen as bioethically permissible or moral to allow being selected for.[232]

5 THE EXPRESSIVIST ARGUMENT & IMPACT ON DISABILITY RIGHTS AND INTERESTS

Thus far in the thesis, we have outlined what PGT is and its beneficial contributions in the genomic era and set out its importance for individuals exercising the alleged right to reproductive autonomy in a liberal and democratic society. The importance of reproductive autonomy and the academic and bioethical debates on when is the appropriate situation to limit reproductive autonomy in the name of preventing harm to others has also been explored at length in this chapter. The relevant interested party that is alleged to be protected against harm that has been explored here is to the future child, and future generations generally. However, whilst there has been difficulty in agreeing on whether reproductive autonomy can be limited based on a harm to a potential future person, there has also been the claim that autonomy can be limited in order to prevent unacceptable social consequences as a result of the cumulative effect of individually acceptable decisions,[233] or put another way that the victims of harm from reproductive autonomy can be an interest third party, being the disability community. The Convention on the Rights of Persons with Disabilities ("**CRPD**"), as we will discuss, presents through Article 8 the notion of a collective right of the disability community to not be stigmatised and discriminated against,[234] and therefore may present a useful backdrop to an argument that the collective right of PWD as a vulnerable minority to invoke limiting reproductive autonomy in the name of harm to these persons or the existence of unacceptable social consequences. In this chapter we will explore the weight of this claim as a limit to reproductive autonomy as well as its importance as a moral consideration by prospective parents in the decision-making process.

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[232] Elizabeth Harman, 'Harming as Causing Harm' in Melinda A. Roberts and David T. Wasserman (eds), *Harming Future Persons: Ethics, Genetics and the Nonidentity Problem* (Springer 2009) at p144

[233] Campbell and Cabrera, supra n139, at p21

[234] Convention on the Rights of Persons with Disabilities (adopted 24 January 2007, entered into force 3 May 2008) 2525 UNTS 3 (CRPD), Article 8

Even with the profound scientific advances, there is still a weighty argument that the application of genetic technologies such as PGT before the IVF process is carried out, can be termed as having 'Neo Eugenic' ends if not carefully considered, appreciated and timely regulated with thorough awareness-raising. A disability-rights critique is often rooted in what is known as the 'expressivist argument' stating that PGT sends a negative, harmful message to the disability community and can trigger a recurrence of traumatic eugenic consequences.[235] In contemplation of the harms perpetrated onto PWD and the ignorant stereotypes associated with PWD as well as a naïve understanding of the quality of life as a PWD due to over-reliance on genetic determinism, the field of disability rights activism has worked towards changing attitudes towards PWD.[236] One feature of this development is seen in the transition from the 'medical model' of international disability rights to the 'social model' with the addition of the well-rounded 'capabilities approach' to disability rights insurance globally.[237]

This chapter addresses the possible future implications of PGT on the human rights of disability community under the CRPD.[238] These consequences include a reinforced stigma and discrimination against PWD already living in our communities, stereotypes that are associated with raising a child with a disability (that can be reinforced without human rights based and ethical genetic counselling guidelines), difficulties with access to disability related services and public policies concerning PWD, and also the impact on our global commitment to respect for human diversity and difference. Finally, we will turn to look at the issues created for PWD in the scenario where PGT is being sought to select embryos with a particular disability, and take a philosophical analysis of whether this constitutes a harm to a future child or further exposes a lack of recognised value of PWD and their ability to live a life worthy of deliberate selection. Therefore, this chapters lays the groundwork for the vitality that widespread use of PGT in

[235] (mentioned a lot – Glover, supra n157 discusses at p4 onwards but trying to find who created the term expressivist argument/objection)
[236] De Paor and Blanck, supra n163, at p49
[237] Caroline Harnacke, 'Disability and Capability: Exploring the Usefulness of Martha Nussbaum's Capabilities Approach for the UN Disability Rights Convention' [2013] 41(4) The Journal of Law, Medicine and Ethics 768, at p773
[238] CRPD, supra n234

practice must be implemented with the care and sufficient public awareness necessary so as to not detrimentally impact the rights of and public care granted to PWD in any given country.[239]

5.1 The Progression of How we Frame Disability & The Disability Rights At Play

5.1.1 The 'Medical Model'

The 'medical model' bares the assumption that disability is an impairment which puts individuals at a disadvantage, and that policies should be therefore implemented to level the playing field for those who suffer with a disability.[240] The medical model surrounded its public policies of the time on the understanding that disability is a 'deviation from biomedical norms' and is viewed as a weakness of the individual, as opposed to the environment PWD exist in being a central contributing factor to actually disabling these human beings from participating fully in society.[241] This political view asserts that disabilities or impairments should be neutralised or improved wherever possible. We can take deafness as a useful example here, where the medical model would allocate hearing aids in order to allow for participation in spheres of life such as education.[242]

Overall, the medical model is widely accepted to embody an outdated view on disability that served to arguably ostracise PWD and emphasise their difference as something to be pitied,[243] which according to Bickenbach and Others, prevailed until around the late 1980s[244] - thus predating the introduction of the Convention on the Rights of Persons with Disabilities.[245]

5.1.2 The 'Social Model'

The 'social model' of viewing disability developed on the back of criticism of the narrow-minded 'medical model,' providing an external reflection on the context that disability operates

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[239] James M. Kemper, Christopher Gynell and Julian Savulescu, 'Subsidizing PGT: The Moral Case for Funding Genetic Selection' [2019] 16(1) Bioethical Inquiry 405, at p411

[240] Francesco Seatzu, 'Empowering Persons with Disabilities: Socio-Economic Rights as a Pathway to Personal Autonomy and Independence' [2020] 18(2) Northwestern Journal of Human Rights 136, at p139

[241] Harnacke, supra n237, at p 773

[242] Patrizia Marti and Annamaria Recupero, 'Is Deafness A Disabiliy? Designing Hearing Aids Beyond Functionality' [2019] C&C '19: Proceedings of the 2019 on Creative and Cognition 133, at p137

[243] Jerome. E. Bickenbach and Others, 'Models of Disablement, Universalism and the International Classification of Impairments, Disabilities and Handicaps' [1999] 48(9) Social Science & Medicine 1173, at p1174

[244] Ibid., at p1185

[245] CRPD, supra n238

in, and the role society plays in *de facto* disabling PWD in practice.[246] Finkelstein embraces the social model in his statement that 'disability is the outcome of an oppressive relationship between people with impairments and the rest of society.'[247] It is not that the impairment of a PWD is being ignored or redacted, but this approach appears to address the barriers that society had built up against PWD, either through ignorance or perhaps complicit discrimination emanating from centuries of stigma and lack of representation of PWD in political and human rights fields. This model accepts societal responsibility for various issues of inaccessibility by PWD to actively participate in and contribute to society, and aims to implement policies and regulations to remove these barriers.[248] Some simple examples of this include where a person with a certain disability that requires a wheelchair needs to access a building that only has steps.[249] Under the social model, policies would be surrounded on the perspective that it is the building that is the issue and that the exclusion experienced by the PWD is at the fault of the barrier posed by inconsiderate design structures, and therefore an effective policy under the social theory would be to require all public buildings (schools, businesses, workplaces) to ensure wheelchair accessibility.[250] The CRPD enshrines the social model approach to disability, basing these rights on the overarching claim that disability should be reframed as a 'socially constructed entity rather than a medicalised pathology.'[251] Therefore, it is worth underlining how the application of new genetic technologies for the purposes of avoiding disability therefore can present a harmful challenge to the core assumption of our international model for ensuring fundamental rights for PWD.

5.1.3 The 'Capabilities Approach'

The Capabilities Approach to disability is not a separate model entirely from the social model, but rather broadens the scope to include a consideration of the variety of factors that impact how a PWD lives their life. Amartya Sen is renowned for having developed this approach to

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[246] Harnacke, supra n237, at p773

[247] Victor Finkelstein, 'Attitudes and disabled people: Issues for discussion' [1980] 5 World Rehabilitation Fund <https://disability-studies.leeds.ac.uk/wp-content/uploads/sites/40/library/finkelstein-attitudes.pdf> last accessed 3 June 2022, at p47

[248] Tania Burchardt, 'Capabilities and disability: the capabilities framework and the social model of disability' [2004] 19(7) Disability and Society 735

[249] Bickenbach and Others, surpa n243, at p1174

[250] Ibid.

[251] Seatzu, supra n240, at p141

understanding disability,[252] maintaining the social model's consideration of barriers that 'disable' PWD in society, but adding to this by considering the economic and environmental barriers to fully realising human rights for PWD on an equal basis to all human beings.[253] The society that traditional eugenic policies operated in, as shown in Chapter 2, attached value to the social utility of the individual, and where a person was unable to contribute to society their value was therefore reduced or their life pitied. Burchardt shows us how the capabilities approach to disability advocates to shift our calculation of value from being based on utility to being based on the capabilities of individuals.[254] The difference here is that capabilities are the opportunities available to a person to be or do a range of things that constitute living a 'full' life in accordance with their human rights.[255] Therefore, a capabilities approach to disability works to ensure that all human beings have equal capability sets to actively participate in society together. This approach aims to increase the autonomy of PWD, and thereby value their dignity, by levelling the playing field of opportunities for all individuals through an understanding that every human differs in their capabilities, needs and interests[256] – thereby aiming to avoid dictating how a PWD should live their life by providing for their needs as an afterthought to already established infrastructure or education systems, for example.[257] In summary, the capabilities approach to disability aims to elevate disability rights as being the same and equal to human rights, and albeit PWD have special needs that require added protection and respect, that this is arguably only required to be established separately in our international human rights framework because of our history of not treating all individuals on an equal footing and all having different capabilities due to nurture, nature or other life events.

5.2 What Does it Mean to be Disabled?

Following our outline of the development away from a medical approach to a functional disability rights framework, towards an approach that more accurately acknowledges the reality of disability being socially constructed and coming to fruition when an individual with an

[252] Amartya Sen, *Commodities and Capabilities* (2nd Edn, Oxford University Press 1999)
[253] Burchardt, supra n248, at p735
[254] Ibid., at p738
[255] Ibid.
[256] Harnacke, supra n237, at p772
[257] Ibid., at p770

impairment interacts with society, we must then question what it means to be disabled and when can a person be considered to have a disability if such a concept is socially constructed to a certain extent? Whilst there is no agreed universal definition of disability, the current capabilities approach and social model, as supported by the WHO, agree that an individual's environment and personal experience has a massive effect on their experience of disabling events or even their identification with disability generally.[258] As aforementioned, Scully and Blankmeyer endorse the notion that, even when we take into consideration the lived experiences of a PWD, disability remains relative to a specific community, context and time which are ever-changing.[259] Also, if we consider disability to be created at the intersection when such an individual begins to interact with a society that is not built with them in mind, then at what point in our global fight for equity and deconstruction of social barriers do we consider a disability to cease? And at what stage in one's life does a disability begin – is it at birth from the mere existence of their abnormal biological constitution, or is it based on their lived experience and interaction with the world around them? We must keep this in mind when we scrutinise the fact that diagnostic tools such as PGT are being created with the goal of preventing serious illnesses, but also disabilities, and how do we scientifically recognise a disability at the stage of an embryo, when it is contextual to a certain time and place in a certain society?

5.3 The Convention on the Rights of Persons with Disabilities – Relevant Provisions

The CRPD was established in 2007,[260] and was the first international treaty that acknowledged that while PWD enjoy all human rights under the Universal Declaration of Human Rights,[261] their particular vulnerability in society must still be counteracted by formulating a category of distinct rights enjoyed by PWD and must be recognised and ensured by all states party to the Convention. Harnacke establishes the fundamental perspective on the reasoning for the establishment of the CRPD, stating that a capabilities approach is often employed to analyse gaps in human rights protection.[262] It is trite that human rights are afforded to all human beings,

[258] 'Disability' (*Who.int*) <https://www.who.int/health-topics/disability#tab=tab_1> last accessed 4 August 2022
[259] Scully and Blankmeyer, supra n195
[260] CRPD, supra n238
[261] Universal Declaration of Human Rights (adopted 10 December 1948 UNGA Res 217 A(III) (UDHR)
[262] Harnacke, supra n237, at p774

but separate conventions are needed when sects of society are having their rights insufficiently neglected so that they are not being afforded the same capability sets to live their life with equal opportunities as others. To counteract this, the CRPD restates various fundamental principles, values and distinct rights relating to PWD. The CRPD was a landmark instrument, most notably for the inclusion of economic social and cultural rights alongside civil political rights on an equal footing, but also for its recognition of collective rights for minority groups. In its acknowledgement of the vulnerability of PWD as a collective to stigma and discrimination on the basis of the understanding that the negative inflictions on the rights of PWD are as a result of social attitudes and environmental barriers, it recognises that these can form the basis of collective claims of denial of rights to PWD in order to fully achieve the goals of the CRPD.[263] Taking the preamble, the CRPD lays a bare claim that disability is a disadvantaged situation created by the 'interaction between persons with impairments and attitudinal and environmental barriers that hinders their full and effective participation in society on an equal basis with others.'[264] This follows this global step away from the medical model of viewing disability as purely something that is the fault of the individual that should be corrected or minimised where possible. The preamble further promotes the recognition of the valued *existing* and *potential* contributions made by PWD to the well-being and diversity of our communities, and the fact that protecting and promoting the full participation of PWD in our society will result in advances not only for their dignity and 'sense of belonging' but advances in the development of our human development worldwide – socially and economically.[265] This is an important statement, to strongly impact our view on the importance of human difference for all. Section (o) of the Preamble represents a distinct feature of the capabilities approach to disability, stating that PWD should be involved in decision-making processes about policies and programmes that concern them, directly or indirectly.[266] This is important to bear in mind when we discuss the regulation of PGT, but bears relevance as a background consideration in this chapter as we understand how it does in fact directly concern PWD.

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[263] Lucy Series, 'Disability and Human Rights' in Nick Watson and Simo Vehman (eds) *Routledge Handbook of Disability Studies* (2nd Edn, Routledge 2020), at p76
[264] CRPD, supra n238, Preamble (e)
[265] Ibid., Preamble (m)
[266] Ibid., Preamble (o)

Article 3 sets out the principles that lie at the core of disability rights and the values the international community should uphold in order to guarantee such rights.[267] The principles specifically relevant to this thesis set out in this article include the 'respect for inherent dignity, individual autonomy… and independence of persons,' 'non-discrimination,' 'full and effective participation and inclusion in society,' 'respect for difference and acceptance of persons with disabilities as part of human diversity and humanity,' 'equality of opportunity,' and 'accessibility' of PWD, and finally the 'respect for the evolving capacities of children with disabilities and respect for the right of children with disabilities to preserve their identities.'[268] Article 4 establishes the general obligation on all state parties to ensure and promote the realisation of the rights under the CRPD through legislative, administrative or other means, with (e) specifically referring to measures to eliminate discrimination against PWD.[269] Under Article 5, the right to equality and non-discrimination is underlined, with the important inclusion of the immediately invokable obligation that states 'take all appropriate steps to ensure that reasonable accommodation is provided.'[270] Reasonable accommodation is consistent with the capabilities approach, ensuring that modifications and adjustments are made that don't impose an undue burden or disproportionate opportunities for PWD to enjoy rights and freedoms on an equal basis with others.[271] Article 8, as aforementioned, recognises the stigma and stereotypes associated with living with a disability, and thereby establishes the obligation to raise awareness amongst members of society and combat harmful practices that reinforce these prejudices, in order to recognise the 'capabilities and contributions' of PWD in our communities.[272] Finally, relevant to this chapter is Article 9 then which underlines the necessity of effective accessibility in order to reduce social barriers for PWD and allow them to participate fully in society.[273]

[267] Ibid., Article 3
[268] Ibid., Article 3
[269] Ibid., Article 4
[270] Ibid., Article 5 (3)
[271] Ibid., Article 2
[272] Ibid., Article 8
[273] Ibid., Article 9

5.4 The Impact of PGT on Disability Rights and the Disability Community

5.4.1 Introducing the Expressivist Argument: Reinforcing Stigma & Discrimination

After our discussion in Chapter 4, concerning the arguments on limiting reproductive autonomy where harm to a future child is concerned by either purposely or negligently brining into the world a child with a disability, and the moral obligation to avoid such acts, we must follow this with analysis of the arguments against this and the harm that such views are alleged to be perpetrating. The 'expressivist argument' or 'expressivist objection' that disability activists, or scholars generally, hold states that the advocacy for and use of PGT expresses the view that people with disabilities should not be born where this is avoidable. The argument has been made in various ways, with some objections including that PGT and embryo selection of healthy embryos or those with 'normal human functioning' not only express that the birth of a PWD should be avoided, but that those already born should not have been as their life is 'not worth living' and thereby totally undervaluing the lives and discriminating against PWD. Boardman and Hale's 2018 study on the views of 43 genetically disabled persons through qualitative interviews in the UK resulted in a strong majority (65%) expressing disapproval or at least a strong hesitancy toward the process of embryo selection against disability, even for disabilities such as Cystic Fibrosis which is commonly considered to be severely disabling.[274] As Scully mentions, the aims of PGT are particularly harmful where a PWD considers their disability to have formed part of their personal identity.[275] Boardman and Hales' study gives empirical data to support this claim, with participants stating that the expressivist effect of PGT works to exacerbate social factors that already create the majority of problems associated with disability, due to its partial social construction.[276]

Edwards presents the converse argument that exists, which is that disability is comparable to illness and disease, and where medical advances and healthcare allow for the reduction of illness or prevention of disease such as cancer, it does not send a negative message to those that have suffered with cancer, and therefore the same should be thought for disability and that

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[274] Felitcity K Boardman and Rachel Hale, 'How Do Genetically Disabled Adults View Selective Reproduction? Impairment, Identity and Genetic Screening' [2018] 6(6) Molecular Genetics and Genomic Medicine 941, at p
[275]

[276] Boardman and Hale, supra n274

the ends are merely to avoid suffering in future generations.[277] However, for many members of the disability community, their disability is not just a variation in capability that they have to deal with, but can form a large part of their identity and the community it places them within can develop throughout history to be considered a distinct culture.[278] The Nuffield Council on Bioethics maintains that the more acceptable account of the expressivist claim is that an individual's decision and reasons for deciding to use PGT to select against disability can be morally and ethically unproblematic exercises of reproductive autonomy, but that it is rather health policies that encourage and fund embryo selection to avoid the birth of disability and prohibit selection of disability that send a harmful message with harmful effects on the disability community.[279] This version of the expressivist argument can be read consistently with the harm limitation on reproductive autonomy in a way, if we consider the argument that Campbell and Cabrera raise that autonomy may be limited to protect harm against an interested third party, being the disability community, as a consequence of social outcomes at risk from the 'cumulative effect of otherwise acceptable individual choices.'[280]

It can hardly be counter-argued that the use of genetic technologies, including PGT, under the general advocacy for the New Genetics school of thought correlates with a social assumption that disability should be avoided where possible – some even stating that it is a 'moral obligation' to act in accordance with this insurance.[281] As we illustrated at length in the previous chapter, the principle of procreative beneficence and the attested obligation being so strong as to limit reproductive autonomy or at least allow for medical professionals to encourage, directly or indirectly, in order to prevent harm and increase the opportunity of a flourishing life for future children can be clearly read to infer an assumption that all disability is at variance with normal human functioning will hinder flourishing to an extent that it would be a harm to cause such disability intentionally, or to avoid PGT where you are aware of such risk. As Wasserman and Asch highlight in their defence of the expressivist argument, 'to

[277] S D Edwards, 'Disability, Identity and the "Expressivist Objection"' [2004] 30 Journal of Medical Ethics 418, at p418

[278] Scully, Choosing Disability, supra n197

[279] 'Genome Editing And Human Reproduction: Social And Ethical Issues' (Nuffield Council on Bioethics 2018) <https://www.nuffieldbioethics.org/assets/pdfs/Genome-editing-and-human-reproduction-report.pdf> accessed 10 June 2022, at p83

[280] Campbell and Cabrera, supra n139, at p21

[281] Sparrow, supra n109, at p32

assume genetic disabilities will impair the flourishing of the individual in a way that other detectable genetic characteristics don't (such as laziness or shyness as we previously mentioned) is to truly stigmatise disability.'[282]

In accordance with disability rights activism and the CRPD's immediate positive duty on states to have reasonable accommodation to ensure that PWD enjoy all human rights and freedoms on an equal basis with others, we are progressing toward a capabilities approach and breaking down environmental barriers and discriminatory attitudes in ensuring the rights of PWD are positively upheld.[283] However, there is still a lot of work to be done – PWD are in a vulnerable position in our communities, and even outside of their access to resources and services, they are often subject to discrimination and are negatively stigmatised as being of lesser value and capability.[284] Therefore, if we are to rely on what eugenic policies tended to rely on, being 'genetic determinism' then we may open the door to 'profound forms of stigmatisation'[285] through societal rejection, devaluation, isolation and thereby mistreatment that may amount to discrimination.[286] The Nuffield Council on Bioethics add useful empirical data in the UK from a 2018 report, stating that some PWD have found that PGT, and reproductive technologies generally being used to avoid disability are 'distressing, devaluing or offensive.'[287]

O'Brien illustrates these contradicting ideals of committing to ensuring disability rights and advocating for their respect and dignity, and the advocacy for the use of genetic technologies in the name of public health and reproductive autonomy through two 'meta-messages.'[288] The first meta message states that communities across the world are increasingly progressing with disability rights activism to accept PWD as 'full citizens' and that discrimination or prejudice against them is condemned by society. Then, the alternate meta message is that prospective children in the prenatal or pre-embryotic stage that carry the possibility of bringing about a human being that carries a disability are undesirable and parents should take all steps necessary

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[282] David Wasserman, JD, MA and Adrienne Asch, PhD, 'Op-Ed: The Uncertain Rationale for Prenatal Disability Screening' [2006] 8(1) Ethics Journal of the American Medical Association 53, at p55
[283] CRPD, supra n238, Article 2
[284] De Paor and Blanck, supra n163, at p37
[285] Jerome Bickenbach, 'The Perils of Human Genetics' [1996] 1 Ethics and Intellectual Disability 1, at p2
[286] De Paor, supra n118, at p103
[287] Nuffield Council on Bioethics 2018, supra n279, at p84
[288] Gerald V. O'Brien, 'Eugenics, Genetics and the Minority Group Model of Disabilities: Implications for Social Work Advocacy' [2011] 56(4) Social Work 347, at p351

to avoid such manifestations.[289] It is hard to understand how these two assertions can exist in harmony in a democratic state that purports to uphold fundamental human rights. Therefore, there is a logical assumption that the widespread acceptance of the New Genetics dogma and the introduction of routine application of genetic technologies, without very careful regulation and public awareness raising, will be accompanied by the reintroduction of stigma towards persons with disabilities and the message that bringing PWD into the world should be avoided where possible.[290]

It can be foreseen that this increase in stigma and discriminatory, even eugenic, attitudes emulated through the advocacy for PGT amongst application of other genetic technologies will not only rest on the prospective child, but in turn onto people with current or future disabilities living today.[291] This may manifest itself that being viewed as inferior within society will lead to PWD being isolated and unlawfully discriminated against in contexts such as employment, education and insurance.[292] PWD may have less employment opportunities because of them being viewed as less capable or susceptible to long periods of absence, and may be excluded from attending certain third level institutions because of these same reasons, and may even be discriminated against in private contexts when trying to take out insurance on, for example, their car, because of perceived risk they present.[293] Although this may appear to be an overly predictive issue to rely on, there is already evidence of genetic discrimination occurring in current society with the rapid growth of direct to consumer genetic testing in many contexts,[294] and the fear of such discrimination and stigma increasing in the event of the number of PWD being born and raised in the future is a natural consequence. Going back to Hsu's predicition that over time the unease around genetic technologies and reprogenetics will fade,[295] and without careful and thorough public education and bioethical policies and listening to and incorporating the concerns of PWD, is there a possibility that uses for PGT will expand as what is unhealthy or serious increases over time if we overly rely on genetic determinism and ignore

[289] Ibid.
[290] Rubeis and Steger, supra n222, at p92
[291] De Paor and Blanck, supra n163, at p40
[292] Ibid., at p41
[293] Ibid., at p44
[294] Aisling de Paor, 'Direct to consumer genetic testing – law and policy concerns in Ireland' [2018] 187 Irish Journal of Medical Science 575, at p578
[295] Pells, supra n

the factors of disability that are socially constructed? In doing so, are we running the risk of creating of a genetic underclass and the resulting entrenchment of stigmatising, marginalising and discriminating against PWD?[296]

5.4.2 Stereotypes and Unfortunate Realities of Raising a Child with a Disability

A common phrase we hear amongst prospective parents – "we don't care, as long as our baby is healthy."[297] Unfortunately, this often well-intending phrase of wanting the best life for a parents child and wishing them no health-related pain and harm, can be associated with ableism and attaches negative stereotypes to those that are raising a child with a disability.[298] These stereotypes are often pity-related, and feeling sadness for those who are perceived as 'burdened' by their own child.[299] This is often referred to as 'courtesy stigma,' coined by Goffman to describe the experiences of those who are associated with an already stigmatised group, namely PWD.[300]

Rochman puts this difficult reality quite simply, highlighting that our approach to disability rights and tolerance in our society changes in different contexts, and whilst we may advocate for representation in mainstream media or for increased accessibility in public spaces, the same 'we' may then also decide to not have a child with a disability if given the choice.[301] Although this may be for a plethora of reasons, such as the unfortunate reality of societal standards and public funding as we will discuss, it is hard to argue that our perceived difficulty of raising such a child is a deterrent for many prospective parents. This 'burden' is materialised through the presumed difficult and lesser quality life that the child will have and the reduced quality of life of parents due to the strain that this child will be on their families[302] – emotionally, mentally

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[296] De Paor and Blanck, supra n163, at p43
[297] Sarah Sahagian, 'Let's Stop Saying: "We Don't Care, as Long as Our Baby's Healthy"' *HuffPost* (17 December 2014)
[298] Ibid.
[299] Rubeis and Steger, supra n290, at p91
[300] Sydney H. Kinnear and Others, 'Understanding the Experience of Stigma for Parents of Children with Autism Spectrum Disorder and the Role Stigma Plays in Families' Lives' [2016] 46 Journal of Autism and Developmental Disorders 942, at p943
[301] Rochman, supra n102, at p79
[302] Rubeis and Steger, supra n290, at p93

and financially.[303] This strain or negative impact on others can be described as the 'person-affecting'[304] approach to implying a responsibility on parents to undergo PGT to avoid genetic disability and to prohibit genetic disenhancement, because of the harms this disability will have on the family and the wider societal resources, such as education, assistance and healthcare. Unfortunately it cannot be said that any state has fully and successfully implemented the CRPD,[305] and therefore these difficulties are very real and make decisions harder for parents. There are two ways to look at these challenges and stereotypes. Employing the medical model of disability, we would assume that it is solely the existence of the disability that is creating the strain on families and thereby the effective solution is to avoid disability where possible, for example through genetic testing and avoidance of the birth of such a child. However, when we employ our contemporary disability rights critique of the situation in accordance with the CRPD[306] which encompasses the social model and capabilities approach, we may begin to make it clear that many of the feared difficulties of raising a child with a disability are created externally – through barriers such as insufficient disability care services, accessibility and financial support, both for the PWD and their family and care provider.[307] Tailored and accessible supports would mean that a PWD reliance on their family would reduce as they are raised and mature, and would be in accordance with the right to independent living under Article 19 of the CRPD.[308] This concern was echoed by the UN Human Rights Council in 2020, stating that genetic screening should never be considered as an alternative to a particular state providing the highest standard of services for PWD, as to do so would harm the dignity of PWD and negatively impact prospective parents choice to raise a child with a disability.[309] Therefore, are states circumventing these responsibilities under the CRPD by advocating for

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[303] Social Finance, 'Understanding the Financial Needs of Families with Disabled Children' (*Social Finance UK,* 12 December 2011) <https://www.socialfinance.org.uk/resources/publications/understanding-financial-needs-families-disabled-children> last accessed 10 June 2022, at p15

[304] Melinda A. Roberts and David T. Wasserman, 'Harming Future Persons: Introduction' in Melinda A. Roberts and David T. Wasserman (eds) *Harming Future Persons: Ethics, Genetics and the Nonidentity Problem* 35 International Library of Ethics, Law and the New Medicine (Springer 2009), at p xiv

[305] Series, supra n263

[306] CRPD, supra n238

[307] UNGA 'Report of the Special Rapporteur on the Rights of Persons with Disabilities' (24 February – 20 March 2020) A/HRC/43/41, at p4

[308] Gauthier De Beco, 'The Indivisibility of Human Rights and the Convention on the Rights of Persons with Disabilities' [2019] 68 International and Comparative Law Quarterly 141, at p151

[309] UNGA Report, supra n307 at p15

reprogenetic technologies and thereby reinforcing the notion that having a child with a disability is undesirable and irresponsible. And does this have the effect of coercing parents into making these decisions because of the harsh reality that is raising a child with a disability with limited assistance and within the context of social stigma and discrimination. Does this coercion then make this process de facto eugenic?

An obvious and important reminder exists that when choosing whether to undergo PGT and therefore the decision whether to raise a child with a disability varies depending on the severity of the illness or disability and the probability of it coming to fruition.[310] However, this decision arguably carries more weight during the prenatal screening and subsequent decision of terminating a pregnancy, than it does during PGT during IVF. This is said because often terminating a pregnancy is seen as a more traumatising decision than deselecting embryos, as a foetus often has a stronger moral status in many states and is more likely to result in a full term pregnancy, and also because some embryos are inevitably discarded during the IVF process anyway, even if PGT is not carried out.[311] Also, often with PGT as aforementioned in chapter 1, once a prospective parent chooses to undergo PGT there is no subsequent choice of which embryo to implant through IVF, rather the 'unfit' embryos are often automatically discarded by the practitioner and the healthy ones implanted.[312] This will be elaborated on further in the paper.

Taking a look back at the damage that was done in the era of eugenic policies and the over-reliance on genetic determinism, we must be careful not to repeat those mistakes in light of the scientific and technological advances of today. As supported by De Paor and Blanck, a 'developed' and contexed view of disability understands the 'myriad of circumstances' that make up a person's characteristics and quality of life, such as their personal relationships and the environment they are placed in and opportunities they have.[313] Taking this balance of a sort of nature versus nurture understanding of how a child develops and the importance of sufficient governmental supports in accordance with the CRPD, it is important that these are communicated fully to parents during the genetic counselling so that a fully informed,

[310] King, supra n8, at p178
[311] Ibid., at p176
[312] Ibid., at p176
[313] De Paor and Blanck, supra n163, at p46

autonomous and non-directive decision can be made.[314] This will help to ensure that some of those stereotypes associated with raising a child with a disability are counteracted. Where genetic counselling can employ considerations of barriers such as financial strains or accessibility, it could be interpreted as eugenic and have harmful impacts on the disability community.

5.4.3 Future Impacts on Funding, Accessibility and Services

As we have shown in the first section of this chapter, our global human rights community has moved away from the medical model of disability rights, towards a social model and a capabilities approach as employed in the CRPD. As the social model and capabilities approach work towards breaking down barriers in terms of accessibility and ensuring full participation in social life and equal opportunities for PWD on an equal basis to those who don't have such impairments, this would likely mean an increased need for allocated public funding and special services and mechanisms in order to realise such obligations. One, albeit perhaps one of the more far-reaching, predictions in terms of the impact on the disability community is that if PGT and the 'Neo Eugenics' application of genetic technologies generally have the effect of reducing the total number of PWD living in the human race, that it could detrimentally reduce the focus on public policies and funding orientated towards ensuring the accessibility and equal opportunities for PWD, in accordance with Article 3 of the CRPD. [315]

Kemper, Gynell and Savulescu provide us with a comprehensive example to illustrate this concern, asking us to consider the fact that for persons in wheelchairs, many governments have no justifiable issue with creating obligations on businesses and public places to have ramps and other modifications such as wheelchair accessible toilets and parking spaces.[316] However, is this, arguably quite costly obligation, more justifiable in terms of government budgeting and weighted concern for accessibility of PWD because of the high prevalence of persons in wheelchairs in society? And following on from this, there is a concern that if genetic technologies such as PGT allow for children with impairments that cause them to rely on a wheelchair results in the number of such human beings decreasing in our communities, that

[314] Zuckerman, supra n160, at p537
[315] CRPD, supra n238, Article 3
[316] Kemper, Gynell and Savulescu, supra n239, at p411

this may result in the incentive to provide assistance and work to remove all existing barriers.[317] Whilst this concern when phrased in the extreme sense is valid, it can be rebutted by stating that not only do impairments and disabilities arise throughout a person's life and are not just something you are born with, but also by arguing the possibility that a reduction in the number of persons with a particular disability may actually decrease the pressure and strain on the publicly funded resources and services and would allow for existing PWD to better benefit from such.[318] It is important to caveat this with a consideration of whether the reduction in PWD through PGT being seen as possibly beneficial due to the increased expenditure on those that do exist can be framed in a eugenic light, by inferring that PWD are a strain on public resources. Therefore, not only will an decrease in the number of persons with a genetic disability risk a decrease in the public funding allocated to treatment, cures and other accessibility or services, but may correlate with an underlying political message that the government and public services should not have to bear the costs and strain of caring for a child with a disability where it could have been avoided.[319]

The ESHRE Task Force on Ethics and Law set out an opinion on this issue in , stating that although PGT may have an overall cost saving effect on publicly funded services and resources for PWD, this should in no circumstances be regarded as a rationale for the routine use of PGT so as to provide an alternative to the treatment or care of future PWD.[320] The ESHRE Task Force added that there exists a concern that prospective parents considering the use of PGT may feel pressured to do so because of a fear that countries may not be willing to provide care and treatment of their possibly affected children. We will discuss later in the thesis the impact these attitudes have on the reproductive autonomy of prospective parents and the importance of non-directive genetic counselling to counteract this. However, the mere existence of a concern by parents that a reduction in public incentive to care for future children with disabilities is also grave for the aforementioned stereotypes attached to having a child with a disability and also for the negative feelings towards parents who may be perceived as negligent

[317] Ibid.
[318] Ibid.
[319] Felitcity K Boardman and Rachel Hale, 'How Do Genetically Disabled Adults View Selective Reproduction? Impairment, Identity and Genetic Screening' [2018] 6(6) Molecular Genetics and Genomic Medicine 941, at p942
[320] ESHRE Task Force 2014, supra n214, at p1612

towards their future child for not availing of PGT in the best interests of their future child's health and possibly a disregard for their country's social welfare.[321]

5.4.4 Respect for Human Diversity and Human Dignity

One of the major pillars of the UN Convention on the Rights of Persons with Disabilities is the importance of 'recognising the valued existing and potential contributions made by persons with disabilities to the overall well-being and diversity of their communities' and of the fundamental principle of 'respect for difference and acceptance of persons with disabilities as part of human diversity and humanity' under Article 3.[322] This final consideration of the impact that 'Neo Eugenics' practices and PGT may have on PWD in terms of their right as a community to have their intrinsic value respected and the importance that societies have respect for human diversity and difference in line with the spectrum of human variation, and that 'all human beings are born free and equal in [human] dignity'[323] is an overarching principle of concern that runs through this entire thesis and can be fragile to impact by genetic technologies as a whole. Safeguarding respect for human dignity is a core principle in both the bioethical field and the any given human rights framework. The Universal Declaration on the Human Genome and Human Rights also underlines that everyone's right to respect for dignity and rights are to be protected 'regardless of their genetic characteristics.'[324] The same article states that human dignity implies that individuals shall not be reduced to their genetic characteristics, thus rejecting in principle a notion of eugenic genetic determinism, and stating that uniqueness and diversity must be respected.[325]The Universal Declaration on Bioethics and Human Rights restates this core principle of human dignity in Article 2 and 3 as an aim to promote and a commitment to uphold in any standards and practices within the bioethical field.[326] The Oviedo Convention on Biomedicine similarly commits to protect the dignity and identity of all human

[321] Ibid.
[322] CRPD, supra n238, Article 3
[323] UDHR, supra n261, Article 1
[324] Universal Declaration on the Human Genome and Human Rights (adopted by acclamation 11 November 1997 29th General Conference), Article 2
[325] Ibid.
[326] Universal Declaration on Bioethics and Human Rights, supra n150, Article 2 and Article 3

beings in Article 1,[327] a convention of which notably Ireland nor the UK have signed or ratified albeit Portugal has.[328] Therefore, when we discuss harming factors such as stigma, stereotyping, discrimination and a reduced incentive to orient policies and funding towards disability issues all contribute to weakening the principle of respect for diversity and the inherent dignity of all human beings equally.

This paper does not bear the claim that unregulated use of PGT could lead to the eradication of people with genetically associated disabilities, and it is maintained that the majority of disability and disease is caused from other illness, ageing, injury and other causes apart from genetics.[329] Therefore, human difference and diversity will never be simply deleted from planet earth, but it remains a concern that the routine, easily accessible use of such technologies could in fact decrease the number of PWD in certain communities or amongst certain classes of people, and that the policies we use to guide practice will have real impact on PWD in our communities and the way that we promote and truly value and respect of diversity amongst individuals. When we discuss the feelings of disability forming part of a person's identity, it can result in PGT being considered as used to eradicate a devalued identity in society,[330] in the name of giving children the best chance at a good flourished life.

The aforementioned 'expressivist argument' on what message the introduction of PGT sends,[331] may lead us to asking whether we can say we truly respect and recognise the value of human difference and the contributions of PWD in our global society, by then advocating that where we have the opportunity to avoid such disability, we should – and as will be discussed in the next chapter, it is often phrased as a moral *responsibility* to do so. [332] The notion of reprogenetics as a feat for public health and a major benefit for avoiding the suffering and fatality attached to gravely debilitating disabilities that lead to an extremely poor quality of life

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[327] Convention for the protection of Human Rights and Dignity of the Human Being with regard to the Application of Biology and Medicine: Convention on Human Rights and Biomedicine, open for signature 4 April 1997, ETS No 164 (entered into force 1 December 1999), Article 1

[328] 'Treaty Office: Chart Of Signatures And Ratifications Of Treaty 164' (*Council of Europe Portal*, 2022) <https://www.coe.int/en/web/conventions/full-list?module=signatures-by-treaty&treatynum=164> last accessed 11 June 2022

[329] De Paor and Blanck, supra n163, at p46

[330] Tim Stainton, 'Missing the Forest for the Trees? A Disability Rights Take on Genetics: Commentary on Stowe et al.' [2007] 13(2) Journal on Developmental Disabilities 89, at p90

[331] Kemper, Gynell and Savulescu, supra n239, at p321

[332] Sparrow, supra n109, at p34

is advocated by many, and when we consider genetic anomalies that lead to Huntington's Disease or Cystic Fibrosis, is easy to understand and more agreeable. However, Roberts breaks down the purpose for reprogenetics, meaning the combination of reproductive technologies and genetics, in a simplified political manner, stating that it is a means of shifting the responsibility of healthcare from the state and onto the individual, and has a negative impact on our respect for diversity by aiming to minimalize the cost of social welfare and externalise this by making reproductive health subject to free market conditions.[333] This arguably makes a commodity out of ensuring a child is as 'perfect' as it can be where there is not careful regulation.[334]

On this idea of possibly making a commodity out of a prospective child and the message this sends detrimentally impacting the intrinsic value of PWD and their contribution to society, we turn to consider the fluctuation in cost and access to IVF globally, and by association thereby PGT. We do this because barriers to accessibility or the total privatisation of IVF due to a lack of state regulation or public funding, may turn reproductive autonomy into a class issue and therefore the insurance of having a 'healthy' child through PGT may in turn be something only the wealthy in society can ensure.[335] A concern related to this is the future possibility that disability from birth may be associated not only with a parental irresponsibility, but as an identification of class and a poverty issue, as private access to IVF is so expensive, averaging at €5000 per round without calculating the added expense of PGT which can often be another €2000.[336] The correlation between poverty and disability is already a global issue that reinforces stigma and pity towards PWD, as poverty can increase exposure to health risks due to malnutrition or increased exposure to disease from inadequate healthcare.[337] Therefore, the introduction of genetic technology designed to avoid disability should be done with care and mindfulness of this issue, and to not ensure equal access to this by all persons regardless of

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[333] Roberts, supra n51, at p785

[334] Sonia M. Suter, 'A Brave New World of Designer Babies?' [2007] 22 Berkeley Technology Law Journal 897, at p960

[335] Ibid., at p960

[336] Jakub Dejewski and Aleksander Wiecki, 'IVF Abroad – Patient's Guide Europe 2022' (*Fertility Clinics Abroad,* 2022) < https://www.fertilityclinicsabroad.com/publications/IVF-Abroad-Patients-Guide-2nd-Edition.pdf> last accessed 13 June 2022

[337] Brigitte Rohwerder, 'Disability Inclusion: Poverty and Disability' (*GSDRC Applied Knowledge Services,* November 2015) <https://gsdrc.org/topic-guides/disability-inclusion/the-situation-of-people-with-disabilities/poverty-and-disability/> last accessed 13 June 2022

their economic background can reinforce a disregard for the appreciation of the value of PWD and difference, and sets a double standard for those who can increase 'perfection' in another avenue of their lives when money can permit it.[338]

Referring back to our case studies, in the UK and Portugal it is usually the case that where a couple is struggling with infertility for a set amount of time (usually 2 years) or at risk of passing on a 'serious' genetic condition to their prospective child, they will be allowed to avail of publicly funded IVF treatment.[339] In Ireland, whilst there have been governmental promises for a state-funded system of IVF, these are yet to be made into fruitful plans and IVF is currently defaulted to be regulated by the private sector and is not publicly funded under the national health system, even where individuals are suffering from infertility or at risk of passing on hereditary genetic conditions.[340] This creates a private free market for accessing fertility treatment and therefore PGT, where prospective parents have to go to expensive private clinics or travel elsewhere. The UK and Portugal have clearly more accessible treatments for those who are infertile or at risk of passing on a 'serious' genetic abnormality. However, there does not appear to be restrictions on couples who do not suffer from infertility or serious genetic risks, from availing of PGT and IVF in private clinics anyway, to ensure a healthy child.

What is clear from this section is that states must carefully consider their commitment to respecting human difference and diversity when they introduce reprogenetic technologies and avoid doing so as an alternative to 'eliminating systemic inequality.' Studies carried out in the UK on the feelings and impression of PWD through interviews have shown how government policies advocating for genetic technologies do in fact impact their understanding of how their country views disability and the values they uphold to ensuring their dignity is respected and their rights protected.[341]

Following the discussion on the progressive broadening of genetic abnormalities that become authorised for PGT over time, as aforementioned by Hsu and supported by scholars such as

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[338] John H. Evans, 'A Brave New World? How Genetic Technology Could Change Us' [2003] 2(2) Contexts 2, at p22

[339] NHS Commissioning Board Clinical Reference Group for Genetics, *Clinical Commissioning Policy: Pre-implantation Genetic Diagnosis (PGT)*, NHSCB/E01/P/a, (2013) <https://www.england.nhs.uk/wp-content/uploads/2013/04/e01-p-a.pdf> last accessed 12 June 2022, at p7

[340] Citizens Information, supra n45

[341] Nuffield Council on Bioethics, supra n279, at p84

Freeman and Petersen,[342] this threat to increasing stigma and discrimination towards the disability community and perhaps opening floodgates to creating a commodity out of the 'healthy child' and a by-product being the creation of a genetic underclass, but it also prompts a serious scepticism about our respect for the inherent human dignity of individuals and calls into question what it means to be a human being deserving of dignity according to our global society we are crafting.

Perhaps the issue of deliberately selecting for disability or avoiding PGT provides an alternative view of the notion of respect for human difference and diversity, and that it is merely a 'tolerance,' as distinct from an appreciation of the value and contribution of difference and diversity and PWD in our global community. It can be inferred from this that the expressivist argument illuminates a dichotomy between valuing the lives of PWD equally to all other human beings, and at the same time allowing and often encouraging the idea that where disability can be avoided, it should be. James Watson embodies the rebuttal to the argument in favour of selecting for disability, opining that 'seeing the bright side of being handicapped is like praising the virtues of extreme poverty.'[343] This overtly negative view of disability being perpetuated by a famous geneticist and discoverer of the double helix can raise concerns in the alleged dichotomy between eugenics and the new genetic practices. This therefore reflects the reservation that we as a society merely tolerate and pity those *struggling* with a disability, and their value disappears whenever we have the chance to prevent such afflictions in future generations.

This chapter has illustrated the concerns of the disability community toward embryo selection and the risk of harm being perpetrated on PWD, albeit some risks perhaps existing in a worst case scenario. The backdrop of the history of eugenics that the exists in the bioethical sphere which traumatises the disability community is still alive today in the fears and hesitancy of PWD towards PGT for the existence and vulnerability of their community and identity. It is crucial that we listen to the disability community and implement their voices within ethics committees and policy debates, as well as implementing their views and empirical experiences into genetic counselling procedures.

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[342] T. S Petersen, Just Diagnosis? Preimplantation Genetic Diagnosis and Injustices to Disabled People [2005] 31 Journal of Medical Ethics 231, at p232

[343] Supra n236 at p42

6 CONCLUDING OBSERVATIONS

The purpose of this thesis is the theoretical exploration of the conflict of arguments in favour and against embryo selection grounded on reproductive autonomy and disability rights. This does not attempt to undermine the advantages PGT present in today's world to go 'from chance to choice' in relation to having a child, or the desire of prospective parents to increase their child's chances of a good start in life and reduce their risk of suffering, whether that be physically, socially or mentally. The impact that eugenics had on the disability community and the trauma of this history still exists today and creates fear for an increase in stigma, discrimination and intolerance by virtue of reprogenetics. Unless addressed, this may damage the work of disability organisations and the international human rights field advocating for respect for natural human diversity and the inherent dignity of all human beings on an equal footing. As aforementioned, a strong majority of disability globally is attributed to non-genetic factors. Therefore, whilst a dangerous transhumanist agenda that is comparable to eugenic attitudes, with its desire to improve the strength of the human genome, the notion of eradicating disability in our communities is not possible. But what is possible, is the erosion of tolerance by creating a genetic hierarchy that can impact attitudes on the value and dignity of all human beings equally. This could have the effect of broadening what it means to be disabled as we almost make normal *more* normal - and permit the means for doing this to be exercisable by right and state funded. The harmful traditional eugenics policies may be successfully contrasted from reprogenetics today, due to an absence of state coercion and ignorant genetic determinism. However, the consequential world that is directly or indirectly advocated for is eerily similar, the gradual destruction of the disability population and their rights. Is this a world we want to live in? Conti presents three provoking yet importantly simplified questions to highlight the threat to respecting human dignity and the value of PWD in the society we have been endeavouring to make a better world to live in for all. Firstly, 'will society's attitudes towards and treatment of PWD become determinant purely on their genetic makeup?' Secondly, 'will

there be active eugenic practices to 'eradicate' genetic disability?' and thirdly, 'will there be a way to stop that from happening?'[344]

There has been progression throughout history in how society, law and policymakers view and approach disability. This approach has moved away from a medical understanding that a person's disability is a fault within them that should be eradicated or minimised, which can be attached to eugenic ways of thinking. Since, it has become almost trite that most of the issues experienced by PWD occur when they interact with societal norms and environmental barriers. Therefore, when we tackle these, then we can create equal opportunities for all human beings and respect the importance of having tolerance for and seeing the value in human variation. In doing this, we can work to minimise the harmful facets of living with a disability and factor in the strides that are made with modern medicine and the improvements to the treatability and curability of impairments and diseases. Therefore, how can we say that what is considered a serious disability today would be considered serious in 10 years' time? And should allocation of public funding work towards minimising and eradicating the existence of persons with a certain genetic disability, or to improve social, economic and health circumstances for PWD in the knowledge that disability does not render the quality of life so diminished as to have no possibility of participating in society in a meaningful way?

Regulating new technologies and scientific advances is always a difficult challenge in consequence of the speed of new developments and the cyclical difficulty for the law to keep up. Any regulatory approach must be flexible enough to remain as relevant as possible to any apprehended changes or future consequences, and we have seen from our case studies that there are different ways to tackle the ethical and rights-based issues that arise from the use and routinisation of PGT. We can compare the Portuguese and UK approaches in the sense that an independent or semi-independent body establishes a list of 'serious' genetic abnormalities that bring about such suffering or reduction in life-span that justify being selected against before implantation – and over time these lists have been extended quite regularly. The limitation of PGT for severe abnormalities only can be considered a reasonable approach so as to not open floodgates to how far one can intervene with the genotype of their future child and preserve a level of respect for human variation. At the same time, those living with a genetic

[344] Adam Conti, 'Drawing the Line: Disability, Genetic Intervention and Bioethics' [2017] 6 Laws 9, at p10

disability that is on such lists could feel as though the 'expressionist view' renders the inherent value of their life somewhat reduced based on an assumption without experiential value of the reduced quality of life, and that their state sees benefit in the avoidance of their birth, and those like them, where possible. Through a destruction of this inherent value and dignity as a person, comes with it a plethora of other harms we discussed in chapter 5, such as stigmatisation, discrimination, stereotyping and a reduction in funding and services (when the disability population decreases).

If we consider jurisdictions that do not make available a deliberated list of serious diseases, or that do not provide for PGT through public health systems for those that so require, such as Ireland, we can see another plethora of issues. There is a question of whether the state should intervene and implement regulations regarding one's reproductive autonomy, and that such laws would constitute the societal view on these issues. This could be consistent with the 'expressivist view' that PGT regulations reflect a state and society's view on disability and who should be accepted within our community. However, the reality of reproductive tourism, which is not a novel phenomenon and is well-known to states such as Ireland where its citizens travelled to avail of reproductive healthcare such as abortion or surrogacy for decades, can render any efforts to step away from this entire situation implausible and ineffective in practice. In fact, such reproductive tourism to states where PGT is made more easily accessible or where individuals avail of PGT through private clinics that abide by their own norms and guidelines, can only result in the commodification of the 'healthy' child and entrench the notion of a genetic underclass and further ostracization and discrimination of PWD in communities.

Therefore, there are difficulties in determining the appropriate level of regulation, but also in the mere fact that there is such irregularity in accessibility and regulations for PGT in various countries across Europe. This creates the opportunity for creating a commodity out of healthy children with the so-called 'best chance of a good life' for those who can afford it, and thus in jurisdictions like Ireland can unfairly deter those who bear a risk of passing on a serious genetic abnormality from having a child, or at least a child with an equitable opportunity for a flourished life. This also proves to confirm that the unfortunate social circumstances that have been outlined throughout this thesis for both the threat to reproductive autonomy and the harm threatened to the disability community of stigmatisation, discrimination, funding for services

and accessibility, and erosion of our respect for human diversity and inherent human dignity for all human beings cannot be addressed through legal means in isolation.

In theory, a liberal and democratic society that claims to uphold human rights and standards does not purport any de jure conflict between reproductive autonomy and the rights of PWD through PGT. There is no direct causation between the acts of a prospective parent in relation to the future child, and the experiences of PWD in society. All three of our case studies have signed and ratified the CRPD, and therefore purport to respecting all rights of PWD. In reality, no state can be said to have successfully implemented the entirety of the CRPD. In addition, we've shown how PGT is ethical and a moralistic exercise of an individual's reproductive autonomy in our case study jurisdictions. Any limitation on reproductive autonomy must be legitimised by showing an unjustifiable harm to another person's rights. In addition, we have shown that the embryo does not carry such rights and therefore any harm to a future or potential person is circumvented through the non-identity theory. However, the expressivist objection and the disability rights critique generally could be said to form a rejection based on an indirect harm to the collective rights under the CRPD. Therefore, the rights of PWD cannot be seen to be directly conflicted with the rights of an individual who is exercising their own reproductive autonomy through PGT, because there is no direct connection between a prospective parent who has a righteous and principled desire to minimise the risk of having a child with a disability. And with the knowledge that statistically this child will have a tougher start in life due to unfortunate realities of stigma and discrimination that exist as well as the empirical fact of economic and mental distress and often turmoil that can be experienced by a family affected by disability, then should we attempt to fault these individual acts? Or rather should we work to address the issues around the relative autonomy of prospective parents, and to improve the real-life experiences of PWD in our communities today so that we can truly destigmatise the perception that disability should be 'feared and eliminated.'[345]

This creates a complex issue, and one that cannot be solved through law or policy guidelines alone. The CRPD states that views of PWD must be ascertained and implemented in a meaningful way when enacting policies and regulations that will affect them, including PGT. In addition however, tools such as public awareness raising and implementing the voices of

[345] Stainton, supra n330, at p91

the disability community within the genetic counselling phase of PGT based on real-life experiences that don't make far-reaching assumptions that an embryo without a genetic disability will have a far more flourished life. Ultimately, these decisions should be made autonomously by parents free from coercion, whereas the reality is that societal norms and economic standards act as a means of coercing these decisions. A stark example of the failure to uphold reproductive autonomy synonymously with respect for PWD is when an individual wants to select for a disability in an embryo. This highlights a problematic dichotomy when regulations purport to allow for PGT in order to embrace reproductive autonomy, whilst stating that selecting against disability should not send a message that the lives of PWD currently living are devalued, yet at the same time it is prohibited either de jure or de facto in our case studies to implant an embryo with a disability. This situation rejects both reproductive autonomy and respect for the dignity of PWD and value of human difference within our world, and embodies the expressivist claim that disability should be avoided where possible and to knowingly risk the birth of a child with a genetic disability is wrong and should be prohibited.

How can we defend arguments that selecting for disability is immoral and irresponsible yet the widening of genetic disability that will be publicly funded to eradicate through PGT is not eugenic in practice? Would full respect for reproductive autonomy and the rights of PWD not allow for embryo selection decisions to be made by parents? This is contradictory yet complicated. If we grant unlimited procreative autonomy, we may alleviate the issues with drawing a line between what is a serious disability that should be prevented and allow these decisions to be made on subjective considerations of what a good life for their child should look like. But may we also open up the possibility for further commodification of healthy babies through genetic enhancement. When we allow for the selection of the biological constitutions of children in accordance with what parents consider will allow them to flourish, who's to say this should be confined to so-called 'disabling' traits? Couldn't we say that to select against embryos with a predisposition for a slower metabolism or sex selection against female embryos because the unfortunate realities of fatphobia or misogyny mean this will give them a better start in life in accordance with procreative beneficence?

Is it wrong to allow people to interfere with the genotype of their future children, or should a liberal democracy allow individuals to freely organise their life, especially when it is for moral reasons of avoiding suffering? Depending on how we answer this, the impact on the

discrimination and denial of rights of PWD or those who differ from the norm is going to be threatened. One could attest the selection of embryos according to non-medical characteristics is unethical, but the view that disability is not a purely medical issue brings us into a contradicting view of the situation. What is at stake here is not only the harmful future impact of PWD living whilst PGT practices continue to be normalised, but that it could allow us to chip away at our understanding of the importance of human dignity and when a person is afforded such dignity. We are risking the value of a human being and their dignity measured in accordance with their biological constitution. In practice, this works directly against the Universal Declaration on the Human Genome and Human Rights, clearly stating that human dignity shall be afforded regardless of one's genetic constitution, in order to truly uphold our respect for human difference. When we put this respect at risk in the name of reproductive autonomy and procreative beneficence, we threaten our tolerance for one another within our global community. And in the knowledge of our global history of war and widespread deprivation of fundamental rights, it is no ground-breaking statement to say that intolerance can light the spark for some of the most heinous atrocities amongst human beings.

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