Chapter VI: Genetic testing or screening at a pre-birth stage

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1. Introduction

As we enter the fourth industrial revolution, our communities boasting unprecedented advancements in the field of genetics and genomics, the proliferation of successful genetics and genomics companies and their service offerings teether the line between general for-profit commercialization and a larger social sustainability and justiciability issue. After the completion of the Human Genome Project in 2003, the reducing costs of full personal genome sequencing and testing services over the last decade, amongst other services, mean that these services have become more accessible to members of the public. In part, this is spear-headed in recent years by start-up personal genetics and genomics companies, that have employed powerful and innovative means to transform the landscape of accessing genomics services. Personal genetics and genomics services are generally provided on a direct-to-consumer basis, and the resulting outcomes target findings, amongst others, that delineate one's ancestry and susceptibility to genetic conditions.

It is not surprising that these genetic testing services have also permeated the realm of reproductive healthcare and services, often offered as part of a bundle of testing services in assisted reproduction technologies (ARTs).[1] It has become increasingly common that genetic testing, particularly, is employed in in-vitro fertilisation (IVF) procedures, prior to the implantation of an embryo into the womb (the pre-birth stage). Considering that the global infertility rate is increasing, and affects approximately 186 million people worldwide,[2] genetic testing services were initially

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[1] The term "ART" is commonly used to refer to a host of techniques used to assist infertile couples achieve pregnancy through anon-coital methods of contraception. The techniques in ART involve the manipulation of gametes and was introduced together with in-vitro fertilization. Other variations of ART were later developed, including, inter alia, intracystoplasmic sperm injection (ICSI), gamete intra-fallopian transfer (GIFT), zygote intra-fallopian transfer (ZIFf). It must be noted that ARTs do not provide for a cure for infertility, and do not necessarily guarantee success for a couple to have a baby

[2] Márcia Mendonça Carneiro and Márcia Crisitna França Ferreira, 'Infertility Awareness: Why Should We Care?' (2021) 61 Women & Health 501.

invented as a way of countering infertility by ensuring that implanted embryos are healthy and would survive. The most common of this technology is called preimplantation genetic testing (PGT) or preimplantation genetic screening (PGS) – where embryos are broadly genetically analysed prior to transfer (where there is no prior knowledge of known, potentially inheritable genetic conditions). In PGT/PGS, when an embryo has reached the blastocyst stage in IVF, some cells are taken from it for purposes of biopsy to screen for potential genetic mutations. The screening test results would show if an embryo has the right number of chromosomes for future development, or that it does not have any abnormal genetic mutations – all these will contribute to an increased in success during the IVF cycle, and reduce the chance of miscarriages.[3]

A slight variation of PGT/PGS is preimplantation genetic diagnosis (PGD), which is more focused, because this is used when there is a known specific disorder attributable to either one of, or both biological parents. This is especially useful if there is a known heritable genetic condition or disorder that is likely to affect the future child. PGD was developed as an alternative means to PGS,[4] and primarily "revolved around the determination of gender as an indirect means of avoiding an X-linked disorder."[5] Hence, if an embryo is found to be free of genetic mutations, particularly the disease which the parents do not wish to pass to their offspring, it appears that PGD might seem to be a more attractive option in preventing heritable genetic diseases, as it eliminates the dilemma of terminating a pregnancy following unfavourable prenatal diagnosis.[6] Whilst both PGS and PGD are genetic screening tests at a pre-birth stage, they do present different ethical, legal and social implications (ELSIs), with PGD arguably raising more concern. These include: the destruction of prenatal life in PGD, which has been placed on equal footing with the destruction of prenatal life in abortions;[7] non-medical or non-therapeutic uses of PGD (sex selection as an example);[8] fears about selection of embryos leading to eugenic outcomes;[9] and concerns about "designer babies" being made possible,[10] amongst others.[11] For this reason, this chapter pivots on PGD as the focus of genetic testing at pre-birth stage.

There has been some divergence in the regulatory landscape relating to PGD, even in the European context.[12] Much of the existing literature focuses on the ELSIs of PGD, with only a small fraction devoted to the rights of children, or more accurately, the rights of the future child, or other relevant children in the equation,[13] in this biomedical intervention. This chapter maps out the divergence of national legislation for PGD in selected European Union (EU) and/or Council of Europe (CoE) Member States (MS), posed against the wider background of EU-level laws and directives, international human rights treaties, and United Nations (UN) level framework of governance. Of particular note is the analysis and assessment of children's rights within the scope of these

[3] Courtney Dickens, 'Preimplantation Genetic Testing (PGT)' (*Johns Hopkins Fertility Centre*).

[4] Molina B Dayal, 'Preimplantation Genetic Diagnosis: Overview, Indications and Conditions, Process' (*MedScape*, 29 August 2018) <https://emedicine.medscape.com/article/273415-overview> accessed 11 July 2022.

[5] ibid. An X-linked disorder is essentially a recessive, sex-linked genetic disorder attributable to the X chromosome from a male or female parent. See https://www.nlm.nih.gov/medlineplus/ency/imagepages/19097.htm. Examples of x-linked disorders include haemophilia, muscular dystrophy, colour blindness, Hunter's disease, and Lesch-Nyhan Syndrome, amongst many others.

[6] Pin Lean Lau, *Comparative Legal Frameworks for Pre-Implantation Embryonic Genetic Interventions* (Springer International Publishing 2019) 3 <http://link.springer.com/10.1007/978-3-030-22308-3> accessed 19 November 2019.

[7] Jeffrey R Botkin, 'Ethical Issues and Practical Problems in Preimplantation Genetic Diagnosis' (1998) 26 The Journal of Law, Medicine & Ethics 17, 21.

[8] M Shelby Deeney, 'Bioethical Considerations of Preimplantation Genetic Diagnosis for Sex Selection' (2013) 5 Washington University Jurisprudence Review 333, 333.

[9] R Scott, 'Choosing between Possible Lives: Legal and Ethical Issues in Preimplantation Genetic Diagnosis' (2006) 26 Oxford Journal of Legal Studies 153, 161.

[10] Dov Fox, 'Retracing Liberalism and Remaking Nature: Designer Children, Research Embryos, and Featherless Chickens' (2010) 24 Bioethics 170, 170.

[11] Lau (n 6) 3.

[12] Sirpa Soini, 'Preimplantation Genetic Diagnosis (PGD) in Europe: Diversity of Legislation a Challenge to the Community and Its Citizens' [2007] Medicine and Law 309.

[13] Michael Gross, 'Dawn of the Saviour Sibling' (2003) 13 Current Biology R541.

technologies and the level of consideration provided by MS for their "highest attainable standard of health."[14]

2. State of the Art for Pre-Birth Genetic Screening: Preimplantation Genetic Diagnosis (PGD)

PGD is no longer a new advancement in the field of ARTs, but its potential for use may not yet be fully explored. PGD requires IVF, embryo biopsy and using either fluorescent in situ hybridization (FISH) or polymerase chain reaction (PCR) at the single cell level. Although it has also been recognised that PGD is a complex procedure and requires high level of skills on the part of the medical professionals,[15] it is a far superior technology than previous iterations for genetic screening such as amniocentesis or chronic villus sampling. With this recognition comes the startling discovery that, despite its popularity trajectory in many countries around the globe, PGD as an emerging and continually growing technology is subject to different levels of regulation (and in some countries, none at all). In addition, due to the remarkable advances in science and technology, coupled with greater financial resources and an elevated academic and scholarly pursuit of technological knowledge, the emergence of genome editing tools such as CRISPR[16] is likely to change the landscape of medical and scientific treatments. If genome editing becomes a viable possibility in PGD use, the once-taboo questions of germ line gene therapy and genetic enhancements or interventions, may now represent a dramatic change to how PGD may be marketed and offered as part of fertility treatment services.[17]

The literature review conducted for this chapter is a modified systematic literature review (MSLR), undertaken to analyse and synthesise existing literature on ELSIs of PGD, and particularly, to attempt an investigation into existing gaps regarding the rights of children in these biomedical interventions. This is particularly useful in the realm of health, and the review herein attempts to model as closely as possible, the steps articulated by Briner and Denyer.[18]

Following the literature review, an overarching assessment of the landscape of laws, regulations and other guidelines in Europe for PGD is conducted. An overview of international instruments is also relevant, although these are more general rights-based conventions, such as the United Nations Convention on the Rights of Children (CRC), and each MS would have ratified this Convention and translated it into relevant children's rights legislation at the national level. In the meantime, there are some differences in national laws in MS relating to PGD,[19] as there is, to date, no specific EU-level, regional or international legislation or instrument that governs its use (with the exception of some international guidelines). Within the EU, pursuant to Article 5(2)[20] of the Maastricht Treaty (The Treaty on European Union), health (under which PGD is encompassed) is generally not regarded as an EU competency and would come under national MS competencies. The Treaty of Amsterdam meanwhile amended Article 152 of the EC Treaty (Treaty on the Functioning of the European Union) (previously Article 129) for matters relating to public health.[21] This may include areas

[14] Jani Bryson, *The Right of the Child to the Enjoyment of the Highest Attainable Standard of Health* (United Nations Human Rights Office of the High Commissioner 2012).
[15] Lau (n 6) 3.
[16] Poh Kuan Wong and others, 'CRISPR Gene-Editing Models Geared Toward Therapy for Hereditary and Developmental Neurological Disorders' (2021) 9 Frontiers in Pediatrics 592571.
[17] Lau (n 6) 10.
[18] Rob B Briner and David Denyer, *Systematic Review and Evidence Synthesis as a Practice and Scholarship Tool* (Oxford University Press 2012).
[19] Soini (n 12).
[20] Article 5(2) provides: *Under the principle of conferral, the Union shall act only within the limits of the competences conferred upon it by the Member States in the Treaties to attain the objectives set out therein. Competences not conferred upon the Union in the Treaties remain with the Member States.*
[21] Article 152 provides:
1. A high level of human health protection shall be ensured in the definition and implementation of all Community policies and activities.

of cooperation relating to "not only diseases and major health scourges but also, more generally, all causes of danger to human health, as well as the general objective of improving health."[22] Hence, it is for individual MS to regulate PGD as part of their national regulations, if necessary.

2.1 Laws, regulations, guidelines and legal cases in Europe for PGD

2.1.1 European Union (EU)

Besides the general EU treaties mentioned above, another EU-level directive that may be relevant in some aspects for PGD applications is Directive 2004/23/EC.[23] There is, however, a lack of clarity as to whether PGD applications would be covered by the Directive. Whilst the categories of tissues covered expressly mention gametes, embryos and human embryonic stem-cell lines (meant for human applications),[24] the wordings in the Directives require further clarity as to whether it would apply to PGD. The Directives covers a range of items relating to traceability, import and export of tissues, as well as quality assurance standards, risk management and technical requirements for processing and coding tissues.[25] There is no guidance thus far as to how PGD may be affected by this Directive.

Finally, a broad application of the Charter of Fundamental Rights of the EU may offer some relevancy to PGD. Article 3 (Right to Integrity of the Person) of the Charter states:

> 1. Everyone has the right to respect for his or her physical and mental integrity.
> 2. In the fields of medicine and biology, the following must be respected in particular:
> (a) the free and informed consent of the person concerned, according to the procedures laid down by law;
> (b) the prohibition of eugenic practices, in particular those aiming at the selection of persons;

Community action, which shall complement national policies, shall be directed towards improving public health, preventing human illness and diseases, and obviating sources of danger to human health. Such action shall cover the fight against the major health scourges, by promoting research into their causes, their transmission and their prevention, as well as health information and education.

The Community shall complement the Member States' action in reducing drugs-related health damage, including information and prevention.

2. The Community shall encourage cooperation between the Member States in the areas referred to in this Article and, if necessary, lend support to their action.

Member States shall, in liaison with the Commission, coordinate among themselves their policies and programmes in the areas referred to in paragraph 1. The Commission may, in close contact with the Member States, take any useful initiative to promote such coordination.

3. The Community and the Member States shall foster cooperation with third countries and the competent international organisations in the sphere of public health.

4. The Council, acting in accordance with the procedure referred to in Article 251 and after consulting the Economic and Social Committee and the Committee of the Regions, shall contribute to the achievement of the objectives referred to in this article through adopting:

(a) measures setting high standards of quality and safety of organs and substances of human origin, blood and blood derivatives; these measures shall not prevent any Member State from maintaining or introducing more stringent protective measures;

(b) by way of derogation from Article 37, measures in the veterinary and phytosanitary fields which have as their direct objective the protection of public health;

(c) incentive measures designed to protect and improve human health, excluding any harmonisation of the laws and regulations of the Member States.

The Council, acting by a qualified majority on a proposal from the Commission, may also adopt recommendations for the purposes set out in this article.

5. Community action in the field of public health shall fully respect the responsibilities of the Member States for the organisation and delivery of health services and medical care. In particular, measures referred to in paragraph 4(a) shall not affect national provisions on the donation or medical use of organs and blood.

[22] EUR-Lex, 'Public Health' (*EUR-Lex*) <https://eur-lex.europa.eu/EN/legal-content/summary/public-health.html> accessed 13 July 2022.

[23] Directive 2004/23/EC of the European Parliament and of the Council of 31 March 2004 on setting standards of quality and safety for the donation, procurement, testing, processing, preservation, storage and distribution of human tissues and cells

[24] Anniek Corveleyn and others, *Preimplantation Genetic Diagnosis in Europe* (Publications Office 2007) 57.

[25] ibid.

(c) the prohibition on making the human body and its parts as such a source of financial gain;
(d) the prohibition of the reproductive cloning of human beings.

Sub-section 2 would most likely be applicable to biomedical technologies like PGD as these are the main ELSI concerns that generally arise. Although the Charter has come into force pursuant to the Treaty of Lisbon, it would still need to be ratified by MS, and consequently, MS would be bound by the ratification only insofar as EU law is implemented. The purview, governance and regulation for health and medical issues would still come under the scope of MS competencies.[26]

The European Commission, in 2021, following the 13th European Forum on the Rights of the Child in 2020, published the EU Strategy regarding children's rights.[27] This Strategy covers six thematic areas such as education, digital and information society, protection from violence, and also includes health / healthcare. The EU commitment to health and healthcare for children, however, is much more focused on access to healthcare, vaccinations, mental health, and food and nutrition. Unfortunately, the issue of scientific advancements and biomedical interventions for the rights of children in health have not been expressly addressed as part of the Strategy.

Hence, besides the EU Strategy on the Rights of the Child, what is abundantly clear is that there is a lack of special recognition for the status and rights of children at this EU level, insofar as biomedical technologies and interventions are concerned. General application laws would, of course, encompass the rights of children in biomedicine – but clarity should also be sought regarding the rights of future children. Particularly so in the case of PGD, the pertinent question that will arise is, the extent to which parents are given full autonomy to make biomedical decisions for the best interest of the future child.

2.1.2 Council of Europe (CoE) & The European Court of Human Rights

The jurisdiction of the Council of Europe (CoE) is also highly relevant when considering PGD. Whilst the aims and competencies of the EU are broadly for the wellbeing and peace of the union and the regulation of a unified single market in various aspects, sharing similar values with the CoE, the CoE's competencies are more focused on protection of individual and fundamental human rights. Besides Article 8 (right to private and family life) of the Convention for the Protection of Human Rights and Fundamental Freedoms (the European Convention on Human Rights), there is a specific Convention that directly applies to biomedical interventions such as PGD.

This is the Convention for the Protection of Human Rights and Dignity of the Human Being with regard to the Application of Biology and Medicine (the Oviedo Convention). Of particular note are: Articles 10 (privacy and right to information), 11 (non-discrimination), 12 (predictive genetic testing), 13 (interventions into the human genome) 14 (non-selection of sex), 16 (protection of persons undergoing research), and 18 (research on embryos in vitro).[28] These are the key provisions in which biomedical interventions such as PGD would need to ensure protection. Corveleyn et al additionally provided the following insights into how these particular provisions are likely to apply to PGD:[29]

> The Explanatory Report on the Convention provides additional insight into how these Articles are intended to be applied. In particular, paragraph 83 of the Explanatory Report states that "Article 12 as such does not imply any limitation of the right to carry out diagnostic interventions at the embryonic stage to find out whether an embryo carries hereditary traits that will lead to serious diseases in the future child." Furthermore, with regard to Article 14 (see above), paragraph 94 of the Explanatory Report provides that it is "…for internal law to determine, according to the procedures applied in each state, the seriousness of a hereditary sex-related disease."

[26] ibid 58.
[27] European Commission, *EU Strategy on the Rights of the Child* (European Commission 2021).
[28] Lau (n 6) 193.
[29] Corveleyn and others (n 22) 60.

Hence, the implications of the treatment of the Articles, pursuant to the Explanatory Report on the Convention, confirm the following hypotheses: firstly, that genetic screening (including screening for hereditary genetic diseases) at the embryonic stage (pre-birth stage) is not expressly prohibited; and secondly, the manner in which national laws would deal with biomedical interventions such as PGD, would fall under the scope of their own competencies. The Explanatory Note, however, does seem to have considered the rights of the future child, particularly insofar as serious diseases are concerned, and how predictive genetic testing is employed for this purpose. Whilst Article 14 also prohibits sex selection, it appears that sex selection of embryos is permissible if linked to a sex-specific genetic disease. Other than these interpretations, not much is mentioned in the way of protection for children, particularly existing children and future children. Hence, it is clear as to why MS do not really have a uniform regulatory framework PGD more specifically, and even, more broadly, laws relating to assisted reproduction. A general position has been taken *vis-à-vis* the Oviedo Convention, but the specifics of dealing with the position must be determined by individual MS.

Another observation that can be made is that the Oviedo Convention is not widely ratified enough, even though it is (likely) the only international or regional instrument that deals with applications of biology and medicine in the human body. Authors have noted some of the initial difficulties in drafting the Oviedo Convention, and hence, the best solution was to have it in broad and generic terms addressing bioethics and biomedicine.[30] This explains why there are certain gaps that can be noticed, including specific provisions for the protection of children thereunder. Notwithstanding the criticisms levelled against it, and with several MS not ratifying it as yet, the Oviedo Convention remains a stalwart instrument in compelling the recognition of bioethical and biomedical laws and issues at an international level.

In addition, the jurisprudence of the European Court of Human Rights (ECtHR) may provide a glimpse into how PGD or other types of prenatal screening are interpreted in accordance with the national laws of some MS. The most notable of these cases is ***Costa and Pavan v Italy***,[31] where an Italian couple wanted to avail of PGD so that they would be able to have a healthy future child and avoid transmitting a hereditary genetic disease. The couple were known carriers of cystic fibrosis. The relevant national law of Italy, Law No. 40, 19 February 2004, only permitted the use ARTs for sterile or infertile couples, as well as included a blanket ban on the use of PGD. As the couple could not have access to PGD, they argued that this was in violation of Article 8 of the European Convention on Human Rights, that their right to respect for private and family life was unjustly hindered by the denial of access to genetic screening of the embryo. The Court found that there was indeed such a violation of their rights under Article 8. Interestingly, the Italian government's justification for the PGD ban was to protect the interest of the mother and the health of the child. Ultimately, the Court found that these reasons could not be justified, and in particular, that 'child' was not the same as embryo and therefore, could not be affected by in-vitro fertilization or PGD.

2.1.3 Member States' National Laws or Guidelines

Ranging from liberal permissibility in the United Kingdom, to a strict ban in Italy, often for specific ELSI reasons or even religious reasons, the reality is that there may be limited access to PGD in some countries. A comprehensive study[32] commissioned in 2015 (updated in October 2021) by the Steering Committee for Human Rights in the fields of Biomedicine and Health (CDBIO) (formerly DH-BIO) has mapped out the legal and clinical situation for PGD in some MS. A selection of these MS' national laws or guidelines is indicated in Table 1 below.[33] The Table also includes specific children's protection laws

[30] Vera Lúcia Raposo, 'The Convention of Human Rights and Biomedicine Revisited: Critical Assessment' (2016) 20 The International Journal of Human Rights 1277.
[31] *Costa and Pavan v Italy* [2012] ECtHR 54270/10.
[32] DH-BIO/INF (2015) 6, 'Background Document on Preimplantation and Prenatal Genetic Testing'.
[33] ibid 22–28.

in the MS, although it is to be noted that these are general application laws (with the exception of the Netherlands), and are not specific to the protection of children in biomedicine.

Country	Is PGD regulated?	Is PGD permitted?	Relevant Laws	General Rights of Children
Austria	✓	✓	Genetic Engineering Act (process) and Reproductive Medicine Act (definition)	Federal Constitutional Act on the Rights of Children (Children's Rights Act) (BGBI. 4/2011).
Belgium	✓	✓	Law of 6/7/07 concerning medically assisted procreation and the use of supernumerary embryo and gametes (Moniteur Belgique du 17/07/2007)	Belgian Constitution, Article 22bis: each child is entitled to have his or her moral, physical, mental and sexual integrity respected" and that "[t]he law, federate law or rule referred to in Article 134 guarantees the protection of this right." The Protection of Young Persons Act of 8th Apr. 1965
Czech Republic	✓	✓	Act no. 227/2006 Coll. and its implementing regulations	Civil Code (Nr. 40/1964 GBl.)
Denmark	✓	✓	Law on medically assisted procreation in connection with medical treatment, diagnosis and research etc. adopted in 1997 and recently amended in December 2018	Parental Responsibility Act of 1 December 2017 no. 1417. Social Services Act of 29 January 2018 no. 102 (Serviceloven). Children's Act of 23 December 2015 no. 1817
France	✓	✓	Law (articles L. 2131-4-1 of the Code of Public Health); Decree (articles R.2131-22-1 a R. 2131-34 of the Code of Public Health)	Law No. 2016-297 of March 14, 2016, Regarding the Protection of the Child
Germany	✓	Prohibited as a general rule	The Embryo Protection Act of 13th December 1990, amended by the Act regulating pre-implantation genetic diagnosis of 21st November 2011 (Federal Law Gazette I, p. 2228); Ordinance having the force of law regulating pre-implantation genetic diagnosis of 21st February 2013 (Federal Law Gazette I, p. 323)	Article 6(2) of the German Basic Law: Article 6 (2) is to be extended to include the following: "The constitutional rights of children, including their right to develop as responsible individuals must be respected and protected. Children's best interests must be taken into account in an appropriate manner. The constitutional entitlement of children to a fair hearing in front of the law must be ensured. The

				primary responsibility of parents shall remain unaffected."
Greece	✓	✓	Law 3305/05 Medically assisted reproduction	Act 4538/2018 titled "Measures for the promotion of the institutions of foster care and adoption and other provisions"
Italy	✓	Neither prohibited nor permitted expressly	Law 40/2004 on medically assisted procreation Law 40/2004 on medically assisted procreation	Law 977/1967, 'Protection of children and adolescent child workers' Law 176/1991, 'Ratification and execution of the CRC
The Netherlands	✓	✓	Regulation Preïmplantatie Genetische Diagnostiek	Child and Youth Act 2015 Agreement of Medical Treatment (Wet op de Geneeskundige Behandelingsovereenkomst, WGBO)
Norway	✓	✓	The act relating to the application of biotechnology in human medicine etc. (Biotechnology Act)	Act of 17 July 1992 No. 100 relating to Child Welfare Services (the Child Welfare Act).
Portugal	✓	✓	Law no. 32/2006 of the Parliament, Art. 28	Law 147/99, 1 September - Protection of Children and Young Persons
Romania	✓	✓	Law 17/on 22 February 2001	Romanian Law on the protection and promotion of the rights of the child [272/2004]
Spain	✓	✓	Law 14/2006, May 26: Assisted Human Reproduction Techniques	Child Protection Law (2021)
Sweden	✓	✓	Act on Genetic Integrity (SFS 2006:351)	Social Services Act 1980 (supplemented by the Care of Young Persons Act)
Switzerland	✓	Prohibited (but currently being reviewed)	Federal Law of 18 December 1998 on medically assisted procreation (LMAP) (currently re-examined)	Swiss Constitution No specific child protection legislation, ratified the CRC and child protection is contained in different legislations
United Kingdom	✓	✓	The Human Fertilisation and Embryology Act 1990 (the HFE Act)	The Human Fertilisation and Embryology Act 1990 (the HFE Act)

				Children's Act 1989

2.2 Key Ethical-Legal Concerns in PGD Involving Children

Whilst there are many concerns regarding PGD, and there is no lack of scholarship and divisive debates in this area, this chapter seeks to highlight particularly the issues that are relevant to children and aspects of considering their rights in the broader context of PGD. The MSLR methodology was able to reveal that PGD has reached a point at which it is generally considered safe enough for broader use. Nevertheless, most literature regarding concerns in PGD have centred on it being a 'gateway' technology to further concerns that could be coupled with reproductive processes:[34] germ line gene therapies or interventions; and genetic enhancement. Both are these are already pressing concerns that are presently being debated and discussed on a global level. Nevertheless, the MSLR methodology also allowed this chapter to identify the key legal-ethical concerns in PGD that impact upon children and their rights, more specifically detailed in the following sub-sections; and allows us to raise questions about the implications that PGD could have on a long-term basis.

2.2.1 Saviour siblings and tissue typing

In PGD, a saviour sibling is essentially "created" by selecting an embryo that, when born, will be able to provide stem cells or healthy tissue to an older sibling suffering from a serious medical condition, that may be treated by the donation from the saviour sibling. In many instances, a further process called Human Leukocyte Antigen (HLA) tissue typing is also carried out simultaneously, as this will enable patients to be matched to their donors through the HLA protein markers in their bodies. HLA tissue typing is typically carried out to match patients and donors for bone marrow or cord blood transplants.

It is generally accepted that the birth of the world's first 'designer baby' (saviour sibling) was recorded in 2000 in the United States. The child's name is Adam Nash,[35] and he was conceived through IVF and PGD, for the purpose of being a saviour sibling for his older sister, Molly, who suffered from Fanconi's Anemia. Whilst there was a large garnering of support and empathy in the media for Molly's condition, and the almost fantastical birth of her younger brother to save her life, there are serious questions to be considered, especially for Adam Nash as the saviour sibling.

Within biomedical and bioethical circles – there are numerous justifiable reasons why the saviour sibling phenomenon creates problems. Firstly, it opens up debates about the treatment of children as commodities, as they are instrumentalised and produced in such a way that they would be used as 'spare parts'. Linked to this is the pressing question that inevitably arises, relating to "the limits or extent to which genetic materials, tissue, blood, samples and the like, may be 'harvested' from the saviour sibling."[36] Secondly, there is the issue of impossibility of informed consent, and obtaining such informed consent from the saviour sibling child. Finally, there is a real possibility of ancillary consequences in authorising a saviour sibling's creation; for example, sex selection (which will also be discussed below).

We take a case study of the UK to determine if, and to what extent, the welfare of the child is taken into account. As a preliminary point, Paragraph 1ZA of Schedule 2 of the HFE Act refers expressly to embryo testing. The paragraph begins in exclusionary language that states embryo testing is not permitted, but there are exceptions to this general rule (Paragraph 1, sub-paragraph 1). Sub-paragraph (d) specifically permits the creation of saviour siblings as an exception to the general rule

[34] Botkin (n 7).
[35] A Cecile JW Janssens, 'Those Designer Babies Everyone Is Freaking out about – It's Not Likely to Happen' (*The Conversation*, 10 December 2018) <http://theconversation.com/those-designer-babies-everyone-is-freaking-out-about-its-not-likely-to-happen-103079> accessed 21 July 2022.
[36] Lau, *Comparative Legal Frameworks for Pre-Implantation Embryonic Genetic Interventions* (n 7) 97.

regarding embryo testing.[37] In ***R (on the application of Quintavalle) v Human Fertilisation and Embryology Authority***,[38] a couple named the Hashmis received the approval of Human Fertilisation and Embryology Authority (HFEA) under Section 3(1) of the 1990 HFEA Act, to carry out PGD for the purpose of ensuring that they would have a child born free of hereditary beta thalassemia, and HLA tissue typing to ensure that such embryo would be a blood match for their existing child so that they would be able to use the umbilical cord blood to save their child's life. Comment on Reproductive Ethics (CORE), a pro-life activist group, challenged the decision of the HFEA in 2002, and sought for judicial review of the same. The House of Lords rule that the decision made by the HFEA was a lawful one and contained within the scope of its powers under the 1990 HFEA Act. The judgment of the House of Lords focused on the background, construction, interpretation and the legislative intent of the 1990 HFEA Act. Interpretive guidance was also sought from the case of ***Royal College of Nursing of the United Kingdom v Department of Health and Social Security***[39] especially in connection with legislation that "[deals] with a controversial subject involving moral and social judgment on which opinions strongly differ."

Nevertheless, references to the welfare of the child, is indeed, within the policies of the HFEA, and that "the best interest of the child produced by assisted reproduction must be paramount." Whilst expressly identified, there is a lack of guidance as to what 'best interests' really mean, and the latitude of parental determinism given. Because of this lack of clarity, there are many difficult unanswered questions about the "best interest" of the child. And, unlike other PGD scenarios, the benefit of the procedures in this instance would be gained by the sick sibling, and not the saviour sibling. For example, an extended ethical concern could arise regarding informed consent. We have already noted that it would be impossible to obtain the consent of the future child – but does this preclude informed consent of a saviour sibling once they are older? Are they in a position to refuse donation of stem cells or other tissues to their siblings? The law is silent on this matter – although in bioethical circles, there remains debates about the ethical and legal concerns about saviour siblings. Robert Boyle and Julian Savulescu particularly highlight why the sustainability of the argument of harms that may potentially befall a future saviour sibling cannot be reasonably founded;[40] as is also the view of Malcolm K. Smith, who propagates for a safe relaxation of legal rules relating to saviour siblings.[41] But a more balanced perspective is offered by Thomas Cordelia, who takes into account a variable consideration of consent derived from the ***Gillick*** competence test,[42] and the invasion into the potential child's bodies.[43] In fact, in England and Wales, the ***Gillick*** case demonstrated that the courts considered consent of the child more broadly, and whether the child understand the proposed medical treatment. If the child does, then in these circumstances, even parental power cannot override it; interestingly, the Court held that parental rights do not exist, other than to safeguard the interests of a minor child.

In other jurisdictions in Europe, although it can be seen that PGD is generally more tolerated and authorised, creating a saviour sibling through HLA tissue typing is much less common. Nevertheless, a number of countries in Western Europe, besides the UK, do permit the creation of

[37] ibid 92. Paragraph 1, sub-paragraph 1(d) states: "*In a case where a person ("the sibling") who is the child of the persons whose gametes are used to bring about the creation of the embryo (or of either of those persons) suffers from a serious medical condition which could be treated by umbilical cord blood stem cells, bone marrow or other tissue of any resulting child, establishing whether the tissue of any resulting child would be compatible with that of the sibling."*

[38] R (on the application of Quintavalle) v Human Fertilisation and Embryology Authority [2005] UKHL 28.

[39] Royal College of Nursing of the United Kingdom v Department of Health and Social Security [1981] AC 800.

[40] Robert J Boyle and Julian Savulescu, 'Ethics of Using Preimplantation Genetic Diagnosis to Select a Stem Cell Donor for an Existing Person' (2001) 323 BMJ: British Medical Journal 1240.

[41] Malcolm K Smith, *Saviour Siblings and the Regulation of Assisted Reproductive Technology: Harm, Ethics and Law* (Routledge 2016).

[42] The Gillick competence test comes from the case of *Gillick v West Norfolk and Wisbech Area Health Authority [1985] UKHL 7*, and determines whether a child under 16 years old can consent to medical treatment without parental approval or knowledge. Lord Scarman's judgment states the Gillick competence test: "*As a matter of law the parental right to determine whether or not their minor child below the age of sixteen will have medical treatment terminates if and when the child achieves sufficient understanding and intelligence to understand fully what is proposed."*

[43] Thomas Cordelia, 'Pre-Implantation Testing and the Protection of the Savior Sibling' (2004) 5 Deakin Law Review 121.

saviour siblings *vis-à-vis* PGD and HLA tissue typing with similar conditions under the UK HFE Act. These include Norway, Sweden, Denmark, Germany, France, Belgium, the Netherlands, Spain, and Portugal.

2.2.2 Sex selection and family balancing

As a general rule, sex selection appears to be strictly frowned upon and prohibited in Europe, unless for exceptional circumstances – where pre-implantation embryos may be stricken with inheritable chromosomal disorders linked to either the X or Y-chromosome. In most MS legislation or guidelines (in the countries where PGD is authorised), sex selection of an embryo prior to implantation is strictly prohibited, unless it is strictly for medical reasons. Sex selection is also prohibited as per Article 14 of the Oviedo Convention; although the latitude in which exceptional sex selection is allowed for medical reasons would be left for MS to individually determine based on their own interpretations on the level of seriousness of such X or Y-linked diseases. In most circumstances, non-medical sex selection, which may include purposes of family balancing, is not allowed.

The phenomenon of sex selection of embryos at the pre-implantation level, although less common in Europe, predominantly occurs in Central and Southeast Asia.[44] In countries such as China, especially when the One-Child Policy was implemented in 1980 (ending in 2016), and India, and several others in Southeast Asia, there is a historical and patriarchal preference for male offspring. Of course, this impacts negatively particularly upon the rights of women and girls as it "perpetuates a culture of gender inequality, and jeopardises sustainable social development and stability."[45] In Europe, however, recent studies have begun to emerge regarding skewed sex ratios for births – however, the study's findings indicate that these have been limited to countries such as Albania, Armenia, Azerbaijan, and Kosovo in Southeast Europe.[46] Not enough research or statistical evidence is provided regarding skewed sex ratios in birth in other countries in East and Central Europe.[47]

However, due to the legal ambiguities in legislation, or non-regulation, countries such as Cyprus, have been able to offer PGD for family balancing purposes, ie non-medical reasons. It has, in fact, become popular for 'tourists' from other countries to visit Cyprus for reproductive tourism.[48] Whilst reproductive tourism is much more prevalent in developing or third world countries in Asia, the European context is not without its challenges. Because of restrictive national laws regarding PGD in some countries, there may now be a "tendency towards tolerance of reproductive markets and reproductive travel,"[49] where negating the effects of foreign fertility tourism could be achieved by pragmatic solutions to evaluate existing national ART laws.[50] This phenomenon will not be covered as part of this chapter; but is raised to allow a brief reflection on the difficulties and challenges that plague the governance of PGD in Europe.

Sex selection in PGD continues to be a topic that is debated. In fact, some ethicists question as to why sex selection for family balancing should be prohibited as it would be consistent with the notion of reproductive liberties.[51] Others are, however, more cautious for reproductive liberties not to teether down the slippery slope towards eugenics.[52]

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[44] UNFPA, 'Preventing Gender-Biased Sex Selection in Eastern Europe and Central Asia' (United Nations Population Fund 2015) Issue 4.
[45] ibid 1.
[46] ibid 3.
[47] ibid.
[48] Raywat Deonandan, 'Recent Trends in Reproductive Tourism and International Surrogacy: Ethical Considerations and Challenges for Policy' (2015) 8 Risk Management and Healthcare Policy 111.
[49] Britta C Van Beers, 'Is Europe "Giving In To Baby Markets?" Reproductive Tourism in Europe and the Gradual Erosion of Existing Legal Limits to Reproductive Markets' (2015) 23 Medical Law Review 103.
[50] ibid.
[51] Soini (n 13) 314.
[52] GK Chesterton, *Eugenics and Other Evils: An Argument Against The Scientifically Organized State* (Inkling Books 2000).

2.2.3 Avoidance of disabilities (genetic mutations/disorders)

Whilst most MS in Europe do authorise the use of PGD to avoid implanting an embryo with genetic mutations or disorders (and depending on the seriousness of the genetic disease), this, in itself, creates an incongruent dichotomy within the narrative of reproductive liberty. For instance, PGD has generally been authorised in most European countries to avoid serious genetic conditions in the future child; but the question of 'eradicating' these diseases, especially when related to disabilities such as deafness, trisomy 21 (Down's Syndrome) or achondroplasia (dwarfism) has sparked intense debates as to the value attributed to disabled lives. For example, how can we give effect to the rights of children with disabilities, or prospective future children with disabilities, within the PGD narrative, and is it even possible? Disability discourse is already fraught with challenges and battling with historically systemic discrimination that all disabilities should be cured.[53] The pre-eminent issue with eradicating disabilities *vis-à-vis* PGD and the selection of embryos is the devaluation of lives of those living with disabilities, including children. According to some critics, facilitating an attainment of the highest standard of health does not mean that disabilities should be eradicated; instead, adaptation to allow realisation of this right to health is necessary.[54]

In fact, persons with disabilities often rally against the notion that disability is a problem that needs to be solved, and contend that ableism arguments are harmful and discriminatory against the disabled population. Lennard J. Davis, a leading disabilities studies scholar states that "the problem is not the person with disabilities; the problem is the way normalcy is constructed to create the problem of the disabled person."[55] There is a wealth of disability-positive scholarship honing on the fact that persons with disabilities do not necessarily want to have their disabilities eradicated, or that they were born 'normal', because "this creates the (wrongful) narrative that persons with disabilities are less than, trailing on the fringes of 'other'."[56] This is in direct opposition to the views of some bioethicists, who contend that parents have a moral imperative and obligation to select the best child possible, known as the principle of procreative beneficence.[57] Some also contend that a reinterpreted version of "liberal eugenics"[58] could be justified, in allowing parents to select the best embryos, as this would be aligned with the concept of reproductive liberty.

The problem with these narratives is that the interest of the future child is often treated as being synonymous with parental decision-making, autonomy and reproductive liberty. For example, criticisms were levied against a lesbian couple, Sharon Duchesneau and Candy McCullough in the United States, who both wanted to have a deaf child as they were both also deaf.[59] In the UK, a deaf British couple, Tomato Lichy and Paula Garfield, wished to use IVF with PGD to select embryos that are also deaf. The couple were denied from doing this, as the HFE Act prohibits the use of reproductive technologies to select an embryo with "a serious physical or mental disability."[60] The spectrum of seriousness of disability upon which deafness falls, is a matter of interpretation – and there is still, to date, no consistent determination on how aspects of the future child should be considered in these circumstances.

Whilst many have vocalised that it would be unethical to bring into the world a child with disabilities (with the level of seriousness of disability open to interpretation), would this opinion reflect

[53] Stephen Banbury, 'Unconscious Bias and the Medical Model: How the Social Model May Hold the Key to Transformative Thinking about Disability Discrimination' (2019) 19 International Journal of Discrimination and the Law 26.
[54] Pin Lean Lau, 'Addressing Cognitive Vulnerabilities through Genome and Epigenome Editing: Techno-Legal Adaptations for Persons with Intellectual Disabilities' [2022] European Journal of Health Law 1.
[55] Lennard J Davis, 'Introduction: Disability, Normality and Power' in Lennard J Davis (ed), *The Disability Reader* (Routledge 2017).
[56] Lau (n 54) 20.
[57] Julian Savulescu, 'Procreative Beneficence: Why We Should Select the Best Children.' (2001) 15 Bioethics 413.
[58] Nicholas Agar, 'Liberal Eugenics' (1998) 12 Public Affairs Quarterly 137.
[59] M Spriggs, 'Lesbian Couple Create a Child Who Is Deaf like Them' (2002) 28 Journal of Medical Ethics 283.
[60] Jacob M Appel, 'Deaf Parents Want Deaf Baby: Bioethicist Weighs In' (*MedPage Today*, 11 October 2019).

our own presumed values, practices, and experiences, of what it means to be 'normal'?[61] A classic example of this is Iceland, that has almost completely eradicated Down's Syndrome in its national population, through pre-birth genetic screening and abortion.[62] Only 2 or 3 babies with Down's Syndrome are born in Iceland per year; geneticists in Iceland estimate that 80% to 85% of pregnant women opt for genetic testing, and out of these, there is an almost 100% termination rate of the pregnancy if it tests positive for Down's Syndrome. With the exception of the UK and Iceland, through an assessment in the MSLR, it was difficult to determine the legislative position of individual MS on using PGD to select for embryos with physical or mental disabilities, as opposed to selecting a healthy embryo.

2.3 Reconciling A Child's Right to an Open Future, Parental Autonomy, and Reproductive Liberties in PGD

The question still remains as to how MS should regulate PGD or even PGS/PGT to the extent that would considerably advance the interest of a child, or the future child, as the case may be. How can a child's right to an open future (CROF)[63] be safeguarded and protected? Is it adequate to accept that parental autonomy is the best and most appropriate arbiter for deciding in CROF? Whilst parental autonomy and reproductive liberty is respected, there should also be grounded reasons for limiting PGD use as "directed procreation"[64] in that there must be a balancing exercise between such reproductive liberty and the CROF to ensure that the future child is not limited in their prospective life plans. Besides this, it is also paramount that the associated human rights that accompany a child's right to achieve the highest attainable standard of health, can be protected by individual MS. These associated rights more broadly include: a right to life, privacy and autonomy of the child (including the child's understanding in informed consent), protection from harms and discrimination, and the child's bodily, physical and mental integrity, amongst others.[65]

This chapter notes that the roots of autonomy and choice, on the part of parents, may be a delusive constituent within the framework of reproductive liberty. It is not likely that parental autonomy can be completely value-free.[66] Even when parental autonomy is acceptable as the arbiter in making decisions for the best interests of the future child, this chapter acknowledges the sentiments that this kind of seemingly autonomous power is essentially an extension of social structures,[67] thereby, once again, impacting on the true autonomy of parents.[68] Whilst the 'power' of decision making has shifted from state to parent, it is noted that "individual choices made are often inextricably linked to some variation of societal control with links to communities; an informal mechanism of social control and a possible watered-down version of cultural and societal hegemony."[69] One thing that we are still not being able to determine is how we should attribute importance to ethical values within

[61] TS Petersen, 'Just Diagnosis? Preimplantation Genetic Diagnosis and Injustices to Disabled People' (2005) 31 Journal of Medical Ethics 231.
[62] George F Will, 'Opinion | The Real Down Syndrome Problem: Accepting Genocide' *Washington Post* (14 March 2018) <https://www.washingtonpost.com/opinions/whats-the-real-down-syndrome-problem-the-genocide/2018/03/14/3c4f8ab8-26ee-11e8-b79d-f3d931db7f68_story.html> accessed 26 July 2022.
[63] Davide Battisti, 'Genetic Enhancement and the Child's Right to an Open Future' (2020) 19 Phenomenology and Mind 212.
[64] Dena S. Davis, 'The Parental Investment Factor and the Child's Right to an Open Future' (2009) 39 Hastings Center Report 24.
[65] Kavot Zillen, Jameson Garland and Santa Slokenberga, 'The Rights of Children in Biomedicine: Challenges Posed by Scientific Advances and Uncertainties' (Committee on Bioethics of the Council of Europe 2017) 75.
[66] Pin Lean Lau, 'The Genius & The Imbecile: Disentangling the "Legal" Framework of Autonomy in Modern Liberal Eugenics, From Non-Therapeutic Gene Enhancement Use in Gene Editing Technologies', *Current Debates in International Relations and Law*, vol 4 (IJOPEC 2018) 315.
[67] David L Wiesenthal and Neil I Wiener, 'Ethical Questions in the Age of the New Eugenics' (1999) 5 Science and Engineering Ethics 383.
[68] Lau, 'The Genius & The Imbecile: Disentangling the "Legal" Framework of Autonomy in Modern Liberal Eugenics, From Non-Therapeutic Gene Enhancement Use in Gene Editing Technologies' (n 62) 315.
[69] ibid 317.

the scope of communities,[70] and if, and how, parents may be constrained from selection in PGD, and trying to choose endowments that could lead their future child down the path of "socially defined successes."[71]

We are also no closer to resolution in the debate on the CROF, and simultaneously, the kind of influence this might wield in the discourse of biomedical interventions like PGD. In J.S. Mill's concept of human liberty,[72] it was proclaimed that children, in their own right as small persons, do not possess the necessary wherewithal to exercise personal liberties.[73] Of course, this Millean exclusion of children from human liberties has been extensively criticised;[74] with critics accusing Mill of imposing the persistence of moral and legal paternalism,[75] and also rejecting Mill's notion that adult autonomy[76] "is a legitimate means of imposing one's choice over another person, namely, the child."[77] If we accept that a child's rights to an open future must be safeguarded, then we must ask the difficult questions, as the author of this chapter postulates:[78]

> Should we choose to accept, that as a child, I may have been 'directed' into a certain future plan by my parents, or is this simply a by-product of the natural ripples of parenting? The views in response to this question will undoubtedly be polarized by the affectations of our understanding of the concept of autonomy, and to whom it extends, with or without justifiable exclusion. Dare we be so bold as to say that parental decisions made for the welfare of their offspring, is usually motivated by a desire to provide 'the best' (in their reasoned opinion)? Dare we further say, that the innate desire to want 'the best' may disturbingly run close to some form of eugenics when it becomes humanly feasible to bestow upon this future offspring an actual 'the best' of human characteristics? These dialectic questions test the foundational tenets of autonomy, which is by no means, an alien concept in moral and legal philosophy. Although by its presentation, one is likely to recognize that a certain thing requires 'autonomy' on the part of the person exercising such decision, it is more difficult to conceptualize and distil the spherical scope of autonomy in different facets of everyday lives, particularly where children or future offspring are concerned.

Hence, although most of the MS in Europe have ratified the Oviedo Convention, which does, to a certain extent, recognise that children's rights should be properly considered – and most have also ratified the CRC, the MSLR was not able to assess the specific entry points at which children's rights in biomedicine are prioritised. What is clear is that PGD is authorised in most MS, with varying levels of permissibility, and most often appearing to prioritise the welfare and autonomy of parents, and trusting the parents to prioritise the future welfare of the child. If we accept the adequacy of empirical studies conducted so far, this seems to suggest that "the total sum of welfare is greater in a society where PGD is used than it is in a society where it is not."[79] The crucial delineation, therefore, is the balancing exercise between parental autonomy and the CROF; and it is likely that further investigations are necessitated in drawing out the nuances between how each MS treats this dilemma.

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[70] ibid.
[71] Wiesenthal and Wiener (n 63) 391.
[72] John Stuart Mill, *On Liberty* (John W Parker And Son, West Strand 1859).
[73] Sharon Stanley, 'John Stuart Mill, Children's Liberty, and the Unraveling of Autonomy' (2017) 79 The Review of Politics 49.
[74] Lau, 'The Genius & The Imbecile: Disentangling the "Legal" Framework of Autonomy in Modern Liberal Eugenics, From Non-Therapeutic Gene Enhancement Use in Gene Editing Technologies' (n 63) 302.
[75] Mauro Cardoso Simões, 'Paternalism and Antipaternalism' (2011) 10 ethic@-An international Journal for Moral Philosophy 65.
[76] Stanley (n 71) 50.
[77] Lau, 'The Genius & The Imbecile: Disentangling the "Legal" Framework of Autonomy in Modern Liberal Eugenics, From Non-Therapeutic Gene Enhancement Use in Gene Editing Technologies' (n 63) 302.
[78] ibid 304.
[79] Petersen (n 61).

3. Conclusion

In the discussions regarding the rights of children in biomedicine, it appears that much more needs to be achieved to crystallise these rights into fruition. However, the recent measures that have been proposed and launched by the CoE and the EU bear some promise in addressing some of the key concerns that impact upon children's rights in biomedicine. These recent efforts, such as the Committee on Bioethics (DH-BIO) Strategic Action Plan on Human Rights and Technologies in Biomedicine (2020 – 2025)[80] and the EU Strategy on the Rights of the Child,[81] hold the promise of advancing the protection of fundamental rights, and not only those of children, in our contemporary technological environment. As Sheila Jasanoff states, there is a highly "complex relationship between our technologies, our societies, and our institutions, and the implications of those relationships for ethics, rights and human dignity"[82], and the intense polarization of opinions and concerns in biomedical issues such as PGD and the impact on children's rights, is generally evidence of this truth.[83]

[80] Committee on Bioethics (DH-BIO), 'Committee on Bioethics (DH-BIO) Strategic Action Plan on Human Rights and Technologies in Biomedicine (2020-2025)' (2020).
[81] European Commission (n 27).
[82] Sheila Jasanoff, *The Ethics of Invention: Technology and the Human Future* (First edition, WW Norton & Company 2016).
[83] Lau, 'The Genius & The Imbecile: Disentangling the "Legal" Framework of Autonomy in Modern Liberal Eugenics, From Non-Therapeutic Gene Enhancement Use in Gene Editing Technologies' (n 66) 320.

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