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Twenty-Seven Years of Controversy: The Perils of PGD

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Abstract

It has been 27 years since the Human Fertilisation and Embryology Act 1990 was passed in the United Kingdom in response to advances in fertility treatment. Preimplantation genetic diagnosis - the screening of embryos for genetic diseases - has led to lengthy ethical debates on sex selection, eugenics, disabilities, saviour siblings, surplus embryos and most recently, adult-onset diseases (the BRCA cancer gene). This article provides an overview of how the law and practice of PGD in the United Kingdom and United States over the last quarter of a century has developed into new 'branches' of PGD, and predicts where they may be heading in the future. It concludes that many of the adverse views on PGD are unfounded and that some of these unique branches may develop to accommodate the screening of additional social traits. An underlying conflict between reproductive autonomy and a right to an open future is also rising under the surface to be noted for the future.

Keywords: Preimplantation Genetic Diagnosis, Eugenics, Disabilities, Saviour Siblings.

Introduction

When a team of scientists announced in 1989 that Preimplantation Genetic Diagnosis (PGD) was taking place on embryos, no one could have foreseen its potential. The procedure itself is highly complex - the embryo created in vitro is biopsied and one or two blastomeres (cells) are removed to be screened for the presence of a genetic disease. Originally developed as an experimental procedure at the Reproductive Genetics Institute in Chicago, Illinois to screen for X-linked diseases during fertility treatment, PGD quickly gathered pace when the first birth was announced in 1992. PGD was expanded further to detect late-onset diseases with a genetic predisposition such as breast cancer following the discovery of the BRCA gene, discovered in 1994. A controversial development came in 2001 when screening for a human leukocyte antigen (HLA) tissue match allowed couples to select an embryo to be a blood or bone marrow donor to an existing child, referred to as preimplantation tissue typing (PTT).

PGD can now detect hundreds of genetic diseases. The Human Fertilisation and Embryology Authority in the United Kingdom is currently licenced to screen for over 250 conditions. However, the ethical debates surrounding PGD are a constant reminder of the strain between reproductive autonomy (i.e. couples should be able to choose their embryos based on whatever genetic criteria they want) and the right to an open future (i.e. the child should not be born against a 'design'). Where is the line drawn in regards to ensuring that our children are born with or without certain traits, characteristics and disorders? This article briefly overviews the main 'branches' that have stemmed from PGD over the last 25 years including: social sex selection, the selection of disabilities, saviour siblings and the screening of adult-onset diseases, to clarify how the UK and US law has developed and where, in light of the ethical debates on eugenics and surplus embryos, PGD may be heading in the future.

Preimplantation Genetic Diagnosis: Legal Development In The Uk And USA

The United Kingdom

The Human Fertilisation and Embryology Act 1990 was passed on 1st November 1990, setting up the Human Fertilisation and Embryology Authority (HFE Authority) under section 5. The 1990 Act was the first in the world to place embryonic research on a statutory footing and contains intricate licencing laws. PGD is now found under schedule 2:

Schedule 2: Activities that may be licenced under the 1990 Act.

Paragraph 1ZA(1): A licence cannot authorise the testing of an em-

bryo, except for one or more of the following purposes:
(a) establishing whether the embryo has a gene, chromosome or mitochondrial abnormality that may affect its capacity to result in a live birth;
(b) in a case where there is a particular risk that the embryo may have a gene, chromosome or mitochondrion abnormality, establishing whether it has that abnormality or any other gene, chromosome or mitochondrion abnormality.
(2) A licence cannot authorise the testing of embryos for the purpose mentioned in sub-paragraph (1)(b) unless the Authority is satisfied:
(a) in relation to the abnormality of which there is a particular risk, and
(b) in relation to any other abnormality for which testing is to be authorised under sub-paragraph (1)(b), 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.
The 1990 Act (as amended) comes with a lengthy Code of Practice to help with interpretation and is available on the official website. The HFE Authority also regularly publish national trends and figures on fertility treatment. The current picture in the United Kingdom, 25 years after the passing of the 1990 Act, states the following:
• In 2014, 52,288 women had 67,708 cycles of IVF treatment;
• In 2014, 2,511 women had 4,675 cycles of donor insemination;
• 22 clinics provided PGD for 594 IVF cycles in 2014, with a birth rate of 25.6%;
• Donor sperm was used in 2,691 of IVF cycles in 2014;
• Donor eggs were used in 1,866 of IVF cycles in 2014;
• A grand total of 84,720 embryos were transferred in 2014;
• 28,263 pregnancies were reported in 2013-2014 following IVF treatment;
• The pregnancy rate has increased from 34.6% in 2012 to 36.3% in 2014;
• The live birth rate has increased from 25.4% in 2011 to 26.5% in 2013;
• The frozen embryo live birth rate has increased from 19.9% in 2011 to 24.8% in 2013;
• 1285 cycles of IVF were performed on same-sex female couples;
• It is estimated that 2.2% of babies born in the UK in 2013 were IVF babies.
The UK approach to fertility treatment thus consists of a regulatory body, a complex statute, strict licencing provisions and a detailed Code of Practice, and has inspired other countries to follow suit. PGD has advanced differently in the United States because of its research quality.

The United States

In the United States, there are no laws in place at a national level to regulate fertility treatment. The Food and Drug Administration (FDA) does not require premarket approval for PGD because it is considered 'research'. The Fertility Clinic Success Rate and Certification Act 1992 requires fertility clinics across the country to report pregnancy rates to the Centre for Disease Control and Prevention, but this excludes pregnancies using PGD. It is therefore left to advisory bodies to guide embryologists on what is acceptable practice in the field. The American Society for Reproductive Medicine (ASRM) was founded in 1944 as a non-profit organisation to support reproductive medicine in the U.S. and members now include biologists, embryologists, gynaecologists, urologists, reproductive endocrinologists, mental health professionals, internists, nurses, practice administrators, laboratory technicians, paediatricians and research scientists (membership is voluntary).
The ASRM publishes guidelines for correct laboratory procedures to ensure that member clinics adhere to the same high standards of practice. A laboratory director oversees his own embryology lab and is in charge of key performance indicators such as success rates, quality control programs, policy and procedure manuals for safety, infection, disaster, insurance, chemicals, personnel, patient identification, specimen collection, preservation, transportation, processing and reporting of results. In addition, the Society for Assisted Reproductive Technology (SART) recommends that the laboratory director must ensure that if his clinic is registered with SART and has a SART number, that the highest standards of quality, safety and patient care in assisted reproductive technology are met. 90% of assisted reproductive technology clinics in the U.S. are members of SART, and insurance companies only provide coverage for SART member clinics.
What is interesting about the U.S. approach to fertility treatment is now laissez-faire it is. For example, there is no formal definition of an 'embryologist' but a suggested definition put forward by the ASRM is "trained and certified by the laboratory director to perform all or most of the laboratory's embryology procedures". A clinic must be registered, accredited and certified at national level and report fertility cycles to the Centre for Disease Control and Prevention by law (excluding PGD), but membership to the ASRM and SART is voluntary. It is therefore up to the patient to do their research, pay the money and take the risks. This is in stark contrast to the United Kingdom, where every element of fertility treatment is subject to strict licencing conditions and statutory definitions.
Annual fertility treatment statistics are published by SART and as of September 2015 the current picture in the United States was as follows:
• Of the 101,600 treatment cycles that were carried out in 2014:
o 48.6% resulted in live births for patients under 35;
o 16.1% resulted in live births for patients over 40;
o Thawed embryos were used in 33,383 cycles;
o Donor eggs were used in 9,961 cycles.

The International Picture.

PGD has not been welcomed in every developed country. Its link to eugenics (i.e. eradicating diseased or disabled embryos to produce 'perfect' human beings) means it is banned in Chile, Switzerland, China, the Ivory Coast, the Philippines, Algeria, Ireland and Austria. Germany only recently changed the law in 2011 to allow PGD in cases with a very high risk of genetic disease, stillbirth or miscarriage. PGD is offered in Canada, Hungary, Italy, Norway, Demark, India, South Africa, Ukraine, France, Australia (South & Victoria), the Netherlands, China, Israel and Japan. Regulations are difficult to obtain in some of these countries because of the language barrier and a tendency to leave it up to individual States

to regulate the practice. In Canada for example, the Assisted Human Reproduction Act 2004 was repealed in 2012 leaving each province to regulate fertility treatment at its own discretion. Quebec, Alberta and Manitoba have chosen to publically fund fertility treatment with clear regulation and numerous clinics, whereas Ontario has no clear regulation and only a few private clinics. There are other countries such as Finland and Portugal where no laws have been passed but discussion is ongoing. Patients in these countries usually have to travel abroad.

The growing availability of PGD worldwide has led to an increasing number of clinics offering its controversial 'branches' (i.e. social sex selection, preference of disabled embryos, saviour siblings and adult-onset diseases). The ethical discussions surrounding these unique developments shed some light on where PGD may be heading in the future.

PGD and Sex Selection

PGD was originally designed to locate cystic fibrosis in female embryos before implantation. The technology has now expanded to include other X-linked diseases such as Huntington's chorea, duchenne muscular dystrophy, spinal muscular dystrophy, fragile X syndrome, haemophilia, myotonic dystrophy, beta-thalassemia and sickle cell anaemia. These genetic diseases cause significant disability, a very low quality of life and premature death, allowing couples to select male embryos using PGD.

The sex selection of embryos for purely social reasons has not been received so favourably. PGD for social sex selection is illegal in the United Kingdom, Canada, Taiwan, Denmark, India, Germany, Italy, Portugal and Spain. The European Convention on Human Rights and Biomedicine (1997) states that: "the use of techniques of medically assisted procreation shall not be allowed for the purpose of choosing a future child's sex, except where serious hereditary sex-related disease is to be avoided" under article 14 but Germany, Ireland, Italy and the United Kingdom did not ratify the convention. This places the legality of social sex selection in a strange position.

In the United Kingdom, the Human Fertilisation and Embryology Authority has spent considerable time researching the issue of social sex selection. A report entitled, Sex Selection: Options for Regulation (2002) was published after a brief consultation and concluded that sex selection should only be offered to couples who are seeking to avoid X-linked diseases or disorders:

A great many respondents felt that sex selection was unqualifiedly wrong because it involved interference with divine will or with what they saw as the intrinsically virtuous course of nature. Many of those who used these arguments used them to express a profound concern that human intervention in reproduction to achieve specific goals might result in unintended and undesirable side effects.

The Human Fertilisation and Embryology Act 2008 (the 'amending' Act) was passed a few years later restricting sex selection to gender-related conditions under schedule 2 paragraph 1ZB. It seems a little strange to prohibit social sex selection on the grounds that it poses an interference with "divine will" when the very nature of assisted reproductive technology takes the conception out of the hands of nature. In future, it is possible that the United Kingdom may relax the 1990 Act to allow for families with two or more boys, for example, to select a female embryo in the name of family balancing.

In the United States, no legislation exists to govern the controversial branches of PGD but the American Society for Reproductive Medicine has commented on the advantages and disadvantages of social sex selection and concluded in a posted opinion that each clinic may use its discretion. Advantages include patient autonomy, reproductive liberty and family balancing. Disadvantages include unknown long term risks of assisted reproductive technologies, pressure from a partner, disrespect for embryos, public opposition, conditional acceptance from parents, a 'slippery slope' to other traits, denying the child an open future, imposition of gender norms, psychiatric harm to the child, potential disruption to the parent-child relationship and gender imbalances in society.

The American College of Obstetricians and Gynaecologists has a stricter opinion in light of the United Nations International Conference on Population and Development (September 1994):

The committee shares the concern expressed by the United Nations and the International Federation of Gynaecology and Obstetrics that sex selection can be motivated by and reinforce the devaluation of women. The committee supports the ethical principle of equality between the sexes…The committee concludes that the use of sex selection techniques for family balancing violates the norm of equality between the sexes; moreover, this ethical objection arises regardless of the timing of the selection (i.e. preconception or post conception) or the stage of development of the embryo or foetus.

Commentators have focussed on the social implications of couples being able to choose the sex of their child rather than geographical imbalances: could it lead to some form of psychological harm? Seavilleklein and Sherwin, who oppose PGD for social sex selection, point out that gender does not always conform with social norms leading to disappointed parents:

What, we must ask, will be the response of parents who have gone to a great deal of time, trouble and expense to ensure a baby of a chosen gender if that child ends up failing to meet standard gender norms or rejects the prescribed gender identity entirely?…The assumption that gender is easily characterised and reducible to sex is problematic for society in the sense that it may serve to make people in general less tolerant of diversity; this intolerance can have a significant impact on matters of social justice. Those who fall outside accepted gender norms [transsexuals, homosexuals, bisexuals, intersexuals and transvestites] are often stigmatised by virtue of this difference, which can to various degrees affect their self-worth, self-confidence, psychological stability, bodily comfort, personal safety, and personal relationships.

Supporters of PGD for social sex selection prefer to focus on reproductive autonomy and argue that the State should provide a good reason for interfering with this right. In a rather unique view, Malpani compares social sex selection to choosing a spouse for their personal traits:

Their argument seems to be that it is acceptable to discriminate against children with birth defects (negative deselection) but it is not acceptable to select for certain desirable traits (positive selec-

tion). I find this hard to understand, After all, the reason we select our spouses is that they have certain traits we place a premium on (intelligence or good looks) and we then hope that our children will inherit these qualities. Vive la difference. The best society is one where individuals have the freedom to decide their own course of action for themselves.

We do see in our spouses what we see in ourselves and those of us who desire children hope that the positive traits in our spouses are carried forward into the next generation, but selecting a spouse for character traits is not quite the same as selecting an embryo for its sex. Gender carries with it a whole host of assumed characteristics, the absence of which can lead to a completely different child to the one 'hoped for'.

PGD for social sex selection presents a clear example of the conflict between reproductive autonomy and the right to an open future, because by selecting a female embryo (a parental right) the mother surely expects a feminine child (a closed future). A happy medium would be to legislate for social sex selection for family-balancing purposes with an ethics committee in place to enquire about gender assumptions within the family, protecting the prospective child from supremacism, discrimination and ignorance.

Commentators have suggested that an overabundance of males in Western society could lead to an increase in prostitution, molestation and rape. This is probably scaremongering - Baruch reports that 42% of IVF clinics in the United States have provided PGD for social sex selection and there have been no reports of gender imbalances in any State. The gender imbalance in India and China is widely known, but caused by quite different reasons. There are approximately 50 million 'missing' women in these countries as a result of selective abortion (which has been illegal in India since 1996) and infanticide. These gender imbalances are not down to PGD but to deeply entrenched social and cultural attitudes which will take generations to change. The growth of the sex-selection branch of PGD is, therefore, difficult to forecast as a result of such varied international social norms.

Eugenics

Eugenics - from the Greek 'eugenes' (well born) and 'genos' (race) - means to improve the genetic quality of the human race through reproduction or science. PGD immediately raised concerns about eugenics because of its promise of a perfect birth. The Charter of Fundamental Rights, passed by the European Council in June 1999, contains fundamental rights and freedoms protected by the EU and Article 3 of the Charter, the right to the integrity of the person, prohibits: "eugenic practices, in particular those aiming at the selection of persons". PGD is a eugenic practice in that it aims to create humans free of disease, but the Charter is not applicable to the UK or the US because it was not signed or implemented into national law, leaving the science to develop on its own.

PGD has raised two eugenic concerns: the discrimination of disabled people known as the 'loss of support' argument, and the potential selection of social traits (such as hair colour, height, metabolism, sexuality, perfect pitch and intelligence) known as social eugenics. This is a concern for the future, but the technology is developing now.

The first concern raised by commentators is that individuals with genetic diseases will lose support (research, funding, healthcare and compassion) for their genetic disease if fewer babies are born with the disease, as detailed by Gavaghan:

The most straightforward suggestion is that a reduction in the numbers (either absolutely or as a proportion of the population) of persons affected by particular conditions will reduce the perceived importance of finding cures, treatments, or ways to improve the lives of those remaining affected persons. As regular commentator on disability issues Tom Shakespeare says: "as a condition becomes rarer, the impetus to discover a cure or treatment diminishes. This reinforces my wider feeling, that genetic screening will never be total, which means that the proportion of congenital impairment may be reduced, but not eliminated, which means that disabled people will be further isolated, face increasing prejudice, and the pressure to make society accessible to all will be reduced."

It is probably an exaggeration to say that as a result of PGD support for people with genetic diseases would decrease because, as long as naturally-conceived babies are capable of being born with these serious ailments, there will be an impetus to treat them. Besides, imagine if the diagnosis rate for cancer were to fall steadily by 10% every year as a result of embryonic screening for BRCA1 - would we stop screening for cancer in fear that sporadic adult cases would lose support? Would we be discriminating against people who suffered from cancer by eliminating their disease from preimplanted embryos? No - the statistics would be celebrated and sporadic cases would have access to the same healthcare resources.

Supporters of PGD prefer to focus on the reason why PGD was developed in the first place - to prevent genetic diseases (Lau and Jansen):

About 1000 children affected with cystic fibrosis are born annually in the US, in some part due to reluctance to terminate affected pregnancies. There is the potential to save 33 billion dollars in lifetime medical care for those affected with this disorder if carrier parents had the option of undergoing government-backed or insurance-mandated PGD and IVF. For couples who are carriers of severe inherited genetic disorders, prevention of affected pregnancy by PGD may be a preferred option to the termination of affected foetuses. Thus, economic and medical considerations favour a universal and affordance access to IVF, PGD or PGS services for carrier couples of severe single-gene disorders such as CF, or for individuals at risk for transmitting chromosomal translocations but cannot afford it.

It is widely accepted that the discarding of embryos is preferred to the termination of an established pregnancy. This was the main aim of PGD, as stated by Dr Yury Verlinsky who helped develop the practice:

Preimplantation genetic diagnosis has allowed hundreds of at-risk couples not only to avoid producing off-spring with genetic disorders, but more importantly, to have unaffected healthy babies of their own without facing the risk of pregnancy termination after traditional prenatal diagnosis.

It appears that the 'loss of support' argument is based on concerns of ostracism and has the potential to instigate a complete halt to PGD for fear of isolating people with genetic diseases. These concerns are unfounded. Abortions carried out in cases of disease

or disability do not appear to have caused a 'loss of support' to sufferers and they are more distressing to parents than embryonic disposal.

The second concern raised by commentators is that of social eugenics. The House of Commons Science and Technology Committee in the United Kingdom published a report, Reproductive Technologies and the Law (2005) to explore the development of fertility treatment, and social genetics was clearly frowned upon by experts in the field:

The term "designer babies" is often employed to describe any child that has been born as a result of PGD, although in our view this term is highly misleading since they are no more designed than a child who has been born following a negative genetic test during pregnancy. Professor Alastair Campbell from the University of Bristol expresses similar sentiments: "we should view children as gifts, not as products. On this basis, I argue against conceptions and pregnancies using PND (pre-natal diagnosis) or PGD (preimplantation genetic diagnosis) when these are based on social reasons (gender, height, intelligence, physical appearance, etc.). These are all examples of treating the child not as a person in her own right, but as a product designed by parental wishes."

Professor Campbell raises an interesting point - if an embryo with blond hair, blue eyes, perfect pitch and a high metabolism is selected out of a group of screened embryos, has it been "designed" by the parents? It may be more accurate to say it is selected against a design, weakening the threat of 'eugenics' somewhat.

Caplan, in contrast, fails to see what is wrong with individual designs when they are not part of a grand plan enforced by a State:

No moral principle seems to provide sufficient reason to condemn individual eugenic goals. While force, coercion, compulsion and threat have no place in procreative choice…it is not clear that it is any less ethical to allow parents to pick the eye colour of their child or to try and create a foetus with a propensity for mathematics than it is to permit them to teach their children the values of a particular religion, try to inculcate a love of sports by taking them to football game, or to require them to play the piano. In so far as coercion and force are absent and individual choice is allowed to hold sway, then…it is hard to see what exactly is wrong with parents choosing to use genetic knowledge to improve the health and wellbeing of their offspring.

Caplan suggests that selecting a talented embryo is the same as giving a child piano lessons, but it could be argued that the former child would have no choice in his pastime whereas the latter child could walk away from his pastime. The former child would also be expected to reach a certain level, whereas the latter child would achieve a certain level. It is clear that the use of PGD for social eugenics presents a strong conflict between reproductive autonomy (the right of the couple) and the right to an open future (the right of the child).

The 'social eugenic' branch of PGD is probably on the cusp of a boom. There is no doubt that social characteristics such as eye colour, hair colour and height will be discovered over the next few years if they are determined by DNA. The lack of law in the United States suggests that the boom will occur there, but there is no evidence to suggest that should these social characteristics be offered to couples, a 'superior race' would begin to emerge or people with genetic diseases would be cast out into the cold.

In future, the most coveted characteristic yet to be found (and likely to have a genetic link) is metabolism, presenting an alternative way of curbing the global obesity crisis in the West. The ethical debates upon the discovery of this gene would rage: knowledge of a high metabolism may encourage an even worse diet and it is a characteristic linked to beauty and attraction. It may be the beginning of a quest for eugenic perfection, making the need for international regulation particularly urgent.

Selecting for Disability

The ability to screen out an increasing number of genetic diseases has taken an unexpected turn: couples have been known to request a particular disability for implantation. These couples may be disabled themselves and want a similarly disabled child to share their lives with, may already have a child with the disease and seek a matching sibling, or may genuinely want to care for a disabled child but rather than foster one, they would prefer their own. Negative dysgenics, as it is coined, is by far the most controversial development in assisted reproductive technology because couples are using PGD to select the diseases that the technology was designed to avoid (Nunes):

…if two deaf people have the same autosomal recessive type (like DFNB1) only deaf children will be born. However, this situation is clearly different, both from a social and a professional ethics perspective, from the direct intervention of medicine and repro-genetics to deliberately create a deaf child. The question then is how to balance reproductive autonomy with dysgenic practices…negative dysgenics can be obtained through careful prenatal or preimplantation selection and abortion (or discarding) of normal embryos and foetuses…this dysgenic practice could be regarded as unethical because individual rights - namely the right to an open future - are at stake.

Dr Yury Verlinsky, who helped pioneer PGD, has refused requests for disabled embryos, stating: "if we make a diagnostic tool, the purpose is to avoid disease". The United Kingdom has ignored this advice. The Human Fertilisation and Embryology Act 1990 allows a mother to select a disabled embryo for implantation under section 13(9) as long as she does not prefer it (i.e. she may select a healthy embryo alongside it), and if she can only produce defective embryos she may select any one of those. The number of couples who may use PGD for this purpose is narrowed under the 1990 Act to carriers or suffers of a particular "disorder, defect or disability" under section 1ZA(1)(b). A healthy (non-carrying) couple can only screen for diseases that may "affect a live birth" under section 1ZA(1)(a). There is a welfare provision under section 13(5) of the Human Fertilisation and Embryology Act 1990 which advises that a woman shall not be provided with treatment services unless account has been taken of the welfare of any child who may be born, but it is widely regarded as unenforceable. The House of Commons Science and Technology Committee Report on Reproductive Technologies and the Law (2005) added that: "in reality, this provision is more akin to a 'fitness for parenting' requirement, which was historically used to prevent certain 'undesirable' groups from parenting and is now widely rejected". It

appears quite shocking that in the United Kingdom there is no welfare protection for disabled embryos selected for implantation. The child would have to be born and the genetic disease would have to manifest before the child could receive welfare protection under the Children Act 1989, which is outside the ambit of fertility law. There is no way of knowing how many women have sought PGD for a disabled embryo because, following a request for information under the Freedom of Information Act 2000 as part of this research, the Human Fertilisation and Embryology Authority responded that it does not keep statistical information on the implantation of disabled embryos. This loophole in embryonic welfare is rather worrying.

The situation in the United States is shrouded in mystery. The American Society for Reproductive Medicine, the Society for Assisted Reproductive Technology and the American College of Obstetricians and Gynaecologists have not published any guidelines or opinions on the implantation of disabled embryos or a suitable benchmark for embryo viability, giving clinics across the country carte blanch to select and implant disabled embryos at the request of patients. The lack of guidance may be because negative dysgenics is rare or simply incomprehensible, but research suggests that it does happen. 3% of 190 PGD clinics across the United States have provided PGD to parents to select an embryo for a disability, a significant proportion of deaf parents would prefer to have deaf children, at least one fertility clinic had complied with a request to select dwarfism because the trait ran in the family, one IVF doctor refused a couple who asked for an embryo with Downs syndrome so they could give their affected child a similar sibling, and patients with dwarfism are reported to be "strong-arming" physicians by threatening to become pregnant at another clinic, test for dwarfism and abort any pregnancy not carrying the gene. The most widely publicised case is that of Candace McCullough and Sharon Duchesneau, a deaf lesbian couple from Maryland, United States who sought a deaf sperm donor for use in artificial insemination and gave birth to two deaf children.

Inevitably, the ethical issues under this branch of PGD have stirred commentators. In an extreme example of support for negative dysgenics, Lane suggests that screening out deafness is tantamount to genocide:

[We should use genetic intervention] in order to enhance the possibility that deaf parents will have deaf children [because] it is unethical for the majority culture to aim to reduce the numbers of children born deaf because measures intended to prevent births within a cultural group constitute genocide.

Lane compares deafness to a culture, making it impossible to view PGD for deaf cases as anything other than genocide. This is an unhelpful approach, as couples should not be made to feel like criminals if they do not wish to have a disabled child. In contrast, Gavaghan points out that the rejection of a disabled embryo should not receive such stigma in light of social abortion:

Those who agree [that the decision to avoid the birth of disabled children constitutes a rejection of disabled people] must demonstrate why a decision to avoid the birth of a disabled child sends an emotionally harmful message to existing people, whereas a decision to avoid the birth of a child into difficult social or economic - as opposed to genetic - circumstances does not send an analogous message to poor families, large families, or families with very young mothers, all groups who are already to some extent the subjects of social stigma.

Further research has supported this view. Kalfoglou found that eight providers of PGD were not supportive of negative dysgenics because it was "contrary to the goals of PGD" and one laboratory director said: "I would have a problem personally with participating in making sure a child was going to be handicapped". It is likely that the Hippocratic Oath plays a large role in the cautious views of some embryologists, but this may not be a bad thing. The vilification of parents who desire only healthy children is rather strange.

The future in this branch of PGD is very uncertain, but the current support for genetic diseases in society should not be mistaken for encouragement to create even more using the very technology that was designed to prevent them. It is under dispute whether the birth of an intentionally disabled child can amount to a criminal or civil action, but a legal test case (brought by the child against the parents or embryologist) would see a fascinating conflict between patient autonomy, the perception of disability and the rights of the child. The result would surely be that the selection of a genetically diseased embryo resigns that child to a closed future at best, or subjects her to pain, exclusion and an early death at worst. This branch of PGD, therefore, is the most at risk from criminal sanctions in the not-too-distant future.

Saviour Siblings

A branch of PGD that has caused strong public opinion is screening embryos for a human leukocyte antigen (HLA) tissue match to cure an older sibling of a serious genetic disease (preimplantation tissue typing or PTT). Adam Nash became the first ever tissue matched sibling to be born at the Reproductive Genetics Institute in Chicago, Illinois in 2001 when his umbilical cord blood successfully cured his older sister from fanconi anaemia. Dr Yury Verlinsky explained the advantages of the treatment in his report:

Although this is the first and only experience (to our knowledge) of PGD for HLA antigen testing, it provides a realistic option for couples desiring to avoid the birth of an affected child, together with the establishment of a healthy pregnancy, potentially providing an HLA antigen match for an affected sibling…These new indications make PGD a genuine alternative to conventional prenatal diagnosis, providing patients with important prospects not only to avoid an inherited risk without facing termination of pregnancy, but also to establish a pregnancy with particular genetic parameters that benefit an affected member of the family.

This first successful birth in the United States sparked a major legal development in the United Kingdom. Mr & Mrs Hashmi asked the Human Fertilisation and Embryology Authority to issue a licence for PTT resulting in the case of R (Quintavalle) v Human Fertilisation and Embryology Authority (and Secretary of State for Health) [2005] 2 A.C. 561. The House of Lords confirmed that the terms 'suitability', 'treatment services' and 'assisting' under the 1990 Act referred not to the viability of the embryo but the desires of the mother to have a tissue-matching child, making PTT available to the public on a case-by-case basis. PTT is now also

available under schedule 2 paragraph 1ZA(1)(d) of the 1990 Act (as amended in 2008):

Schedule 2: Activities that may be licenced under the 1990 Act.

Paragraph 1ZA(1): A licence…cannot authorise the testing of an embryo, except for one or more of the following purposes:

(d) 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.

The HFE Authority published a report, Preimplantation Tissue Typing (2004) to explain their decision to authorise licences for PTT, and a particular quote causes concern about commodification:

…should the existing child relapse, there is likely to be insufficient time to go through the process of creating a tissue-matched sibling. If such a sibling existed already, tissue that could be used in treatment would then be at hand if and when required.

The welfare provision under section 13(5) of the 1990 Act, which would have protected the embryo from commodification, has been shunned as unusable for saviour siblings too (in the House of Commons Science and Technology Committee Report on Reproductive Technologies and the Law). In light of the unworkability of section 13(5) and the fact that an embryo cannot be made a ward of court, the only legal protection left for embryos selected for their HLA tissue match is the welfare provision under section 1(3) of the Children Act 1989, which states: "the child's welfare shall be the court's paramount consideration". This provision has never been used to support a saviour sibling before, nor has there ever been a child donation case in the UK. This second loophole in embryonic welfare is also worrying.

The position on PTT in the United States is just as obscure. The American Society for Reproductive Medicine has not published any views on preimplantation tissue typing but, as in the UK, this is probably because bone marrow donation is outside of its remit. However, the common law regarding donations from children has made more progress, laying down a rigorous test in Curran v Bosze (1990) 566 N.E.2d 1319 that requires the saviour sibling herself to glean a tangible psychological benefit from the donation (per Calvo J):

The psychological benefit is grounded firmly in the fact that the donor and recipient are known to each other as family. Only where there is an existing relationship between a healthy child and his or her ill sister or brother may a psychological benefit to the child from donating bone marrow to a sibling realistically be found to exist.

It is possible for a child to glean an altruistic psychological benefit from a bone marrow donation, but it would have to be a sufficiently mature child. A baby or toddler could not experience such a benefit, meaning that their bone marrow harvest would be unlawful.

Supporters of PTT often endorse the interfamilial principle, which uses a benefit to the wider family to justify the selection of a tissue matching embryo. Pennings provides a good example:

The relationship between the donor and recipient functions in an indirect way: it explains why the donor has an interest in the well-being of the recipient. To the extent that the wellbeing of the others is part of one's own wellbeing, the person is helping himself… Since it is impossible to bring forward medical benefits in cases of organ or bone marrow donation, one concentrates on the psychological and social benefits for the donor as a consequence of his relationship with the recipient and/or other family members… The intervention can be justified even if it goes against the interests of the donor child…it can be argued that refusing this use would be an unacceptable neglect of the sick child's interests…the donor is much too young to have any understanding of what is happening. They psychological effects will have become diluted by the time that the child is able to understand the action in which it took part. Moreover, it is very likely that the child will later agree (hypothetical consent) with the decision his parents made for him for he will then have come to value his relationship with his sibling.

Pennings makes a number of suggestions that require analysis. Firstly, medical benefits are impossible to glean from a bone marrow donation, rendering the procedure unlawful upon a child regardless of a familial/social benefit. Secondly, going against the interests of the saviour sibling conflicts with the notion of paramountancy under section 1(1)(a) of the Children Act 1989 (UK) and the rights of the donor child under Curran v Bosze (1990) 566 N.E.2d 1319 (US). Thirdly, the suggestion that the sick sibling is 'neglected' implies that the saviour sibling is somehow obliged to treat the illness and is to blame if the sick sibling dies. Fourthly, the word 'diluted' suggests that the ignorance of the young saviour sibling would be taken advantage of to harvest bone marrow, and this is commodification. Finally, it is pure speculation to suggest that the saviour sibling will come to agree with the procedure in the future - substituted judgment is not an acceptable form of consent in either UK or US family law. It is of course understandable that desperate parents may make these kinds of pleas in order to save the life of their sick child, but the legal autonomy of the saviour sibling outweighs the plight of the sick child.

Opponents of PTT focus on the conflicts faced by parents (Grewal):

Even when parents love and cherish the donor child, there are concerns regarding the level of risk potentially placed on the donor [child]…parents may be faced with a decision about a bone marrow harvest from the infant in the first months of life, exposing the child to procedure-associated risks. At what point would the risk to the donor child be ethically unacceptable, and who should decide? Parents are conflicted in that they must consider the interests of the donor child and the recipient child. A final concern is that some couples may use PGD to select a disease-free or an HLA-compatible embryo with the intent to harvest tissue only and not to bring another child into the world. This scenario would entail an induced abortion at some point during gestation and the collection of [cells] from the foetal liver. Although such directed donation of tissue from an induced abortion would violate federal law, some couples have already enquired about this possibility.

Additional empirical research by Kalfoglou confirms that some fertility patients are "emphatic" that PTT is an inappropriate use of

PGD because it "put the second child at too much risk, is unethical, and treats him like a junkyard". It appears that commentators will continue to struggle to find a settled ethical approach to this branch of PGD for as long as it is divided between fertility law and donation law. To put it bluntly, PTT is an off-shoot from PGD whereby a tissue-matching embryo disappears down a gap. So, what does the future hold?

There are two possibilities. Firstly, the group of recipients may expand to include parents. Commentators are vehemently against the idea of couples seeking PTT to create a bone marrow donor for themselves, but would parents be taking advantage of their children any more in a parent-child donation than they would in a sibling-sibling donation? The embryo is selected in the same way, it is harvested after birth in the same way and it keeps the family together in the same way. Some may even argue that a donor child would benefit more from a living parent than a living sibling. Secondly, PTT for kidney donation may become a possibility which is currently prohibited in the United Kingdom under section 1ZA(4), schedule 2 of the Human Fertilisation and Embryology Act 1990. There is already substantial case law in the United States regarding sibling kidney donations dating back to the 1950's. It is likely that should the kidney scenario arise in the United Kingdom, the High Court would have to confirm the procedure as in the best interests of the child - who is paramount under the Children Act 1989 - in light of a significant and measurable psychological therapeutic benefit. The younger the child, the less clear the benefit would be which, according to Curran v Bosze (1990) 566 N.E.2d 1319, should be grounded in the pre-existing relationship between the siblings. It is almost impossible to predict how this branch of PGD will develop in light of the potential trespass upon the donor child. This issue is not considered when he/she is merely a tissue-matching embryo. The difficulty is in encouraging two completely separate areas of law – fertility and donation – to work together to protect the welfare of the resulting child. There is a very real threat of criminal and civil action yet remarkably, the creation of saviour siblings is probably the most socially acceptable branch of PGD.

Surplus Embryos

The emergence of PGD has triggered accusations of unnecessary embryo wastage, especially within the branches of social sex selection and PTT. Unused embryos can of course be frozen, but couples who seek only a male embryo or a tissue matching embryo may discard embryos that are surplus to requirements despite them being perfectly healthy. Should we be concerned about this side effect of PGD?

In the United Kingdom, the Warnock Report (1984) suggested that "the embryo of the human species should be afforded some protection in law…we do not want to see a situation in which human embryos are frivolously or unnecessarily used in research". To make good on this promise, the Human Fertilisation and Embryology Act 1990 was passed and section 3(4) stipulates that the preimplanted embryo must be destroyed within fourteen days to coincide with the emergence of the primitive streak (a string of bumps resembling the spine). In 2012, the UK Health Minister Lord Howe revealed that:

• 1.7 million UK embryos created for IVF had been thrown away since August 1991;
• 3.5 million embryos had been created but had produced only 235,480 'gestational sacs;
• 840,000 of the 3.5 million embryos were in storage for future use;
• 2000 of the embryos were stored for donation;
• 5,900 embryos were set aside for scientific research;
• 1.4 million embryos were implanted but fewer than one in six resulted in a pregnancy;
• 23,480 embryos were discarded after being removed from storage.

As a result of these figures, Lord Alton, a Crossbench peer, announced that "embryos were being created and thrown away in industrial numbers".

In the United States, there is no clear legal guidance on the status of the embryo except to say that after an elapse of time they are treated as abandoned. The Ethics Committee of the American Society for Reproductive Medicine (ASRM) has published an opinion on the status of abandoned embryos (which are described as ignored or rejected embryos) and it states that 4% of approximately 400,000 embryos were in storage because: contact with the patients had been lost, the embryos had been abandoned, the patient had died, the embryos were awaiting shipment, the patients were undecided about transfer to another State, the embryos were awaiting a decision, the embryos were to be donated to research or another couple, the embryos were reserved for embryology training, wishes were not specified on the permit, the patients were divorcing, or the embryos were awaiting long-term storage. The ASRM recommends (in light of the vague legal position) that clinics should ask each couple contemplating embryo storage to give written instructions concerning disposition of embryos in the event of death, divorce, separation, failure to pay charges or disagreement, and that five years is long enough to store embryos if efforts have been made to contact the couple and they have left no directions on disposition.

Commentators have handled the destruction of embryos following PGD in different ways. In support of PGD, Dunstan makes a comparison to nature:

The leading fact is that nature itself discards spontaneously some of its defective products. Unfortunately, being as uncertain in its calculations as we are, if not more so, it does not discard them all. Neither is there, beyond a certain point, any exemplary scale in what it discards: some of those which it spares are among the most gravely handicapped. Furthermore (except in conditions fatal before puberty) nature seems not to check the descent of defective genes from generation to generation, which is one of the goals (with recognised limitations) of medical genetics.

It is thought that the destruction of an embryo after genetic screening is far less objectionable than the destruction of an established pregnancy after prenatal genetic diagnosis. Boyle and Savulescu refer directly to the social termination of pregnancy in their support of PGD:

UK legislation allows embryos to be destroyed [upon] 14 days of age. To prohibit couples from rejecting healthy but unwanted embryos in a society that condones the destruction of hundreds

of thousands of healthy but unwanted foetuses would be wildly inconsistent. Moreover, couples should be encouraged to donate their healthy but unwanted embryos to other couples who cannot conceive.

Boyle and Savulescu raise an interesting point: statistics from the Department of Health in the United Kingdom state that in 2015 there were 191,014 abortions in England and Wales, 181,231 of which were under section 1(1)(a) of the Abortion Act 1967 (the 'social' ground). It is difficult to argue for the legal protection of embryos when the social destruction of pregnancies is authorised by law, but should not PGD by its very nature be expected to create life as opposed to contributing to the discarding of healthy embryos for purely social reasons, thereby diminishing its role to a 'sorting system'?

It is perhaps inevitable that thousands of healthy embryos will be discarded by fertility clinics in light of the tradition to create more embryos than are needed, but perhaps the reasons for discarding healthy embryos can be altered to show the respect first suggested by the Warnock Report (1984)? For example, unwanted embryos following PGD could be donated to research to ensure that the embryos are not completely 'wasted'. This could also help with future genetic treatments.

Adult-Onset Diseases

The newest development in PGD, and one of the most topical is the screening of embryos for the BRCA1, BRCA2 or HNPCC gene (a predisposition to cancer). The BRCA gene was first discovered by the University of California, Berkeley in 1990 and can be screened in both embryos and adults. The most recent statistics in the United Kingdom are as follows:

• BRCA1 and BRCA2 mutations account for 25% of hereditary breast cancers, 10% of all breast cancers and 15% of ovarian cancers;

• 12% of women will develop breast cancer but with the BRCA1 gene this rises to 80% and with the BRCA2 gene it rises to 45%;

•1.3% of women will develop ovarian cancer but with the BRCA1 gene it rises to 40% and with the BRCA2 gene it rises to 17%;

• Mutations in BRCA1 and BRCA2 also increase the risk of fallopian tube cancer, peritoneal cancer, prostate cancer, pancreatic cancer and Fanconi anaemia subtype;

• Individuals with the Hereditary Non-Polyposis Colorectal Cancer (HNPCC) gene have up to an 80% lifetime risk of colorectal cancer and up to a 60% risk of uterine cancer as well as other gastrointestinal cancers.

This branch of PGD is unique in that a middle-aged woman who has a history of breast cancer in her family (or even if she does not) can purchase a home DNA test to reveal whether she carries the BRCA gene, leaving her in a difficult position if she receives a positive result. Does she simply wait for the cancer to occur (if at all), or does she have preventative surgery before the cancer is diagnosed? Adult screening is outside the ambit of this article, but it should be noted that academic commentary is building on this controversial issue.

In the United Kingdom, the Human Fertilisation and Embryology Authority launched a consultation document entitled, Choices & Boundaries (2005) to garner public and professional opinion as to whether the BRCA gene should be included in PGD. The crux of the controversy was that most genetic diseases licenced to be screened have a very high penetrance risk (90% or above, such as Huntington's disease) making the likelihood of disability or death almost certain. BRCA and HNPCC are low penetrance genes (30% - 80%) meaning that the embryo may live five decades before being struck with cancer (if at all). Additionally, cancer can be treated effectively in a lot of cases meaning that the embryo could enjoy a perfectly healthy life. The results of the consultation were published in the Choice & Boundaries Report (2006) and inevitably showed a mixed response. Some individuals with a family history of cancer did not wish to pass the BRCA gene onto their children because of the upheaval that a diagnosis could bring. Other individuals could not decide where the line was to be drawn regarding penetrance, and feared a floodgate into learning difficulties. The ultimate decision by the HFE Authority, despite the mixed responses in the consultation, was as follows:

Taking into account the range of views expressed in the public discussion and the recommendations of the Ethics and Law Committee, the Human Fertilisation and Embryology Authority believes that, in principle, it is appropriate that PGD be available for serious, lower penetrance, later-onset genetic disorders such as inherited breast, bowel and ovarian cancer.

In the United States, the American Society for Reproductive Medicine published a Committee Opinion and came to a similar conclusion that PGD for adult-onset genetic diseases should be available to couples seeking fertility treatment as long as a genetic counsellor is there to advise the couple for the following reasons:

Arguments offered in support of PGD for serious adult-onset conditions include the right to reproductive choice on the part of persons who seek to bear children, the medical good of preventing the transmission of genetic disorders, and potential social benefits of reducing the overall burden of disease. Arguments advanced against the use of PGD include expense, the questionable value of the medical benefits obtained in light of our inability to predict medical progress over the longer term, the possibility of misdiagnosis, and the unknown risks of the procedure…a woman who carries the BRCA1 gene has an increased risk for the development of breast and ovarian cancer but may never develop cancer for reasons that are not yet understood. Critics of PGD also argue that utilizing the procedure for embryo selection risks devaluing certain lives.

A particularly upsetting consequence of screening embryos for BRCA1 that is not mentioned by the ASRM is the shock to the mother (or father) upon learning that they carry the gene too. Most couples seeking PGD probably already know they suffer from or carry a particular genetic disorder, but some do not. To learn that their risk of cancer has shot up from 12% to 80% may cause psychological harm. This issue is yet to be canvassed by researchers.

Commentators have made an interesting observation: if a woman already knows she carries the BRCA1, BRCA2 or HNPCC gene, or has some other adult-onset condition such as early-onset Alzheimer's Disease, should she seek fertility treatment to start a family knowing that she may not see her child grow up, or that her child will become her carer within a few short years? Robertson

argues that parents should not be condemned for seeking fertility treatment in these circumstances because the surviving parent will be there to offer the grieving child support, and any psychological trauma caused to the child will not fill his/her life with such grief that it would be harmful for him/her to be born. This argument, however, may be viewed as irresponsible. Robertson may be placing the desires of the parents before the welfare of the child. The death of a parent in childhood would almost certainly cause psychological harm. There is also no guarantee that the father would be able to cope in the midst of losing his wife. The mother is prima facie giving birth to her own carer. Is this a unique form of slavery? It is understandable that a dying woman may wish to experience childbirth and parenthood before her untimely death from an adult-onset genetic disease but it is not an 'entitlement' in law or otherwise, and her desire should not override the right of the prospective child to live an open life without the infliction of pathological grief at a young age. The future in this branch of PGD is uncertain. It is unlikely that the HFE Authority (UK) or the ASRM (US) will refuse to treat patients with genetic diseases for fear of discriminating against disabilities, leaving children to be born into unwell and (sometimes) dying families. This branch of PGD carries the most moral strain, as it would be deemed unfair – but not illegal – to intentionally bring a child into such traumatic circumstances.

Conclusion

The unique branches of PGD that have developed over the last 25 years - sex selection, eugenics, screening for a disability, saviour siblings and adult-onset diseases - have brought multiple controversies to the practice of fertility treatment. Fertility is such a deeply personal issue that there are not likely to be any settled answers as to where the line should be drawn. The Human Fertilisation and Embryology Authority in its Choices & Boundaries Report (2006) asked the public what they thought about PGD and some did not like the idea of screening embryos for any type of genetic disorder: "Specific learning difficulties like Asperger's, dyspraxia, dyslexia, ADHD, etc., could be future candidates for PGD. This would be highly undesirable. It would look like eugenics or social engineering."

"PGD should not be used to test for any condition. Screening embryos, with a view to destroying, if certain criteria are not fulfilled, should not be carried out, as it is eugenic in nature."

The anxiety felt by the public may be the result of ignorance, the ghost of Nazism eugenics, the potential floodgate into learning difficulties, the idea of targeting disabilities, or the notion of removing the element of surprise from birth. The technology is in a strange position in that it encourages the destruction of an increased number of healthy embryos whilst helping to establish an increased number of healthy pregnancies. Can the public trust PGD if it plays such a contentious role?

PGD as part of routine fertility treatment is harmless: it simply ensures that a healthy embryo is selected. It is the non-medical branches of PGD, such as social sex selection, tissue matching and negative dysgenics that should be monitored over the next quarter of a century for unexpected developments. This is where a rising conflict between the reproductive autonomy of the parents and the right of the child to an open future can be found. These growing branches of assisted reproductive technology are being implemented by parents to meet their own ends (the embryos are not 'designed' but they are selected for implantation in line with personal designs) and they may lead to criminal and civil test cases by the 'screened' child should a causal link to harm or loss be proven. In the event that genes for learning difficulties, metabolism or intelligence are found in the near future, the ethical discussions surrounding PGD would quickly intensify on an international scale.

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9. See: http://www.asrm.org

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56. The word "resign" was used instead of "deprive" in light of the Non-Identity Principle developed by Parfit, which claims that the only alternative for that particular embryo is actually not to be born at all: D. Parfit, Reasons and Persons, Oxford University Press (1984).

57. For the earliest natural case of saviour siblings, Anissa Ayala, see: N.S. Jecker, 'Conceiving a Child to Save a Child: Reproductive and Filial Ethics' (1990) The Journal of Clinical Ethics. 1(2):99, also reported in: 'When One Body Can Save Another' TIME, 1992, June, 17:54; 'Anissa Ayala: Thriving on a Sister's Gift of Love and Life' People Magazine, November 28th 1994, vol. 42 no. 22: http://www.people.com/people/archive/article/0,,20104516,00.html

58. Y. Verlinsky, S. Rechitsky, et al., 'Preimplantation Diagnosis for Fanconi Anemia Combined with HLA Matching' (2001) Journal of the American Medical Association vol. 285(24) 3130, at page 3130. Umbilical cord blood was first introduced as a cure for Fanconi anemia in the late eighties: E. Gluckman, H.A. Broxmeyer, et al. 'Hematopoietic Reconstitution in a Patient with Fanconi's Anemia by Means of Umbilical Cord Blood from HLA-Identical Sibling' (1989) New England Journal of Medicine. 321:1174-1178.

59. Per Lord Hoffman at paragraphs 22, 24 and 33, and Lord Brown at paragraphs 61-62.

60. Human Fertilisation and Embryology Authority Report: Preimplantation Tissue Typing, (2004), http://www.hfea.gov.uk/515.html at page 9, paragraph 34. Emphasis added, last accessed 6th September 2017.

61. House of Commons, Science and Technology Committee (n 36), paragraph 251 at page 113.

62. Re F (in Utero) [1988] 2 All ER 193.

63. A sibling bone marrow donation was authorised in Re Y (Mental Patient: Bone Marrow Donation) [1997] Fam. 110 but it was from an incompetent adult who was not protected by the strict welfare test under the Children Act 1989.

64. Per Calvo J at 1343-4. It was added that a speculative benefit did not hold any weight in law, and it could be as much as twenty years before any benefit could manifest if at all, at pages 1319, 1326 and 1336.

65. L. Cherkassky, 'Children and the Doctrine of Substituted Judgment' (2015) Medical Law International, 1:1-23.

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Donor of Haematopoietic Stem Cells to a Sibling' (2002) Human Reproduction 17(3) 534-538, at pages 536 and 538.

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69. A. Kalfoglou, 'PGD Patients' and Providers' Attitudes to the Use and Regulation of Preimplantation Genetic Diagnosis' (2005) Reproductive Biomedicine Online, 11(4): 486-496, at page 492.

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71. The Warnock Report, Report of the Committee of Enquiry into Human Fertilisation and Embryology, Department of Health and Social Security, July 1984, Her Majesty's Stationary Office, at paragraphs 11.17 and 11.18, http://www.hfea.gov.uk/2068.html last accessed 7th April 2017.

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