2009

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Abstract

In 2003, the case of *R (on the Application of Quintavalle) v Human Fertilisation and Embryology Authority*[1] dramatically brought into light the Human Fertilisation and Embryology Act 1990 as outdated and inconsistent. Authorisations for saviour sibling treatment appeared futile as cases were decided illogically, leaving some patients having to seek treatment elsewhere. The procedure of pre-implantation genetic diagnosis alongside tissue typing embryos has been a huge breakthrough in treating children born with serious life threatening diseases. However, this essentially unforeseen technology is poorly regulated in the 1990 Act and has therefore resulted in the new Human Fertilisation and Embryology Act 2008 which aims to make such legal rules regarding this kind of treatment both clear and concise. Whether this has been a success will be seen in time.

Keywords: saviour sibling, human fertilisation, embryology, embryo research

Introduction

This article examines both the Human Fertilisation and Embryology Act 1990 and 2008, looking at their success individually and comparing the changes made as a result of the saviour sibling techniques. By examining not only the legislation, but also religious and ethical aspects of such medical practices, the article seeks to explore the many viewpoints in such a controversial and morally uncertain area, and the difficulty in legislating when a general public consensus does not exist.

Aristotle once advised men to tie off their left testicle to guarantee a male child.[2] Although unlikely to have actually worked, it demonstrates the need people felt even 2,500 years ago, to have a degree of choice and control over the children they

[1] [2003] EWCA Civ 667

[2] Horsey, K., and Boggs, G., *Human Fertilisation and Embryology: Reproducing Regulation*, (2007, Routledge Cavendish), p.2

produced. Similarly, Aldous Huxley's fictitious depiction in *Brave New World* [3] of a society in which children were produced on a conveyer belt of *in vitro* fertilisation and cloned to manufacture citizens for particular roles in society, reflects the notion, far more poignantly, that the breeding of children with the 'right' characteristics was at least in the mind of society. Though this is purely fiction and not scientific prophecy, Huxley's novel plays on anxieties which remain in society today; anxieties of 'designer-babies' and perfect children.

It was the birth of the first *in vitro* baby, Louise Brown, in 1978 which really brought to light the need to implement some form of legislation governing embryo research and its technological developments. However, because of the difficulty in legislating for something which is so ethically controversial and socially uncertain, it took the government many years to bring in the Human Fertilisation and Embryology Act 1990. Though this Act was much needed, it has become outdated as medicine advances and now has to be interpreted in the light of today's society and its many different beliefs. This was brought dramatically into focus by the case of *R (on the Application of Quintavalle) v Human Fertilisation and Embryology Authority* [4] which challenged the drafting and boundaries of the current law, questioning whether it was acceptable to carry out tissue typing alongside pre-implantation genetic diagnosis in order to save a sick sibling. There was a fear that this could be the beginning of (or a move towards) cherry picking the characteristics of babies.

1 The History of Human Fertilisation and Embryology Legislation

Prior to the 1990 legislation there was great 'political disinclination to engage in debate on the sanctity of life', meaning that it took twelve years to implement legislation that was instigated in response to the development of the first *in vitro* baby.[5] The difficulties came from the many different belief systems, both ethical and religious. For example, for a devout Roman Catholic life is considered a gift from God and thus is sacred and any act such as the destruction of an embryo because it may be genetically imperfect in medical terms, is wrong. The belief that life begins at conception makes any form of embryo research simply wrong and puts huge pressure on those who have conflicts of interest in the form of being highly religious but being unable to reproduce.[6] It is not the handicap or the genetic disease that is

[3] Huxley, A., *Brave New World*, (1969)
[4] [2003] EWCA Civ 667
[5] Brazier, M., *Medicine, Patients and the Law*¸(2003, Penguin Books), p.52
[6] Ibid p. 42

vetoed; but the actual child with the handicap or genetic disease which is being prevented. There is a difficult balance between medicine and religion and the Act, allowing for certain forms of fertility treatment and research, tries to find a middle ground.

One of the most disputed issues in this area is the status of the embryo. Those against embryo research argue that

> 'the use of a human embryo for research is morally wrong because of the very fact that they are human…The human embryo is seen as having the same status as a child or adult, by virtue of its potential for human life.[7]

In contrast, those in favour of embryo research suggest that an embryo is simply 'a collection of cells which, unless it implants in the human uterine environment, has no potential for development...'[8] In light of this, the Warnock Report considered that it was inappropriate to endow the embryo of the human species with the full panoply of human rights. However, it was also inappropriate simply to consider it as nothing more than a ball of cells.[9] It was recommended that no live embryo, frozen or unfrozen, may be kept alive beyond 14 days, by which time the primitive streak will have appeared as the cells become more defined, and that research may only be carried out up until this point,[10] providing the embryo with some legal protection. There is much case law examining the status of the embryo and both the UK and US courts seem to arrive at similar opinions. In the Tennessee case of *Davis v Davis* Doughtrey J concluded that '[embryos] are not, strictly speaking, either 'persons' or 'property', but occupy an interim category that entitles them to special respect because of their potential for human life.'[11] In the English case of *Evans v Amicus Healthcare Ltd*[12] Lord Justice Thorpe said:

> 'It has been repeatedly held that a foetus prior to the moment of birth does not have independent rights or interests. Thus...can there be no independent rights or interests in stored embryos. In this respect our law is not inconsistent with the decisions of the ECHR. Article 2 protects the right to life. No Convention jurisprudence extends the right to an embryo, much less to one which at the material point of time is non-viable.'[13]

[7] Warnock Committee, *Report on Human Fertilisation and Embryology*, (1984), para.11.11
[8] Ibid. para.11.15
[9] House of Commons Select Committee on Science & Technology, Fifth Report, *Human Reproductive Technologies and the Law*, (March 2005) para.28
[10] Warnock Committee, *Report on Human Fertilisation and Embryology*, para.11.22
[11] (1992) USA 299 at [63]
[12] [2004] EWCA Civ 727
[13] Ibid at [19] (per Thorpe LJ)

It is not until the embryo is born as a child that full rights are offered.

In 1982 the Conservative government set up the Committee under Dame Mary Warnock to examine medical developments, bearing in mind social, ethical and legal implications, and to make recommendations regarding these developments.[14] It quickly became clear that the differing opinions of various groups, both social and ethical, would create conflicts with most of the recommendations. But, as Brazier rightly stated,

> in medical debates there is no answer that will be accepted as unchangeably right. The question for legislators is not to find the right answer, to achieve a moral consensus, but to determine how in a liberal, democratic society, legislation can be formulated in the absence of such consensus.[15]

Instead of a resolution of moral differences based on philosophical principles, which Warnock described as 'impossible,' she chose 'to try to assemble a coherent policy which might seem, if not right, then at least all right, to the largest possible number of people.'[16] This can be seen by the six years it took for the recommendations of the Warnock Report to be produced in the form of binding legislation. In the introduction to the Report, Dame Mary Warnock remarks that, 'in recognising that there should be limits, people are bearing witness to the existence of a moral ideal of society.' The aim was to make recommendations based on the majority moral opinion within society; as sociologist Michael Mulkay has argued the Warnock position was the outcome of an effort to acknowledge fundamentally opposing views and find the path of greatest social consensus among them.[17]

There were two major focus points of the Report which stood out; the status of the embryo and the importance of regulating standards; little regard was given to the actual processes or the techniques being considered. This could be seen as a way of allowing developments to occur but at the same time not allowing them to occur in a free-for-all kind of way - after all, the whole point was to create rules and lay down guidelines to be followed, not to completely prevent all medical advances. Although Pre-implementation Genetic Diagnosis (PGD) was not developed when the Report was written, there are recommendations relating to potential future developments and how these developments should be regulated. The Warnock strategy of promoting scientific progress subject to strict regulation has continued to this day and

[14] Warnock Committee, *Report on Human Fertilisation and Embryology*, para.1.2.
[15] Brazier, *Medicine, Patients and the Law*, p.55.
[16] Franklin, S., and Roberts, C., *Born and Made: An Ethnography of Preimplantation Genetic Diagnosis*, (2006, Princeton University Press), p.5.
[17] Ibid p.3.

is still a major factor in the 2008 Act; the approach allows room for constant public deliberation as a method of preventing any such technologies going unregulated or uncontrolled.[18]

In introducing the legislation to the House of Commons, the then Secretary of State for Health, Kenneth Clarke, said:

> The Human Fertilisation and Embryology Bill is, in my opinion, one of the most significant measures to be brought forward by a Government in the last 20 years. It is a complex and sensitive Bill that deals with matters that are fundamental to the well-being of our society.[19]

The enactment of the 1990 Act concluded an unprecedented process of public consultation and Parliamentary negotiation. The Act remains the most extensive, substantial, and detailed legal framework ever created to regulate and govern what had previously been the legally unchartered territory of human fertilisation and embryology.[20] Lord Bingham in *R (on the Application of Bruno Quintavalle on behalf of Pro-Life Alliance) v Secretary of State for Health* made clear that,

> '[the] 1990 Act was passed "to make provision in connection with human embryos and any subsequent development of such embryos; to prohibit certain practices in connection with embryos and gametes; to establish a Human Fertilisation and Embryology Authority"... A power is also conferred on the Authority to give binding directions.'[21]

Although a little outdated now, the legislation which emerged in 1990 was extremely advanced and nothing else had been produced of such significance or caused such public concern and comfort simultaneously. The responsibility of legislating for things which were impossible to foresee would always be a daunting task.

2 The Human Fertilisation and Embryology Act 1990

The problem with the 1990 Act lay in its inability to see far enough into the future, and thus regulate fully and effectively on the medical advances. It could be argued that vagueness is necessary when legislating for continuing developments, but it makes the enforcement that much more difficult, with the courts having to attempt to interpret whether ethically and socially difficult procedures are acceptable and legal.

[18] Ibid p.73.
[19] Morgan, D., and Lee, R., *Blackstone's Guide to the Human Fertilisation and Embryology Act 1990*, (1991, Blackstone Press Limited) p.22.
[20] Franklin and Roberts, *Born and Made,'* p.40.
[21] [2003] UKHL 13 per Lord Bingham.

As noted earlier, PGD and tissue typing both struggle to find a place within the Act; though the courts have accepted that PGD is within the scope even if it is not expressly mentioned. However, tissue typing is far from anything mentioned at all. Interpretation of the Act is the courts' job, but it must be questioned, with no mention of such specific procedures, whether the courts and more specifically the Human Fertilisation and Embryology Authority (HFEA), the Act's regulatory body, are actually interpreting the Act or beginning to create new law. This is the crux of the argument in *R (on the application of Quintavalle) v Human Fertilisation and Embryology Authority.*[22] This case involved a child with the disease beta thalasasemia major, who, for his survival, needed a bone marrow transplant. His parents, Mr and Mrs Hashmi, wanted to conceive a child who was not only free from the disease, but also a tissue match for their sick son. For this PGD and tissue typing would have to take place, and the issue in question was whether tissue typing was within the scope of the 1990 Act. In relation to this problem, the main areas which created ambiguity were sections 2(1)(d) which attempts to define 'treatment services,' 13(5) which takes into account the welfare of the child, and Schedule 2 para.1(1)(d) and 1(3) which describes what a licence can authorise. None of the terms in these sections offer clear guidelines for the courts or the HFEA to follow.

The Warnock Report recommended 'a new statutory licensing authority to regulate both research and those infertility services which have been recommended should be subject to control'[23] (artificial insemination, *in vitro* fertilisation, egg or embryo donation, surrogacy, genetic testing and embryo research). This is legislated for in sections 5-11 of the Act which specifies the need for the HFEA, whom it shall consist of and how it shall be run. The HFEA itself takes responsibility for individual licensing decisions and oversees the workings of the statutory licensing scheme. An attempt to make the HFEA merely advisory to the Secretary of State was defeated,[24] thus reinforcing the need to have a body which can actually make executive decisions. Schedule 1 provides that the HFEA shall be made up of both men and woman and that at least half of them shall be lay people. This is a really positive trait of the HFEA, as purely medical practitioners or purely religious practitioners could not necessarily be relied on to make a fair decision serving the needs of the patient or society as a whole.

[22] [2003] EWCA Civ 667.
[23] Warnock Committee, *Report on Human Fertilisation and Embryology*, para.13.3.
[24] Morgan and Lee, *Blackstone's Guide to the Human Fertilisation and Embryology Act 1990*, p.89.

However, the HFEA has an extremely large amount of power including the ability to decide who 'deserves' a licence, and their decisions impact directly on the techniques available to patients seeking treatment for infertility: a prime example being the case of the Whitakers in contrast to the Hashmis, discussed below. What this does is provide consistency in their treatment services, creating trust in its practices. For the Whitakers, PGD was not needed so treatment was disallowed. It could be argued that such a strict, narrow interpretation of the rules would comfort those worried about 'designer babies' and embryo selection going too far. The HFEA will never grant a licence unless is it the only possible option to prevent disease and for the purely medical benefit of the child who would be born as a result. In contrast, it has been argued that although PGD is not prohibited by the Act, the decision to authorise such a procedure alongside tissue typing should be left to a democratic decision in Parliament as this goes beyond 'the mere considerations of the welfare of the child and [has] the potential to affect society's perception of human life'.[25] The HFEA, by making such a decision, is perhaps going beyond its powers to implement the 1990 Act. This point was clarified by Lord Phillips in *Quintavalle* stating that

> screening for embryos before implantation enables a choice to be made as to the characteristics of the child to be born with the assistance of the treatment. Whether and for what purposes such a choice should be permitted raises difficult ethical questions. My conclusion is that Parliament has placed that choice in the hands of the HFEA.

This decision has given the HFEA the discretionary power to make all decisions which are either not covered by the Act, left unclear, or where medical research has overtaken the legislation, granting them an enormous amount of power.

Section 11 of the 1990 Act provides restrictions on what licences can be granted by the HFEA and Schedule 3 broadly provides for what a licence may and may not authorise. Schedule 3(2)(b) allows for a licence to be granted if it appears to the HFEA to be 'necessary or desirable for the purpose of developing methods for detecting the presence of gene or chromosome abnormalities in embryos before implantation'. This allows for research to be done on the development of PGD should the HFEA choose to grant such a licence for this, although the HFEA is under no obligation to grant one. There is only the obligation not to permit particular types of licences, all the positive provisions state that the HFEA 'may' authorise. Another irregularity, though an annual report is put together, is the lack of any checks over the HFEA itself. The Code of Practice put in place to provide guidelines about particular

[25] Callus, T., 'Patient perception of the Human Fertilisation and Embryology Authority,' *Medical Law Review*, (2007), 15(1) at p.64.

procedures is about practices and procedures of clinics and only dedicates one small paragraph to the way the HFEA should behave.[26] Other than this, and the broad provisions in the Act, there is no body to check that it does not abuse its power, as already seen, Lord Phillips has left all decision making to HFEA rather than handing unprecedented cases back to Parliament. There is the possibility of bringing a judicial review action, but this would not be particularly swift. It must be questioned whether a retrospective annual report of what the HFEA has been licensing is enough? The House of Commons Science and Technology Committee Report brought attention to the concern that the HFEA has exceeded its limits and is beginning to 'alter statutory boundaries.' The Lawyers' Christian Fellowship (LCF) has made a number of allegations, arguing that 'the HFEA misunderstands its functions, purports to perform functions that are not within the 1990 Act, and indicates that it would like to extend its jurisdiction even further.'[27] Though the Act does not mention the HFEA setting new policies, its governing role implies that decisions need to be made, thus naturally resulting in policies; it would be difficult to justify going back to Parliament to question their intention for the Act and the HFEA every time a different set of circumstances asked a slightly difficult set of questions. This being said, pro-life organisations, including CORE, Comment on Reproductive Ethics, do their upmost to keep the HFEA vigilant.

3 Critical Analysis of the Act

There are a number of specific problems when looking at the 1990 Act with PGD and tissue typing in mind. Both throw up inconsistencies and ambiguities individually and together. Section 2 aims to define particular terminology used throughout the Act and problems begin to arise immediately. Subsection (1)(d) states that 'treatment services' means medical, surgical or obstetric services provided to the public or a section of the public for the *purpose* (emphasis added) of assisting women to carry children.' Is the purpose to purely assist a woman to carry a child? For example if she has difficulty conceiving, then the purpose of helping conception through *in vitro* fertilisation would be assisting the woman to carry a child. Or is it more specific than that? Could the purpose be that the woman has assistance carrying a healthy child? What if the purpose is to have a particular characteristic such as tissue type? The Oxford English dictionary defines 'purpose' as 'the reason for which something is done or which something exists' or to 'have as one's objective.' Again, this is not

[26] Human Fertilisation and Embryology Authority, *7th Code of Practice*, (2007), para.1.1.
[27] SC on Science & Technology, Fifth Report, *Human Reproductive Technologies and the Law*, para.218.

particularly helpful as it is unclear whether the purpose must be medical, social or personal. On the other hand, when one is seeking PGD, then this section is broad enough to allow for a woman to have the objective of having a healthy child by screening out particular hereditary diseases. Though this is probably an acceptable interpretation of the meaning, where to place tissue typing is less straightforward as a particular characteristic of an embryo does not really fulfil the meaning of purpose when it comes to assisting a woman to carry a child; the tissue type is pretty irrelevant to the process.

The section which perhaps is most relevant to tissue typing and strictly followed through the actions of the HFEA, is section 13(5) which states 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 as a result of the treatment…and of any child who may be affected by the birth.' The reasons behind applying for a licence to grant the ability to carry out tissue typing on an embryo is to significantly improve the well being of another child. However, there is conflict in the way the HFEA grants a licence of this kind. The HFEA has positively stated in its reports that:

> pre-implantation tissue typing would not necessarily compromise the welfare of the child born a result of the procedure because there was no reason to suppose that such a child would necessarily suffer emotional or psychological harm as a result of knowing that they were conceived, at least in part, in order to be a tissue donor to an older sibling.[28]

This is all well and good, but what about the welfare of the child who may not receive treatment because the HFEA refuse to grant a licence, for example the Whitakers, discussed later? If there is no apparent distress caused to the child being born, at least partly, for their tissue type, then how is disallowing tissue typing alone in the interest of 'any child who might be affected by the birth'? Can such a distinction really be justified when to grant the licence would be to create a life, which would be by no means hindered by having a particular tissue type, and to save a life?

Another important part of the 1990 Act is Schedule 2 paragraph 1 which explains what a licence can and cannot be granted for: for example the alteration of the genetic structure of an embryo is prohibited.[29] The most controversial and unintelligible part of Schedule 2 is paragraph 1(1)d) which states: 'a licence under

[28] Human Fertilisation and Embryology Authority Report, *Pre-implantation Tissue Typing*, (2004) p.2.
[29] Schedule 2 para.1(4) of the 1990 Act.

this paragraph may authorise any of the following in the course of providing treatment services – practices designed to secure that embryos are in a *suitable condition* (emphasis added) to be placed in a woman or to determine where embryos are *suitable for that purpose* (emphasis added).' The first thing to note about this is the two different types of embryo being recognised; one being in a suitable condition and the other being an embryo suitable for a particular purpose, as discussed above, whatever that purpose may be. This appears to accommodate almost all kinds of embryo, including particular characteristics of the embryo, if that is the purpose of the mother's treatment services. Parliament does save itself a little here by putting in the word 'suitable' which on face value could be interpreted as an embryo suitable to be placed in the womb in order for a child to be born, thus excluding characteristics, as a suitable embryo for the purpose of having a child makes characteristics irrelevant. But what does 'suitable' actually mean and in medical terms, what falls under the term? The Oxford English Dictionary describes it as 'right or appropriate for a particular person, purpose or situation.' This does not really add clarity to the meaning of the provision, but rather, leaves it open for interpretation. Lord Phillips notes in the Hashmi case that '"suitable" is not defined, but that procedures carried out to ascertain suitability for transfer were considered to be appropriate for licensing.'[30] He later goes into more detail with specific regard to PGD:

> The word 'suitable' takes its meaning from its context. Where the object of the treatment is to enable a woman to bear a child confident that it will not carry a hereditary defect, an embryo will only be suitable for the purpose of being placed within her if it is free from that defect.[31]

Unlike some other parts of the Act, this provision allows for tissue typing to find a place where it may fit and be an acceptable treatment service, suitable for the purpose of carrying a child.

The final important part is Schedule 2 paragraph 1(3) which states that in order for a licence to be to be granted, it must appear to the HFEA 'to be *necessary* or *desirable* (emphasis added) for the purpose of providing treatment services.' This is extremely vague as 'necessary' and 'desirable' have very different meanings; one conveys something which has to be done, the other something which is not necessary but would be nice. In fact the dictionary states that desirable is something 'wished for as being attractive, useful or necessary.' Though necessary is part of the meaning, it is just one of three possible meanings for the word. It may be attractive to have a child

[30] EWCA Civ 667 at [34] per Lord Phillips.
[31] Ibid at [45].

with a particular tissue type, or useful to have a child with blonde hair, but do these things fall within the meaning of the Act? A particular tissue type would be for a genuine medical reason, whereas hair colour is perhaps a parental indulgence, however nothing is mentioned as to which the correct interpretation is.

All that being said, it is up to the HFEA to make a decision which they believe is reasonable and appropriate, using all their medical knowledge and treating each case subjectively. The Act, although it is now very outdated, was created to at least some extent to allow for future developments, which means that, it could be argued, to achieve this aim, it must remain to quite a large degree open and non-specific.

4 R (o/a Quintavalle) v Human Fertilisation and Embryology Authority

This case is so important because it widens the meaning of Schedule 2 paragraph 1(1)(d). The implication of this widening was that the accessibility to fertility treatment for the purpose of being able to help another child suffering from a serious illness was made possible rather than impossible; although the decision is not without its challenges.

In 1992, Chloe O'Brien, the first baby conceived through PGD was born. Both of her parents were carriers of cystic fibrosis and therefore had a 1:4 chance of any child born naturally contracting the disease. This resulted in the Human Genetics Commission releasing a statement explaining that:

> PGD is currently being offered for three major categories of disease, including i) to determine the sex of the embryo to avoid sex-linked disorders..., ii) to identify embryos with single gene disorders... and iii) to identify embryos with chromosomal disorders.[32]

This description implies that the 'designer baby' tag given to many PGD born children is simply inaccurate. Chloe O'Brian was not 'designed' by her parents. Rather, she was selected from a number of candidates, but nothing at all was done to alter her genetic composition.[33] Then in 2002, in the USA, a baby boy named Adam was conceived, again using PGD to test for Fanconi's anaemia, but this time the embryos were also tested for a matching tissue type to his sister, Molly. There was surprisingly little criticism of the parents, however, Kevin Male, on behalf of the anti-abortion group Life, commented, 'in essence it is about people being killed to get the child you

[32] Gavaghan, C., *Defending the Genetic Supermarket: the law and ethics of selecting the next generation*, (2007, Routledge Cavendish), p. 6.
[33] Ibid p.7.

want.'[34] This seems a little misguided as to the actual procedure and reasons behind undergoing PGD, particularly alongside tissue typing. No people are 'killed' and embryos which are discarded for PGD may well be discarded in the use of *in vitro* fertilisation, regardless of their health. A patient who has gone through PGD poignantly commented,

> it's how you approach the word "choice"... [PGD] gives you the choice of healthy from unhealthy, as opposed to choosing...a blonde or brunette, or a boy or a girl. This is a choice out of necessity, not for any other reason.[35]

The authority granted a licence for the procedure of PGD and tissue typing to be carried out in order to save Mr and Mrs Hashmi's son Zain, however the claimant, Mrs Quintavalle, acting for CORE, sought judicial review that the granting of such a licence was outside the scope of the 1990 Act for the purpose of selecting between healthy embryos using tissue typing. The Authority contended that the treatment was for the purposes of allowing a woman to carry a child under section 2(1) of the Act, and that the biopsy to establish the tissue type of the embryo was to ensure it was in a 'suitable condition to be placed in a woman or to determine whether the embryo was suitable for that purpose' under paragraph 1(1)(d) of Schedule 2. It was finally held that the Authority was within its rights to grant a licence for the purposes of tissue typing alongside PGD and was within the scope of the Act.

When considering the outcome of this case the judges had to find the balance between Parliamentary intention when writing the legislation, the needs of Mrs Hashmi and her family, and those with fertility difficulties in general. A purposive approach was taken by the judges following the approach set out by Lord Wilberforce in *Royal College of Nursing of the United Kingdom v Department of Health and Social Security*[36].

> ...when a new state of affairs, or a fresh set of facts bearing on policy, comes into existence, the courts have to consider whether they fall within the parliamentary intention.[37]

However, he went further and clarified that:

> There is one course which the courts cannot take under the law of this country: they cannot fill gaps; they cannot by asking the question, 'What would Parliament have done in this current case, not being one in

[34] Tizzard, J., ''Designer Babies': The case for choice' in Wasserman, D., et al., *Quality of Life and Human Difference: genetic testing, healthcare and disability*, (2005), p.30.
[35] Franklin, and Roberts, *Born and Made: An Ethnography of Pre-implantation Genetic Diagnosis*, p.25
[36] [1981] 1 AllER 545.
[37] Ibid at 565 per Lord Wilberforce.

> contemplation, if the facts had been before it?', attempt themselves to supply the answer, if the answer is not to be found in the terms of the Act itself.[38]

So the intention of Parliament must be found, for if the process of tissue typing falls outside the remit of the Act, it is not the place of the courts to find the answer, but for Parliament to decide the law.

Quintavalle fought for a narrow construction of the Act and thus it was argued that 'suitable' must mean for the purpose of assisting a woman to carry a healthy child, and that tissue typing fell outside this function. CORE contended there were other good reasons for accepting a narrower construction of this term: in taking account of the wishes of Mrs Hashmi as to a future child's particular characteristics, the HFEA's broader construction would pave the way for the creation of 'designer babies' chosen on the basis of such characteristics as hair and eye colour.[39] Lord Phillips submitted that

> [the] screening of embryos before implantation enables a choice to be made as to the characteristics of the child to be born with the assistance of the treatment. Whether and for what purposes such a choice should be permitted raises difficult ethical questions. My conclusion is that Parliament has placed that choice in the hands of the HFEA.[40]

The deliberate placement of such decisions in the hands of the HFEA can allow for a subjective assessment of each case to decide whether the candidates fall into the strict conditions placed on the treatment of tissue typing, and thus the potential of embryo choice coming down to personal taste for particular characteristics is well safeguarded. In fact, some cases decided upon by the HFEA have been criticised as being too harsh. The potential for a licence being granted by the HFEA for social reasons is near impossible. This was clarified by Schiemann:

> Parliament did not impose upon the Authority any express obligation to sanction the grant of licences even if what was proposed was indubitably necessary for the purpose of assisting a woman to carry a child... If the decision of the Authority is upheld in the present case it does not mean that parents have a right to in vitro fertilisation for social selection purposes.[41]

One of the main objections to saviour siblings is an extension of a further concern surrounding the use of PGD in general, that a child conceived in this way is not

[38] Ibid.
[39] Sheldon, S., 'Commentary–Saviour siblings and the discretionary power of the HFEA', *Medical Law Review* (2005) 13(3) at p.405.
[40] *R (on the application of Quintavalle) v Human Fertilisation and Embryology Authority* [2003] EWCA Civ 667 at [50] per Lord Phillips.
[41] Ibid at 98

valued for itself but upon the condition that certain characteristics exist. Many ethical arguments against tissue typing, whether used in conjunction with PGD or alone, cite Immanuel Kant's dictum that one should 'never use people solely as a means but always treat them as an end.'[42] On this issue, Mance LJ looks at the legislation in a wider sense rather than a narrow reading of the specific sections.

> To see the legislation as interested only in women's ability successfully to experience the physical process of pregnancy and birth would seem to me to invert the significance of the human wish to reproduce. Just as 'placing an embryo in a woman' is only a first step towards a successful pregnancy, so pregnancy and the experience of birth are steps towards an expanded family life, not an end in themselves.[43]

The view here is that the birth of the child, for whatever reason, does not depend on characteristics but is a way of having a fulfilling family life, and treating the birth as an end would hinder the bigger picture of having a child; not to see it as a woman's right to have a child, but to place value on its being as a member of a family, of a society. The Act was considered in a very broad sense, taking note of the father and the needs of the future child or sibling who may be affected. In opting for a broad construction of the statute, which is protective of the discretion exercised by the HFEA, the court here takes a clear view that the purpose of establishing a regulatory body was to allow it to reach informed and timely judgements in the light of the best available medical science as new technologies develop.[44]

The Quintavalle challenge demonstrated that the Law Lords were content to entrust the HFEA with the responsibility of ensuring PGD is only used in 'appropriate' circumstances. The manner in which this task is being carried out has been cast into doubt by the apparent ethical confusion underlying the conditions attached to the decision about tissue typing.[45] This was really emphasised by the case of Charlie Whitaker.

The strict controls set out by the HFEA to govern the use of PGD with tissue typing were to be used on a case by case basis and decide that a) the condition of the affected child should be severe or life threatening, of a sufficient seriousness to justify the use of PGD; b) the embryos conceived in the course of this treatment should themselves be at risk from the condition; and c) all other possibilities of

[42] Boggs, H., *Human Fertilisation and Embryology: Reproducing Regulation*, (2007, Routledge Cavendish), p.121
[43] [2003] EWCA Civ 667 at [128] per Mance LJ.
[44] Sheldon, 'Commentary–Saviour siblings and the discretionary power of the HFEA,' 408
[45] Gavaghan, *Defending the Genetic Supermarke*), p.162.

treatment and sources of tissue for the affected child should have been explored;[46] along with five others which are not relevant here. The Whitakers applied for the same licence as the Hashmis to try to cure their son, Charlie, who suffered from Diamond Blackfan anaemia (BDA). However, there was one critical different which would prevent the HFEA granting them a licence; BDA is not a genetic disease, it occurs sporadically, and the chance of the Whitakers having another child at risk from the disease was extremely slim. This meant that they failed part b) of the criteria to qualify for the treatment.

It must be noted that the HFEA have set themselves guidelines which they are keeping to and this creates a sense of certainty, particularly for those worried about the birth of the 'designer baby.' As with many of the decisions regarding embryology, there is a difficult balancing act to be considered between what is right for a single case and what is right in the light of emerging technologies.

In November 2001 the HFEA's Ethics Committee put together a number of recommendations regarding tissue typing in conjunction with PGD. At paragraph 3.14 it was stated that where a licence is sought for the treatment of PGD with tissue typing on an embryo which is not at serious risk of a hereditary disease the treatment 'should also be available where there is an existing sibling with a life-threatening but non-inherited condition.'[47] In 2002 by denying the treatment, the HFEA specifically acted against the recommendations of its own Ethics Committee. The apparent justifications for this refusal, that the Whitakers were testing the tissue of the embryo exclusively for the benefit of another party, and that the future child's welfare might be compromised by the psychological burden of being an "engineered" match for a sibling seem somewhat implausible. The HFEA's (then) Director of Communications explained:

> … if you are carrying out a procedure to prevent a child being born with a serious illness then … one could say that the benefits outweigh the risks... But when you get to PGD solely for the purpose of tissue typing … strictly from the point of view of the physical well-being of that child, you cannot say that it is for its benefit, you may even be doing something which is [harmful].[48]

[46] Sheldon, S., 'Hashmi and Whitaker – a misguided and unjustified distinction?' (2004), 12 *Medical Law Review* at p.319.
[47] Ethics Committee of the Human Fertilisation and Embryology Authority, *Ethical Issues in the Creation and Selection of Preimplantation Embryos to Produce Tissue Donors*, 22 November 2001.
[48] Sheldon, 'Hashmi and Whitaker,' at p.155.

Even so, there was nothing actually in the law to stop the HFEA deciding in favour of the Whitakers.

In contrast to the statement made by the Director of Communications, the consultation document *Sex selection: choice and responsibility in human reproduction* noted that the health risks which might cause an embryo, which has undergone testing involving the removal of a single cell for biopsy, not to develop would never be placed into the womb, and therefore there is no reason to believe that there is an increased health risk to a child following this technique. Any embryos not damaged during biopsy should go on to develop normally.[49] This document was released a mere two months after the Whitaker decision. The argument behind the decision simply does not stand against such contradicting decisions and statements.

The 1990 Act was created to be in line with the Abortion Act 1967 and its guidance on selective abortion. However, there were some distinctions which have caused great concern among many; this was particularly emphasised when Jayson Whitaker gave oral evidence to the Science and Technology Committee.

> When we first suggested PGD to our consultant, we were told, 'You can't do that here but what you can do is get pregnant, you can have amniocentesis, you can have a test and then you can terminate'… The human and emotional and ethical cost for my wife of being pregnant, carrying a child and then terminating was the unethical question. That was actually suggested to us as an alternative, a legal NHS approved alternative that could be done here.[50]

Others have expressed concern over the difference in wording; to undergo PGD there must be 'serious' risk to the child, but to have selective abortion up to the 24th week of pregnancy, there must be 'substantial' risk the child will have an abnormality.[51] The difference in wording is offered no explanation. John Harris expressed the view that PGD and selective abortion should not be afforded the same criteria:

> [The] comparison is seriously misleading if not fallacious... A decision to abort…must be endorsed by two medical practitioners and comply with various Acts of Parliament…A decision not to implant an embryo requires no legal justification whatsoever.[52]

[49] Gavaghan, *Defending the Genetic Supermarket,* p.167.
[50] SC on Science & Technology, Fifth Report, *Human Reproductive Technologies and the Law*, para.119.
[51] Abortion Act 1967 s.1(1)(d).
[52] Scott, R., *Choosing Between Possible Lives: Legal and ethical issues in pre-implantation genetic diagnosis*, (2007, Hart Publishing), p.253.

Though this may be true, it is a little obtuse to the long process of obtaining a licence to have pre-implantation testing carried out at all. As optimistic as the decision to twin PGD guidelines with selective abortion guidelines was, as with much of the 1990 Act, it is not without its contradictions and difficulties.

Is the Act sufficient to cover such a situation?

Although the courts did construe the 1990 Act to include the practice of tissue typing, it was a stretch from the original wording of the Act and the intention of Parliament had to be considered. This implies that should medical technologies develop much further the courts would really struggle to interpret them in light of the old law. Margaret Brazier noted that there is 'little conceptual depth underpinning British Law' thus resulting in repeated debates of 'the same issues in different guises,'[53] which can be seen by the conflicting decisions of the HFEA.

It is also a concern to some that the HFEA have power beyond what was intended in the 1990 Act, whether it was intended that they should have the power to decide whether it is either 'necessary' or 'desirable,'[54] although it was confirmed in the Quintavalle case that they should have such power, and that this was Parliament's intention: 'Whether and for what purposes [a choice to create a saviour sibling] should be permitted raises difficult ethical questions. My conclusion is that Parliament has placed that choice in the hands of the HFEA.'[55] On the other hand, it is probably fair to question how far these decision making powers go, particularly in light of developing technologies. A major conflict is that the courts cannot create new law and the old 1990 Act cannot keep up with the new developments.

One of the most difficult tasks Parliament has is to legislate on issues which are continually evolving, with massive moral and ethical implications attached. Many of the ethical objections attached to PGD are rooted in a general concern for the moral status of the human embryo and the misuse of these technologies. The 'designer baby' phenomenon is all a question of medical limits, of how far science should go and how society will be protected against the possibility of biomedicine 'going too

[53] Brazier, M., 'Regulating Reproduction Business?' *Medical Law Review* (1999) 7, 166 at para.3, Introduction
[54] Scott, *Choosing Between Possible Lives*, p.251
[55] Ibid. at 50

far'.[56] Selecting and discarding embryos, or 'playing God' is no different than that which is done in routine IVF, choosing the most likely to implant in the womb.[57]

Josephine Quintavalle believes that the commoditisation of children in reproductive technology is turning parenthood into an unhealthy model of self-gratification rather than a relationship where unequivocal acceptance and love of the offspring is the primary focus.[58] This seems a little ignorant to the reasons people choose to go through PGD; to prevent future pain and suffering in a child, to eradicate a hereditary disease, to save another child's life. None of the reasons parents choose to go through the procedure is for 'self-gratification' or because the parents are biologically materialistic. Given the limited availability, expense and low success rate of PGD, along with the lengthy and invasive nature of IVF, it is highly unlikely that there will ever be much demand from individuals wanting to use the techniques for 'trivial' reasons.[59]

5 A Need for Reform? The Human Fertilisation and Embryology Act 2008

As has been demonstrated, there are many aspects in the law regarding PGD and tissue typing which are insufficient today. Many of the terms are ambiguous to allow for developments in medicine, but are actually more of a hindrance than a help: having to spend time trying to interpret developments in light of the old Act adds unnecessary time to what is already a lengthy treatment process. Although many of the underlying principles of the 1990 Act remain, 'the Government's aim in undertaking its review was to ensure that the law and regulation remained effective and fit for purpose given the pace of scientific developments and public attitudes associated with them.'[60] There were three main aims behind the new legislation:

> to ensure that legitimate medical and scientific applications of human reproductive technologies can continue to flourish, to promote public confidence in the development and use of human reproductive technologies through effective regulatory controls applicable to them, and to secure that

[56] Franklin and Roberts , *Born and Made: An Ethnography of Pre-implantation Genetic Diagnosis*, p.1.
[57] Boggs, *Human Fertilisation and Embryology: Reproducing Regulation*, p.120.
[58] Quintavalle, J., 'Better by Accident than Design' in Wasserman, D., et al., *Quality of Life and Human Difference: genetic testing, healthcare and disability*, (2005, Cambridge University Press), p.71.
[59] Boggs, , *Human Fertilisation and Embryology: Reproducing Regulation*, p.112.
[60] Department of Health, *Review of the Human Fertilisation and Embryology Act: Proposals for revised legislation (including establishment of the Regulatory Authority for Tissue and Embryos)*, (2006, London, HMSO), para.1.2.

> regulatory controls accord with better regulation principles and encourage best regulatory practice.[61]

It must be questioned whether the 2008 Act has fulfilled these aims, and will it continue to be effective, or as with the 1990 Act, is it more than likely that in the next 15 years or so, the legislation will have to be reviewed once again? What is really required is clarity, consistency and a clear path for access to treatment. Since the consultation documents on the necessary changes and improvements to the old 1990 Act, the draft bill of the Human Fertilisation and Embryology Act 2008 was put together and given Royal Assent in November 2008. It will be implemented in stages between April 2009 and April 2010.

In the original Act there were many difficulties over the meaning of 'treatment services' under section 2(1)(d), however, there has been no change under the 2008 Act to the meaning and therefore the courts will still have to interpret the intention of Parliament when deciding whether new medicines are 'for the purpose of assisting women to carry children.' There could be a number of explanations for this. It could be that due to the case law surrounding the meaning of 'treatment services' and the final interpretation by the House of Lords was considered a sufficient interpretation to set precedent and for those concerned to rely upon. Leaving the meaning a little ambiguous also allows for further interpretation in light of any new developments which may arise: after all, the whole point of this kind of legislation is to try to make it as effective as possible for as long as possible.

Under section 3 prohibitions have been placed upon the use and research of embryos followed by the insertion of section 3ZA to clarify the meaning of 'permitted eggs, permitted sperm and permitted embryos.' Unlike the 1990 Act, there is more clarification of what is meant by some of the terms used, although it is still not perfect. 'A permitted egg is one whose nuclear or mitochondrial DNA has not been altered'[62] which provides comfort to those who worry about designer babies, but may have a slightly more preventative implication. Gene therapy is the introduction of genetic material into cells to bring about a therapeutic effect[63] and can be used to eradicate disease by replacing the damaged cells or carrying out a function which the patient's own genetic material cannot achieve. There are a few ways in which this can be carried out, one of which is called germ-line gene therapy, and involves

[61] Ibid.
[62] Human Fertilisation and Embryology Act 2008 s.3ZA(2)(b).
[63] Lemoine, N., *Understanding Gene Therapy*, (1999, BIOS Scientific Publishers Limited), p.11.

inserting the genetic material into an embryo which is 'pre-emptive treatment of the future being of the child.'[64] If section 3ZA(2)(b) were to be narrowly construed, it could potentially rule out this kind of treatment as it involved the modification of the genetic structure. Although gene therapy is not a common procedure, it is permitted by way of the Council of Europe's Recommendation 1100 on the use of human embryos and foetuses for the purposes of scientific research (1989), which allows for gene cell manipulation if it is for therapeutic purposes. It must therefore be questioned whether the narrow interpretation of this section could be regarded as a breach of EC law.

Another important addition is section 3ZA(5)(b) which states that

> regulations may provide that an embryo can be a permitted embryo, even though the egg or embryo has had applied to it in prescribed circumstances a prescribed process designed to prevent the transmission of serious mitochondrial disease.

This in itself could cause many difficulties. What is meant by a 'prescribed process' is not at all clear within the Act; all that is said is that '"prescribed" means prescribed by regulations' which according to section 45 of the 1990 Act, and amended by section 30 of the 2008 Act, is the power for either the Secretary of State for Health or the HFEA to make regulations as they see fit. It was said by Mr Streeter in the House of Commons debate that section 3ZA(5) 'is a loophole, probably unintended, but a loophole nonetheless. It could end in permitting the kind of reproductive cloning or genetic manipulation that the Government have rightly set their face against.'[65] Though such practices have been made a criminal offence, this clause is ambiguous and creates uncertainty in the legislation; the basic law is in statute, but there may be many regulations brought in over time by either party. It can be concluded that because of section 3ZA(2)(b) which does not allow for DNA alteration, procedures such as PGD and tissue typing to eradicate disease would fall under this section along with any future developments with the same aims.

An important clause in the 1990 Act was Schedule 2 paragraph 1(1)(d) which made provisions for a licence being authorised in the course of providing treatment services '[other] practices designed to secure that embryos are in a suitable condition to be placed in a woman or to determine whether embryos are suitable for that purpose',

[64] Mason, J., and Laurie, G., *Mason and McCall Smith's Law and Medical Ethics*, (2006, 7th edn. Oxford University Press), p.246.
[65] Public Bill Committee, *Human Fertilisation and Embryology Bill [Lords]*, (June 2008) at Column 20.

the latter part of the section causing most difficulty. In the 2008 Act Parliament has decided to omit the words 'or determine whether embryos are suitable for that purpose.' This gives the phrase a much wider meaning as the embryo must be suitable to be placed in a woman, but the need to decide whether the embryo is 'suitable for that purpose' is no longer necessary and thus the purpose of the embryo being placed in the woman could be that of tissue compatibility for a saviour sibling child. The widening of this provision does not sit well with CORE, who believe that the new Act has a too liberal approach stating,

> the extension of the use of embryo diagnosis to create matching embryos for therapeutic purposes [is] moving way beyond the original focus on cord blood stem cells, to now include generically any tissue from the designed baby. How long until this includes 'designer' kidneys and other body parts?[66]

The other element which caused much discussion was Schedule 2 paragraph 1(3) that activities licensed by the Authority must be 'necessary or desirable for the purposes of providing treatment services.' This phrase remains unchanged, but interpretation of it has been made a little easier by the consideration in the Hashmi case.

Unlike the 1990 Act, the new Act does specifically refer to treatments such as tissue typing and PGD. Schedule 2 paragraph 1ZA is specifically about embryo testing and paragraph 1ZB is about sex selection, both of which allow for PGD and tissue typing where there is particular risk to the embryo. What paragraph 1ZA does is put into statute form the conditions set out for undergoing PGD. 1ZA(1)(a)-(c) deals with PGD in general terms; that a licence will be granted to test for embryo abnormalities where there is particular risk that the embryo may contain the abnormalities and the resulting child is at risk of developing a serious medical condition. 1ZA(1)(d)-(e) actually puts the saviour sibling procedure of tissue typing alongside PGD into legislation: a licence cannot authorise the testing of an embryo unless,

> in a case where a person ("the sibling")…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.

Sub-paragraph 2 makes things a little less clear however. It states that a licence under paragraph 1 cannot authorise the testing of embryos for the purpose of sub-paragraph (1)(b) (PGD) unless there is particular risk of the abnormality and there is

[66] 'New Human Fertilisation and Embryology Bill – Dark days ahead for democracy and the Ordre Public,' *Comment on Reproductive Ethics*, 10 November 2007.

significant risk that the person with the abnormality will develop a serious medical condition.[67] So, in order for PGD to be carried out it appears that the embryo undergoing the treatment must be at risk of contracting a serious disease and this appears to exclude PGD for the purpose of tissue typing when there is no serious risk to the embryo being tested because the disease being cured is not one which is hereditary, but one which occurs sporadically; situations which are similar to the Whitakers. Although the remit of this section needs to be tested by case law, a strict interpretation of the Act may leave many couples much like the Whitakers having to seek treatment elsewhere.[68]

Paragraph 1ZB allows for sex selection only where there is a genuine medical reason. 1ZB(3) allows for practices designed to secure that the resulting child will be of a particular sex where there is particular risk of a gender-related disability or illness. It leads to the question of what is meant by 'serious'? Who should decide what it means? What is considered serious to one may be only minor to another. The Oxford dictionary describes 'serious' as 'significant or worrying in terms of danger or risk'. This is helpful in some respects as the potential to be born deaf, for example, is not a life threatening danger to the child in contrast to a disease such as beta thalassaemia major which requires daily blood transfusions to stay alive. But again, there is still a question of interpretation of degree on what one person might consider significant risk. An example of the different perceptions of 'serious' medical conditions, albeit controversial, is the deliberate conception of a deaf child. In 2002 Sharon Duchesneau and Candy McCullough, who were both deaf, used sperm donated by a friend with hereditary deafness to have a deaf baby. They took the view that deafness was not a disability but a difference; Sharon Duchesneau said: 'It would be nice to have a deaf child who is the same as us…A hearing baby would be a blessing. A deaf baby would be a special blessing.'[69] This procedure took place in America and would not be allowed under English law, but it demonstrates the striking difference in peoples perception of what is considered a disorder which should be prevented and a characteristic which just makes a person different. There are some straightforward decisions of serious illness, where the child will die soon after birth without massive amounts of medical attention, but disorders which set in later in life, such as Parkinson's, is a grey area and currently untested in the law.

[67] Human Fertilisation and Embryology Act 2008 s.1ZA(2)(a)-(b).
[68] The Whitakers ended up getting treatment from the Chicago Reproductive Genetics Institute as this kind of treatment is lawful in the USA.
[69] Glover, J., *Choosing Children: Genes, Disability and Design*, (2006, Clarendon Press), p.5.

The final addition to the 2008 Act which may be of some concern is Schedule 2 paragraph 1ZC which contains the power to amend paragraph 1ZA and 1ZB. Any amendment to the paragraphs and their sub-paragraphs may be made by regulations should the Secretary of State feel it necessary or expedient.[70] Although sex selection on social grounds is prohibited from being introduced, the potential of this provision is extremely wide and how far this could go is undefined. There is no process for how an amendment or a decision to amend may take place; it appears that it just can as long as the Secretary of State deems it necessary. CORE has commented on the problems with this kind of legislation:

> Over and over in the Bill one notes prohibitions, but they are a usually qualified with a subsequent exception clause which gives power to amend, either by adding to or repealing, simply through extended regulations. 'No but yes but' law of the most devious kind.[71]

Only time will tell whether this provision will be a dangerous addition to the 2008 Act.

Are the changes sufficient?

On introducing the Bill to the House of Commons, Dawn Primarolo said:

> This Bill will allow legitimate medical and scientific use of human reproductive technologies for research to flourish in this country, while giving the public confidence that they are being used and developed sensibly with appropriate controls in place. I believe this Bill will provide clarity and assurance to patients, researchers, the medical profession, and the public for years to come.[72]

This strong statement creates the same feeling of security and belief in the new Act as the 1990 Act did. Although the 2008 Act is far more modern and up-to-date than the 1990 one, medical technologies are advancing at an increasing rate. The time it will take for the legislation to be once again overtaken by technology is unknown, but it will not be all that long before the courts have to interpret the Act in light of new developments, and find places for technologies which were not even heard of when this Act was passed. It is more than likely that in another fifteen years, the legislation will again have to undergo a major review.

The forthcoming changes will have a huge amount of positive attributes. Access to life saving treatments such as PGD and tissue typing for 'saviour sibling' procedures will be licensed without the worry of a law suit. The scope of the Act being so much

[70] Human Fertilisation and Embryology Act 2008 s.1ZC(2).
[71] 'New Human Fertilisation and Embryology Bill ,'*Comment on Reproductive Ethics*.
[72] House of Lords Library Note on Human Fertilisation and Embryology Bill, (14th November 2007).

wider allows room for new advances to find a place and on the whole provides more clarity without all the ambiguous terminology. As it stands the scope of the Act is as wide as one interprets upon reading, therefore, to really test its limits it will be up to the courts to interpret just how far some of the provisions can go.

Conclusion

From the birth of Louise Brown in 1978 it was clear that legislation on fertilisation and embryology would be vital to society. The Warnock Report and the White Paper aimed to deal with the conflicts that paralleled the developments and temper the growing concern over the 'designer baby' phenomenon, by trying to reach some form of consensus among the parties. Legislating on developing practices is always going to be problematic and this is reflected in the ambiguous and opaque legislation that emerged in 1990 as the Human Fertilisation and Embryology Act. Technologies soon overtook the immediate scope of the legislation and required interpretation by the courts, brought sharply into focus by *R (on the application of Quintavalle) v Human Fertilisation and Embryology Act* which widened the scope of the Act to include pre-implantation genetic diagnosis and tissue typing. To reconcile the difficulties with the 1990 Act, Parliament created the Human Fertilisation and Embryology Act 2008, which aims to amend and modernise the old Act to be in line with today's medical technologies.

All that being said, Parliament is never going to escape the difficulty of legislating on ethical issues with moral implications, just as the courts are always going to have to interpret any legislation upon the emergence of new techniques; creating law that can see into the future is simply impracticable. What there is today though is a combination of legislative and regulatory rules in the form of the 1990 and 2008 Acts and HFEA guidelines, along with strong precedent case law, creating a uniquely robust-but-flexible system.[73] It is the flexibility of the Acts that has allowed for saviour sibling techniques to find a place within them and which will hopefully continue to allow for other such life saving technologies to find a place in the future. There is no way of knowing whether the 2008 Act will last any longer than the 1990 one, or the scope to which it will go; interpretation of the intention of Parliament on creating the Act will be up to the courts and only time will tell what they will decide.

[73] Franklin and Roberts, *Born and Made: An Ethnography of Preimplantation Genetic Diagnosis*, p.3.