

PRE-IMPLANTATION GENETIC DIAGNOSIS: A CASE FOR LAW REFORM?

R. v. Human Fertilisation and Embryology Authority, Ex Parte Josephine Quintavalle

[2003] EWCA Civ 667, [2003] 3 All E.R. 257 (Court of Appeal)
(Lord Phillips M.R., Schiemann and Mance L.JJ.)

INTRODUCTION

Over a decade ago, scientists at Hammersmith hospital in London developed a technique called pre-implantation genetic diagnosis (PGD).¹ PGD involves taking a 6–8 cell *in-vitro* embryo, removing one or two cells from it by biopsy and then analysing genetic material taken from these cells. The development of the technique opened the door to IVF users being able to choose to have some of the genetic characteristics of their *in-vitro* embryos identified. It is possible, for example, to use it to detect certain genetic disorders. Indeed, it is now widely used across Europe for this purpose.² Genetic disorders fall into two categories: chromosomal anomalies and gene defects.

Chromosomes are the structures in the nucleus of a cell which carry the genes of the individual concerned. Normal human (diploid) cells contain 46 chromosomes – 22 pairs of autosomes and 2 sex chromosomes XX (female) and XY (male).³

Some anomalies result in the embryo not surviving, whilst others will cause an abnormality (*e.g.* Down's Syndrome) or disorder. Gene defects are mutations of the genetic code that can result in a genetic disease. Examples of such diseases are cystic fibrosis, beta thalassaemia and Duchenne's muscular dystrophy. It is also possible to use PGD to identify the tissue type of *in-vitro* embryos and the gender, hair and eye colour for which they are encoded. PGD could also be used to predict behaviour and intelligence, *if* science can ever overcome the difficulties of identifying these attributes from genes.⁴

The revolutionary aspect of PGD is the fact that IVF clients can use it to decide which, if any, of their *in-vitro* embryos to implant. For example, if it is found that an *in-vitro* embryo has a particular disorder, the clients may choose not to implant it. Alternatively, the clients might be able to fulfil a desire to implant an embryo that is encoded for blue eyes and blonde hair. Both such uses hint that PGD raises serious ethical issues. Indeed, there are three hurdles that must be overcome if PGD use is to be considered ethical: firstly, it must be shown that IVF itself is ethical. Secondly, it must be shown that to test and carry out a biopsy on an *in-vitro* embryo is not *of itself* unethical. Thirdly, since PGD works within a regime where people can choose to discard *in-vitro* embryos, it must be shown that it is ethically acceptable to discard and to do so selectively according to genetic criteria.

The legal control of PGD hinges on interpretation of the Human Fertilisation and Embryology Act 1990. The Act was passed to make provision in connection with human embryos and subsequent development of such embryos; to prohibit certain

¹ Handyside, A.H., Kontogianni, E.H. *et al.*, "Pregnancies from Biopsied Human Preimplantation Embryos Sexed by Y-Specific DNA Amplification" (1990) 344 *Nature* 768–770.

² Gunning, J., "Pre-implantation Genetic Diagnosis" in Gunning, J. (ed.), *Assisted Conception: Research Ethics and Law* (Ashgate, 2000), p. 21.

³ *Ibid.* at p. 18.

⁴ Nuffield Council on Bioethics, (2002) "Genetics and Human Behaviour: The Ethical Context", para. 13-60, <http://www.nuffieldbioethics.org>.

practices in connection with embryos and gametes, to establish a Human Fertilisation and Embryology Authority and for other related purposes. The Authority can license clinics to undertake some practices which without a licence would be prohibited. The Authority considers PGD to be such a practice. Following a public consultation in 1993 it had concluded that PGD should not be used for gender selection for social reasons.⁵ In 1999 the Authority consulted with the public again on the broader issue of when, if at all, PGD should be used.⁶ At this stage the Authority had already licensed four centres to use the technique to detect chromosomal anomalies and *serious* disorders.⁷

The instant case involved the now famous Hashmi family. Mr. and Mrs. Hashmi wanted to use PGD to test *in-vitro* embryos not just for a serious disorder but also for tissue-type. The context was that one of their existing children, Zain, had a serious inherited blood disorder called beta thalassaemia. A stem cell transplant was a possible cure. However, none of the family was a suitable genetic match for Zain. The Hashmis set about having more children in the hope that if they had one who was both matched *and* free of beta thalassaemia, stem cells from the placenta could be transplanted to Zain. Mrs. Hashmi went on to conceive naturally and abort an embryo that was shown by pre-natal testing (PND) to have beta thalassaemia. From a second natural conception she had a child who was tested free of beta thalassaemia but was not a match. After this she met Dr. Simon Fishel, the Managing and Scientific Director of CARE (Centres for Assisted Reproduction Limited). He suggested that if Mr. and Mrs. Hashmi used IVF, PGD could be performed on the resultant embryos to find one that was beta thalassaemia free and a match. The Authority accepted a request to allow such dual purpose use. However, before anything could proceed, Josephine Quintavalle, acting on behalf of a pressure group called Comment on Reproductive Ethics (CORE) brought an action for judicial review of the Authority's decision.

THE DECISION OF THE HIGH COURT

Giving judgment in the High Court, Kay J. made two findings. Firstly, he found that the biopsy and testing activities involved using an embryo and, hence, could not be unregulated activities because section 3(1) of the Act states that embryos can only be created, kept or *used* pursuant to a licence.⁸ On appeal, the Authority conceded this point.⁹ However, it challenged¹⁰ Kay J.'s second finding: that testing for a tissue match could not be licensed.¹¹ This second conclusion was largely based on an analysis of two provisions: paragraph 1(3) of Schedule 2, which limits the granting of a licence for treatment to activities that "appeared to the Authority to be necessary or desirable for the purpose of providing treatment services";¹² and section 2(1) which defines treatment services as "medical, surgical or obstetric services provided to the public or a section of the public for the purpose of assisting women to carry children". Kay J.

⁵ See the HFEA/ACGT Consultation Document, (1999) "Pre-Implantation Genetic Diagnosis", para. 10, www.hfea.gov.uk.

⁶ *Ibid.*

⁷ *Ibid.* at para. 11. One additional centre is authorised to carry out the biopsy part only.

⁸ [2002] EWHC 2785 (Admin) at paras. 11–14.

⁹ [2003] EWCA Civ 667 at 20.

¹⁰ *Ibid.*

¹¹ [2002] EWHC 2785 (Admin) at paras. 15–18.

¹² Schedule 2 classifies licensable activities into research, storage and treatment. Genetic analysis for the purpose of tissue-typing was clearly purporting to be the last of these.

held that testing for tissue matches was not necessary or desirable for the purpose of assisting a woman to carry a child because it had no impact on the ability of the woman to carry the embryo after implantation.¹³

THE DECISION OF THE COURT OF APPEAL

The Court of Appeal took the view that a biopsy to facilitate testing for the purposes at hand presented no problem provided that testing for these purposes was itself licensable. The court accepted three contentions about the law relating to PGD:¹⁴

1. It was not a totally unlicensable activity when done for the purpose of detecting abnormality.

2. It could be licensed not just for the purpose of detecting abnormalities that threatened carriage and birth *but also* those that only threatened the health of the child after birth and/or the health of future generations.

3. A licence could also cover testing for desirable characteristics (at the very least in the instant case where if the embryo with the desirable characteristics was implanted and given birth to, its mother might be able to cure Zain with a donation of stem cells from the placenta).

The first contention is easy to agree with. Paragraph 1(1)(d) of Schedule 2 allows under licence “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”. Parliamentary proceedings made it clear that Parliament’s view was that this section would allow PGD for the detection of abnormality.¹⁵ Furthermore, paragraph 3(2)(b) of Schedule 2 of the Act permits embryo research activities to be licensed for the purpose of “developing methods for detecting the presence of gene or chromosome abnormalities in embryos before implantation”. It would clearly be inconsistent to allow PGD for the detection of abnormality in the context of research but not in the context of treatment.

In relation to the second contention, counsel for Mrs. Quintavalle sought to reconcile the fact that Parliament had intended to allow PGD to test for abnormalities with Kay J.’s view that the phrase “treatment services” in section 2(1) was restricted to activities that assisted women to overcome problems in conceiving and carrying a child to term.¹⁶ The reasoning was that PGD to screen out embryos with abnormalities was consistent with helping women do this because abnormalities generated a greater risk of problems in pregnancy and birth.¹⁷ However, as Mance L.J. noted, it had been demonstrated in expert evidence that some abnormalities *did not* generate such a risk.¹⁸ Hence, the implication of Kay J.’s approach is that the Act only allows testing abnormalities to be licensed where the abnormality poses an added risk of problems in pregnancy and birth. However, the Court of Appeal held that licensing was not restricted in this fashion for two reasons: firstly, that there was nothing in Parliamentary proceedings or in the Act’s approach to research that supported such a

¹³ [2002] EWHC 2785 (Admin) at para. 17.

¹⁴ See particularly the judgment of Lord Phillips M.R. [2003] EWCA Civ 667 at para. 31 onwards.

¹⁵ The matter was discussed in Parliamentary proceedings with the Health Minister, Kenneth Clarke, making an express statement confirming this position. For detailed arguments to this effect see the judgments of Lord Phillips M.R. at paras. 33–6 and 41 particularly and Mance L.J. at paras. 120–128.

¹⁶ *Ibid.* at para. 118.

¹⁷ *Ibid.*

¹⁸ *Ibid.*

restriction;¹⁹ and secondly, that the phrase “assisting women to carry children” under section 2(1) should be interpreted broadly to include any assistance without which women might be less inclined to have children. This meant that even testing for abnormalities that did not affect pregnancy or birth was licensable since without the security of having it some women would be put off having children altogether.²⁰

The third contention was, did this more generous definition of treatment services also support biopsy and genetic testing that enabled a choice between healthy embryos based on a desire for certain characteristics? The Court of Appeal reasoned that it does, as without it a woman will not get to have the child she wants and this may lead her not to want the child at all. Indeed, this appeared to be the scenario in the immediate case; the Hashmis did not seem to want another child unless it was not only free of beta thalassaemia but had a genetic make-up compatible with Zain.

CRITIQUE OF THE COURT OF APPEAL’S REASONING

The *ratio decidendi* of the Court of Appeal’s decision can be found in the statement of Lord Phillips M.R. that where PGD

has the purpose of producing a child free from genetic defects, or of producing a child with stem cells matching a sick or dying sibling, the IVF treatment that includes the pre-implantation genetic diagnosis constitutes “treatment for the purpose of assisting women to bear children”.²¹

However, this view of the law requires us to accept an extremely broad view of the term “treatment”. The strict view of the term “treatment” is that it is something designed to address an underlying condition. The relevant underlying condition of those seeking IVF is that they have problems having children naturally or at least having *healthy* children naturally. *In-vitro* embryo biopsy and testing can be consistent with the latter when it is to enable people to choose an embryo free of an abnormality, such as beta thalassaemia. However, biopsy and testing to enable people to choose an embryo genetically encoded with a particular eye or hair colour, gender (on a social basis) or tissue match with an existing child is *not* treating an underlying condition. Medical interventions in other contexts that do not treat an underlying condition are on the borderline of the term “treatment” at best when they are designed to undertake an elective “improvement” on a well individual (*e.g.* elective cosmetic surgery). However, where - as in the instant case - they are purely about fulfilling the needs of a third party, they are firmly entrenched within the non-therapeutic category. The Court of Appeal’s view that this was treatment is thus dubious and subversive of the purpose of these sections: that being to help women overcome problems having (healthy) children naturally. Mrs. Hashmi was not using the services for this purpose but to fulfil her desire to help an existing child (to the point where it appeared she would not want a child at all unless guaranteed that both forms of testing were performed).

ETHICAL ISSUES

Is IVF in itself ethical?

Before examining the issues specific to the instant case, I want to consider whether, regardless of the circumstances, the practice of IVF can be justified on ethical grounds.

¹⁹ *Ibid.*

²⁰ *Ibid.* at para. 43.

²¹ *Ibid.* at para. 48.

Clearly, where consenting adults wish to have a family naturally, this is something extremely private in which the state should not interfere. However, the question of whether humans should use technology to reproduce themselves is very much one that the state has a role in determining. I take the view that whilst technology should be used to enhance our lives and overcome certain limits, there is, in Kantian terms, a categorical imperative²² to have humility in relation to the life creation process. Such an imperative would bar the artificial creation of existing forms of life. It would also bar the artificial creation of variants such as pigs with human genes in them; plants with genetic material from other plants and animals artificially inserted into them and finally embryos that have been cloned. The norm is to focus on the consequences of such creation in assessing whether it is right or wrong. However, public concern may also be based on the view that we have no business treading in these areas. The European Convention on Human Rights and Biomedicine appears to voice a form of such absolute thinking by banning the creation of cloned human beings partly on the basis that allowing it offends human dignity.²³ If human cloning is wrong partly because it is an “instrumentalisation of human beings”²⁴ then creating other forms of “artificial” life and creating existing forms of life artificially can be viewed as wrong partly on the same basis.

Is testing the embryo ethical?

Even if IVF is to be used does that mean we should allow PGD? There are concerns about its accuracy and also that it may have adverse effects on the embryo much as it is thought pre-natal diagnosis (PND) may do. Although there are some studies on the accuracy and effect of PGD and some comparisons with the effect of PND, the quality of the evidence appears to be of limited value. In reviewing the data, McIntyre concludes that there is:

no reliable evidence to compare effects of PGD with other pre-natal diagnostic strategies on take home baby rates and congenital anomalies among couples undergoing IVF. We found no reliable evidence regarding diagnostic sensitivity and specificity of PGD for both chromosomal and genetic abnormalities, although case series have reported that missed diagnosis is rare.²⁵

She suggests that:

Controlled studies are needed to compare PGD versus “conventional” pre-natal diagnostic strategies among couples undergoing IVF. Studies should report on a standard set of pre-defined outcomes including take home baby rate per couple, details of neonatal examination, ante-natal testing rates and results and sensitivity and specificity of the diagnostic technique. Until such time, the conclusions suggested by the identified studies should be regarded as tentative.²⁶

²² Kant states that if something “is represented as good in *itself*, and thus as a necessary principle for a will which is in itself in accordance with reason, then the imperative is categorical”, Kant, I., *Groundwork of the Metaphysics of Morals* (Akademie, 1785), p. 414. Ultimately the only difference between the utilitarian and the deontologist is that the former only believes in one categorical imperative - that of utility - and treats all other goals not as ends in their own right but as subservient to the aim of best fulfilling their concept of utility.

²³ The Additional Protocol on Prohibition of Cloning of Human Beings (January 1998) follows partly from “the principle of protecting human dignity found in Art. 1 of the Convention”, Zilgalvis, P., “The European Convention on Human Rights and Biomedicine: Its Past, Present and Future” in Garwood-Gowers, A., Tingle, J. and Lewis, T. (eds.), *Healthcare Law: The Impact of the Human Rights Act 1998* (Cavendish, 2001), p. 44.

²⁴ *Ibid.*

²⁵ McIntyre, L., “Pre-implantation diagnosis” (2001) 1 *Steer* 15 at 7–8, www.signpoststeer.org.

²⁶ *Ibid.*

A dedication to detailed, timely and impartial analysis of the effects of PND and PGD is called for.

The ethical context of PGD use – questions of creation, use and disposal of in-vitro embryos and their selective disposal

Since PGD is designed to facilitate selective disposal of *in-vitro* embryos, a discussion of the ethics of genetic selection and of embryo discarding *per se* is crucial. The law relating to abortion is the traditional means of protecting embryos. The Offences Against the Person Act 1861, section 58, makes it a criminal offence, punishable by life imprisonment to, “procure the miscarriage of any woman”. Section 59 criminalises the supply of drugs or other instruments for use in procurement of a miscarriage. The Infant Life (Preservation) Act 1929, section 1(1) creates an offence of child destruction to protect the “child” (*i.e.* foetus) that is “capable of being born alive” from any person undertaking wilful acts with “intent to destroy” its life. However, the Abortion Act 1967, section 1(1)²⁷ provides that:

- ... a person shall not be guilty of an offence under the law relating to abortion when a pregnancy is terminated by a registered medical practitioner if two registered medical practitioners are of the opinion, formed in good faith-
- (a) that the pregnancy has not exceeded its twenty-fourth week and that the continuance of the pregnancy would involve risk, greater than if the pregnancy were terminated, of injury to the physical or mental health of the pregnant woman or any existing children of her family; or
 - (b) that the termination is necessary to prevent grave permanent injury to the physical or mental health of the pregnant woman; or
 - (c) that the continuance of the pregnancy would involve risk to the life of the pregnant woman, greater than if the pregnancy were terminated; or
 - (d) that there is a substantial risk that if the child were born it would suffer from such physical or mental abnormalities as to be seriously handicapped.

Conflicting categorical imperatives are in operation here. The principal conflict is between the life of a being and the right of the pregnant woman to bodily control. One must give way for the other to be protected. The law comes up with a compromise. As regards medical interventions generally, the pregnant woman’s right to self-determination is protected if she is competent²⁸ and her best interests protected if she is not.²⁹ However, her right to bodily security on its own is treated as insufficient to warrant her having an abortion. There must additionally be a disability of the kind laid out in section 1(1)(d) or (s)he and/or her existing children must have a sufficient health interest (combined effect of sections 1(1)(a) – (c)). An interesting feature of this is that it still requires this interest to be present when conception occurred from rape. The philosophy appears to be that if one is hosting a being – or at least this particular kind of being which is either a potential human being or according to some “a human being or person with potential”³⁰ – one needs a justification not to continue doing so even if that hosting was not brought about by voluntary conduct. This unacceptably contravenes a legal norm that people should not have to sacrifice their right of bodily

²⁷ As amended by the Human Fertilisation and Embryology Act 1990, s. 37.

²⁸ *St. George's Health Care NHS Trust v. S.* [1999] Fam 26 (C.A.).

²⁹ See, for example, *Re M.B. (An Adult: Medical Treatment)* [1997] 2 F.L.R. 426 (C.A.).

³⁰ Ford, N., *When Did I Begin?* (Cambridge University Press, 1998), p. 82. Ford suggests that this does not apply to the embryo that has not yet developed a primitive streak (*ibid.*, at pp. 164–182 especially).

security to meet the needs of others unless they have voluntarily engaged in conduct that results in them owing a duty to give up that security to those others.³¹

Section 1(1) is also clearly aimed at making it more difficult to have an abortion after the 24th week at which point the foetus is capable of being alive.³² This is an example of the law protecting the embryo/foetus differentially according to its level of development. Another is the fact that abortion law does not cover the embryo that is not yet implanted. Offences under the 1861 Act are connected with the procurement of miscarriage, which requires carriage. Carriage does not take place until implantation according to the High Court in *R. v. Secretary of State for Health, Ex Parte John Smeaton (On Behalf of The Society for the Protection of Unborn Children) and (1) Schering Health Care Ltd (2) Family Planning Association (Interested Parties)*.³³ This position protects the freedom to use birth control methods that prevent implantation of a fertilised embryo, such as the morning after pill and IUD.³⁴ Non-implanted embryos are only protected by reproduction law when they are *in-vitro* (by the Human Fertilisation and Embryology Act) and here only to a limited degree. The rationale for this is principally that they have not yet developed a primitive streak. The primitive streak develops at 15–18 days after conception and results in an embryo having cellular identity.³⁵ Up until the middle of the last century, the primitive streak was regarded as sufficiently significant by many to warrant embryos that had not yet developed it being given a separate name within:

a threefold distinction of pre-natal life. So for instance, the physician and Jesuit Austin O'Malley opens Chapter 3 of his book *The Ethics of Medical Homicide* (1921) remarking without ado that: "By embryologists from the moment the spermatozoon joins the nucleus of the ovum until the end of the second week of gestation of conception the product is called the *Ovum*; from the end of the second week to the end of the fourth week it is the *Embryo*; from the end of the fourth week to birth it is the *Fetus* (p. 33)".³⁶

Some thinkers try to make light of the significance of the embryo before the primitive streak lacking cellular identity by using what Lee and Morgan classify as an "I'm in there somewhere" type of argument.³⁷ However, this argument misses the point that the embryo in this state is not, in fact, an embryo at all but a bunch of cells, at this point only an undetermined group of which will go on to become an embryo. This would suggest that we are dealing with something out of which an identity will be formed rather than something that already has an identity within it.

The question is how should we treat this identity-less ovum? The answer depends on what we construe its potential to be and what we make of this. In European terms, Mori notes that the submerging of the ovum into the embryo category became

³¹ For the norm and a general philosophical defence of it see further Garwood-Gowers, A., "Intervention on the Incompetent that Benefits Others: A Clarification and Defence of the Best Interests Test" (paper presented to the SLSA conference at Nottingham Trent University, April 2003). In the abortion context specifically, Thompson gives the hypothetical example of a famous unconscious violinist who has a fatal kidney ailment. The Society of Music Lovers finds you to be suitable for the violinist to be "plugged into". They kidnap you and against your will they connect your circulatory system with his. If you unplug him before the end of a nine-month period he will die. She argues that you should not be forced to stay connected and that by analogy forcing a woman to host an embryo conceived during involuntary sexual intercourse is also wrong (Thomson, J.J., "A defense of abortion" (1971) 1 *Philosophy and Public Affairs* 1).

³² Though there must be doubts over whether "section 1(1)(c)" is harder to satisfy than "section 1(1)(a)".

³³ [2002] EWHC 610 (Admin), [2002] 2 F.L.R. 146.

³⁴ The case itself concerned the morning after pill, Schering being a pharmaceutical company.

³⁵ The then Archbishop of York, John Hapgood, in the legislative debates of 1989 (*House of Lords, Official Report*, 8 February 1990, col. 956).

³⁶ Mori, M., "The Influence of Pluralism in the Perception of the Status of the Embryo" in Gunning, J. (ed.), *Assisted Conception: Research Ethics and Law* (Ashgate, 2000), p. 76.

³⁷ *Human Fertilisation and Embryology: Regulating the Reproductive Revolution* (Blackstone, 2001), at p. 70.

common after the Second World War.³⁸ His thesis is that this was linked to a wider, Christian-dominated, theoretical treatment of the reproductive process. Mainstream Christian churches viewed it as a moral absolute that sexual acts should only be undertaken within the bounds of marriage and for the sole purpose of reproduction. To this end they all opposed contraception until 1930 when the Anglican Church altered its view. St. Augustine's particular view was that contraception was homicidal for "he who is about to become a man is one already, and all the fruit is contained in the seed".³⁹ In the modern context, this is patently absurd, not least because the seed in question does not even have the latent potential to be a fruit within itself; to become an ovum it needs to mix with another type of reproductive material (an egg). Furthermore, more modest expressions of this restrictive view of sexual expression and reproduction are still problematic. As Mori notes, such expressions obviously conflict with the view that it is legitimate to control reproduction,⁴⁰ a view that can be morally located within the perspective that humans are here to grow and that sexual expression is one dimension of experience through which growth can occur. If the overarching purpose is growth, birth control is potentially not just acceptable but a positive personal moral duty where having a child would give rise to more problems than benefits.

Mori's solution to the conflict is to suggest that people "who believe that there are absolutes are allowed to behave accordingly, but they cannot impose their view on people who think that there are no absolutes".⁴¹ However, this defence of reproductive freedom can be criticised as nihilistic. Ultimately, if we do not defend some values as absolute, such as the value of not harming others except in legitimate self-defence, we would be left with a Hobbesian lawless state. A better line of attack is to suggest that it is by no means obvious that we should sacrifice growth for the sake of sexual expression defined in such a limited way. Furthermore, the limited view can be attacked as highly questionable from its own religious basis. The psychologist Wilhelm Reich did this in *The Mass Psychology of Fascism*. He addressed a mass rally in Berlin on the subject of sex and reproduction in the early 1930s through a series of questions:

1. The church contends that the use of contraceptives is contrary to nature, as is any interference with natural procreation. If nature is so strict and so wise, why did it produce a sexual apparatus that does not impel one to engage in coitus only as often as one wants to procreate children, but on the average of two or three thousand times in a lifetime?
2. Would the representatives of the church who were present state openly if they engaged in sexual intercourse only when they wanted to procreate children? (They were Protestant pastors.)
3. Why did God produce two kinds of glands in one's sexual apparatus: one for sexual excitation and one for procreation?
4. How did they explain the fact that even small children developed a sexuality, long before the procreation function begins?⁴²

³⁸ *Ibid.* at p. 7.

³⁹ Meline, P. (Brown, P., translator) *The Moral Law of the Family* (Sands and Co., 1929), p. 111.

⁴⁰ Mori, M., "The Influence of Pluralism in the Perception of the Status of the Embryo" in Gunning, J. (ed.), *Assisted Conception: Research Ethics and Law* (Ashgate, 2000), p. 81.

⁴¹ *Ibid.*

⁴² Reich W., *The Mass Psychology of Fascism* (Souvenir Press, 1970), p. 128.

Reich's thesis is that the restrictive view of the role of sexual expression was in fact merely a distortion and inhibition of its true function. He proceeds to demonstrate that this repression is at the heart of the development of authoritarian character and hence of the development of fascism within the psyche.⁴³

There are sound reasons indeed, then, to suggest that there is nothing wrong with active contraception. The fact that the sperm has the potential to combine with an egg and ultimately become a human means no more than that it is of special value. This brings us back to the ovum. Harris has suggested that just because the ovum/embryo/foetus has potential to become a human does not mean that we should treat it any differently from sperm or even from many ordinary cells in the human body which could be used to clone a human by cell nuclear replacement.⁴⁴ However, the reason why an ovum is different from both sperm and such ordinary cells is that it is already a life-form with the latent potential to become a human already entirely genetically encoded within it. This special nature means that it has special value. However, does it have more than that? It has a much weaker case than the embryo proper for arguing that it has rights because of its lack of identity. The case is too weak to warrant the law restricting the freedom of a woman who has voluntarily allowed its creation to be forced to continue hosting it or be forced to have it inserted after being created *in-vitro*. Equally, it is probably too weak to suggest that she should be restricted to creating the number of *in-vitro* ova that she intends to have implanted. Indeed, if the ovum's significance lies wholly or largely in its potential to become an embryo proper and then a human; creating an excess beyond that number within reasonable limits may even be desirable: it maximises the chance of at least one ovum beating the poor odds of treatment success and fulfilling its latent potential. It would also, on this basis, be desirable to create an excess as an "insurance policy" against one or more ova being found by PGD to have a chromosomal anomaly or serious disorder that would affect pregnancy or birth.

A further category of actions in relation to the *in-vitro* ovum occupies a middle ground because they maximise the ability of ova to fulfil their potential only to the extent that without them women might not want to implant at all. The use of PGD to find an ovum with characteristics that fit the needs of an existing child and to detect genetic disorders that do not affect pregnancy or birth, fall into this category. Interestingly, after granting a licence in the Hashmi case, the Authority rejected an application for tissue-typing from a family whose child suffered from a rare condition called Diamond Blackfan anaemia. The only difference with this case was that the biopsy was being performed to allow testing for tissue-type, not for genetic disorder as well. However, in both cases ova were created to fulfil the needs of a sick child and in both they would be discarded if they could not fulfil that role. Hence, the Authority's own Ethics Committee was right to suggest that there was no ethical basis to treat the two cases differently.⁴⁵

Using PGD to find an ovum genetically encoded with a particular eye or hair colour or gender (for social reasons) also fall into this category. However, they do so in a much more consumer orientated way that implies that there is no case for giving ova *any* moral consideration in their own right. Indeed, such testing may be more

⁴³ *Ibid.*

⁴⁴ Harris, J., *The Value of Life: An Introduction to Medical Ethics* (Routledge, 1985), pp. 11–12.

⁴⁵ HFEA, (November 2001), "Ethical Issues in the Creation and Selection of Pre-Implantation Embryos to Produce Tissue Donors", www.hfea.gov.uk.

questionable than creating *in-vitro* ova purely as subjects for research⁴⁶ which occupies an end ground of actions which have nothing to do with enabling ova to fulfil their potential.

In terms of consequences, it is difficult to evaluate these forms of action *vis-à-vis* the ovum completely without our being certain whether it should have rights. However, one thing is clear: allowing genetic characteristics to influence selection of *in-vitro* ova is eugenic in the broadest sense of the word because it alters the composition of the human gene pool.⁴⁷ When those making this choice do so *because* of genetic characteristics rather than because of the impact on their life of having a child with these characteristics, we enter the realms of eugenics in the narrow sense of the word.

Humans can have powerful instinctive fears as regards their own future, their ability to procreate successfully and the future of their wider group or nation. In the last century, several states expressed, legitimised and even encouraged these deep-rooted fears to perpetrate various forms of narrow eugenics. One example is the sterilisation on social grounds of those whose procreation was deemed to put the future flourishing of the nation under threat.⁴⁸ “Narrow” eugenics on humans is now widely condemned but it continues to be given scope for expression on both the embryo and the ovum. With the implanted embryo, it is almost actively condoned by the structure of the Abortion Act 1967, section 1(1)(d). In setting out the circumstances in which abortion can be authorised, sections 1(1)(a), (b) and (c) weigh the interests of the embryo/foetus with those of the woman/her family. However, the subsection 1(1)(d) merely requires a (substantial) risk of it being born with (serious) handicap. In other words, it encourages a focus on the nature of the problem rather than its impact on others.⁴⁹

With an *in-vitro* ovum the protection is at best similar. Tissue-typing does not give rise to narrow eugenics selection. However, the use of PGD to detect abnormality *may do so* even if that abnormality is serious, as the Authority currently requires. This is because without establishing the intentions of the parties such decisions can be made on the basis of the nature of a disability rather than its impact on others. The Authority leaves it to clinicians to determine what serious means on a case-by-case basis rather than compiling a list of such disorders. This is understandable for a number of reasons. For example, the list would have to be constantly reviewed as understanding and treatment of disorders affected judgment of their seriousness and the list could not take into account family and personal circumstances or the potential nature, severity and likelihood of transmission in an individual case. In addition, the Authority appears to have a significant measure of confidence in the capacity of centres to define the term “serious” in a reasonable way:

⁴⁶ Research can only be carried out on embryos under licence and only until the primitive streak develops (between days 15–18). However, they can be deliberately created for use in research. Article 18(2) of the European Convention on Human Rights and Biomedicine subsequently banned creation for such a purpose but the Convention is not binding on the UK because the UK has not yet signed or *a fortiori* ratified it. The UK is the only country to allow their creation for research and both Germany and Austria ban research on embryos altogether. For the approach of European member states in general on this issue see Gunning, J., “Overview: Legislative Approaches” in Gunning, J. (ed.), *Assisted Conception: Research Ethics and Law* (Ashgate, 2000) and Lee and Morgan, *Human Fertilisation and Embryology: Regulating the Reproductive Revolution* (Blackstone Press Ltd, 2001), pp. 85–87. A dissenting minority of the Warnock committee stated that embryos “should not be used for experimentation. Still less should they be deliberately created for the purpose of experimentation” (*Committee of Inquiry into Human Fertilisation and Embryology*, Cmnd.9314, London: HMSO, 1984, Expression of Dissent, 90, para. 5).

⁴⁷ See Kitcher, P., *The Lives to Come: The Genetic Revolution and Human Possibilities* (Penguin Press: London, 1996). Interestingly Kitcher says it is also eugenic to do nothing when we can do something about the gene pool. On one version of semantics this may be so, but to use the word eugenic in this way is to make discussion unnecessarily difficult by departing from normal usage without good reason.

⁴⁸ See Kelves, D., *In the name of Eugenics* (University of California Press, 1985), p. 73.

⁴⁹ It is more eugenic than the lines of reasoning used to say that some people with extremely low quality of life are better off not having treatment or continued treatment since these are – however misguided – at least based on a genuine attempt to assess interests.

At present . . . centres are understood to be applying the criteria for termination of pregnancy for foetal abnormality published by the Royal College of Obstetricians and Gynaecologists . . . This limits the use of PND to cases where there is a precise diagnosis and a “substantial risk” of “serious” handicap.⁵⁰

In this respect ova are given the same level of protection against being discarded on grounds of disability as is provided to embryos pursuant to these guidelines, which are an interpretation of the Abortion Act 1967, section 1(1)(d). However, on the downside, there are concerns that the term “serious” is given too diluted an interpretation.⁵¹ If so, the likelihood of decisions being made on a narrow eugenics basis is increased. Furthermore, it is far easier emotionally, physically, strategically and practically to give up *in-vitro* ova than a (probably lone) embryo that is already implanted. Hence, despite its financial cost and invasiveness, “PGD has a far greater eugenic potential than prenatal genetic testing”.⁵² If there is an opportunity for decisions to be made on a narrow eugenics basis, PGD will make it easier to take advantage of the opportunity.

Even when selection after PGD is not done on narrow eugenics grounds, it poses potential dangers. Judging the characteristics of *in-vitro* ova could encourage people adversely to judge human characteristics generally, to the extent that, where individuals have characteristics thought of as less desirable, adverse attitudes and prejudicial treatment could be condoned. Social pressure could also be put on potential parents to select. Already, the Authority has rather bizarrely⁵³ asked in its consultation document whether the “principle of the welfare of the child (can) ever be compatible with a decision to begin a pregnancy knowing that a child will be born with a genetic disorder?”⁵⁴ Even if PGD is restricted to more serious purposes, as is currently the case, there may be pressure to allow it in less serious cases to the point at which the process of founding a family is viewed in a destructively consumerist fashion. Indeed, this pressure already exists. The Authority is already considering whether to allow PGD to detect gender beyond situations where there is a special risk of chromosomal anomaly or serious genetic disorder to situations where the parents already have several children of the opposite gender. The Nuffield Council on Bioethics has gone further. It suggests that, should we gain the ability, PGD should not be used to screen for “behavioural traits in the normal range such as intelligence, sexual orientation and personality traits”⁵⁵ but that a case might still be made for using it to enable one to have a child with modestly enhanced behavioural traits.⁵⁶ It suggested that this “would not seriously undermine the present relationship between parents and their children”.⁵⁷ It was not entirely persuaded by conservative reasoning on the matter – such as the view that attempts to control the type of child one has in this way represents a failure to have natural humility.⁵⁸ The Council’s view is difficult to agree with. There may be a right to protect oneself from having a child with a serious handicap on the basis that

⁵⁰ HFEA/ACGT Consultation Document, (1999) “Pre-Implantation Genetic Diagnosis” para. 34, www.hfea.gov.uk. See further the Royal College of Obstetricians and Gynaecologists report *Termination of Pregnancy for Foetal Abnormality* (January 1996).

⁵¹ See Helm, S., “Ethical Issues in Pre-Implantation Diagnosis” in Harris, J. and Holm, S. (eds.), *The Future of Human Reproduction: Ethics, Choice, and Regulation* (Clarendon Press, 1998).

⁵² Human Genetics Alert, (March 2000) “The Regulation of Pre-Implantation Genetic Diagnosis: response to the HFEA/ACGT consultation from the Campaign Against Human Genetic Engineering”, www.hgalert.org.

⁵³ The bizarreness of this question lies in the fact that it implies that some people are better off not being born. Even if that were the case, who would know from assessing their potential physical condition as a child?

⁵⁴ HFEA/ACGT Consultation Document, (1999) “Pre-Implantation Genetic Diagnosis” para. 38, www.hfea.gov.uk.

⁵⁵ Nuffield Council on Bioethics, (2 October 2002) “*Genetics and Human Behaviour: The Ethical Context*”, para. 13.78, www.nuffieldbioethics.org.

⁵⁶ *Ibid.*

⁵⁷ *Ibid.*

⁵⁸ *Ibid.* at para. 13.76.

such a child would be much harder to rear, but there is certainly not such a thing as a right to ensure for social reasons that one has a child of a certain gender, hair or eye colour or with certain behavioural traits that one likes. Decisions to reject ova on the basis that they do not have such characteristics constitute narrow eugenics.

Using PGD to tissue-type for match with an existing sick child also raises problems. For one thing, if the mother's donation from her placenta fails there will be pressure on the resultant child to donate. The Authority has pointed out that there are procedures in place to protect the interests of the new child should such a scenario arise.⁵⁹ However, these procedures do not – in the case of bone marrow donation at least – include mandatory court involvement. Furthermore, from a sociological standpoint there are obvious conflicts of interest. In particular, the medical profession has an interest in “overall utility” and the family in “family utility” both of which can be inconsistent with what is best for the child.

CONCLUSION

The ability of the Human Fertilisation and Embryology Act 1990 to cope with scientific developments that had never been envisaged when it was passed has been under serious scrutiny in recent years. Considerable doubt about the Act's ability to cope was raised when the Hashmis' case and the question of legality of cloning by cell nuclear replacement were going through the courts.⁶⁰ The House of Commons Science and Technology Committee took the view that the Act needed urgent reform to reconnect it with modern science.⁶¹ This call was endorsed by the Authority's new chief executive who suggested that “clearer legislation is desperately needed that takes into account the massive advances that have taken place since the last act was drafted and is less open to misinterpretation”.⁶² The government seemed to be alone in thinking that the Act was functioning sufficiently well not to need an overhaul.⁶³ However, the House of Lords' dexterous interpretation of the Act's applicability to cloning by cell nuclear replacement⁶⁴ along with the Court of Appeal's decision in the instant case has shown that there is some merit to the government's view. The case for Parliament to consider reform is not that the Act is proving difficult to adapt to new conditions as the reverse; the courts are applying the Act to areas which raise very important issues of ethics that Parliament did not contemplate when passing it. PGD is a classic case in point. For the use of it to be controlled by the Authority rather specifically determined by Parliament is democratically deficient. The deficiency was worsened in the Hashmi case by the fact that using PGD for tissue-typing was not something on which it had consulted the public in either its 1999 document or before. Indeed, The House of

⁵⁹ HFEA, (2001) “A summary of the 113th meeting of the HFEA on 29 November 2001”, www.hfea.gov.uk/aboutHFEA.

⁶⁰ In *R. v. Secretary of State for Health, Ex Parte Bruno Quintavalle (On Behalf of the Pro-Life Alliance)* [2001] EWHC (Admin.) 918, [2001] 4 All E.R. 1013, the High Court concluded that cloning a human being by this method was not even covered by the Act. The decision was reversed in the Court of Appeal whose decision was then upheld by the House of Lords, [2003] UKHL 13, [2003] 2 W.L.R. 692. In the meantime Parliament hastily passed the Human Reproductive Cloning Act 2001, section 1(1) of which states that, “a person who places in a woman a human embryo which has been created otherwise than by fertilisation is guilty of an offence”.

⁶¹ House of Commons Science and Technology Committee, (18 July 2002), “Developments in human genetics and embryology”, recommendation 12, www.doh.gov.uk.

⁶² Media Press Release Response to House of Commons Science and Technology Committee report, (18 July 2002) “Developments in human genetics and embryology”, <http://www.hfea.gov.uk/forMedia/archived/18072002.htm>.

⁶³ Department of Health, (November 2002, Cm. 5693) “Government Response to the Report from the House of Commons Science and Technology Committee: Developments in Human Genetics and Embryology”, www.doh.gov.uk.

⁶⁴ *R. v. Secretary of State for Health, ex parte Bruno Quintavalle (on behalf of the Pro-Life Alliance)* [2003] UKHL 13, [2003] 2 W.L.R. 692.

Commons Science and Technology Committee criticised the Authority for authorising this use without specific consultation.⁶⁵ The Department of Health noted that it was not practical to consult further before making the decision.⁶⁶ However, the response to this could be that we should not march forward with expanding the use of an ethically controversial technology without consultation simply because of the exigencies of a single case.

So what position should Parliament take? I would maintain that IVF should not be permitted under any circumstances. Nevertheless, if it is to be permitted, the case for arguing that the ovum has rights appears to be too weak on its own to prevent forms of action on it that are contrary to the actualisation of its potential. However, the need to prevent narrow eugenics is sufficient on its own to ban PGD for purposes beyond those already licensed by the Authority. Furthermore, the slim possibility that the ovum should be afforded rights combined with fears of a slippery slope in terms of how we treat other forms of life, may be enough to warrant a prohibition on the use of PGD for tissue-typing and the creation of ova simply as subjects of research.

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⁶⁵ House of Commons Science and Technology Committee, (18 July 2002), "Developments in human genetics and embryology", www.doh.gov.uk.

⁶⁶ Department of Health, (November 2002, Cm. 5693), "Government Response to the Report from the House of Commons Science and Technology Committee: Developments in Human Genetics and Embryology", www.doh.gov.uk.

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