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SELECTING SAVIOUR SIBLINGS

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The Human Fertilisation and Embryology Authority (HFEA) recently provoked considerable debate with two decisions concerning the use of Pre-implantation Genetic Diagnosis (PGD) and Human Leukocyte Antigen Tissue Typing (HLA typing) to allow parents to select embryos to become 'saviour siblings'.¹ This paper considers the legal and ethical basis for the decisions, focusing firstly on whether the deliberate creation of saviour siblings is (and should be) lawful, and secondly on whether the distinction which the HFEA drew between the two cases is justified.

I. BACKGROUND

A. *The Science*

PGD involves the removal of a cell from an embryo created by in vitro fertilisation (IVF). The cell is then tested to see if the embryo carries a genetic disorder. This is usually three days after fertilisation when the embryo has six to ten cells. Human Leukocyte Antigen (HLA) tissue typing is an additional step carried out on the same cells to determine the tissue-compatibility of embryos free from the disorder with an existing sibling.

PGD is normally practised to enable parents at high risk of conceiving a child with a particular hereditary condition to carry a child with no (or reduced) risk of that disorder. Whilst PGD for the purposes of 'non-therapeutic' sex selection is not currently permitted by HFEA,² the legality of this practice has been broadly accepted for the purposes of screening out genetic disorders.³ The technique was first successfully used in 1990 to produce two sets of twin girls where families were at high risk of

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¹ This term is taken from M. Spriggs and J. Savulescu 'Saviour Siblings' (2002) 28 J.M.E. 289.

² See, however, the HFEA's recent consultation on whether to relax this restriction: 'Sex Selection: Choice and Responsibility in Human Reproduction' (closing date, January 2003).

³ As is confirmed by the Court of Appeal's decision in *R (Quintavalle) v. HFEA* [2002] E.W.C.A. Civ. 667.

passing on a serious X-linked disorder.⁴ Sexing an embryo to avoid X-linked disorders and testing for age-related aneuploidy (an abnormal number of chromosomes) are the most common reasons for PGD worldwide, while testing for cystic fibrosis remains the most common use of PGD for a single gene defect.⁵ Four centres in the UK are currently licensed to carry out PGD and one centre is licensed for the embryo biopsy part of the procedure only.⁶

While the use of PGD for screening out particular kinds of genetic disorder is now broadly accepted in the UK, the new issue posed by two cases recently faced by the HFEA was whether this technology could be used to help parents who already have a child who suffers from a particular genetic disorder to conceive a second child who would be able to donate tissue (in the form of umbilical cord cells) to treat the existing sick child. In this paper, we use the term 'saviour sibling' to describe a child deliberately conceived for such a purpose.

B. Two Cases

1. The Hashmis

Raj and Shahana Hashmi have a three-year-old son, Zain, who suffers from the blood disorder, beta thalassaemia (BT). Zain has to undergo regular blood transfusions and may die without a bone marrow transplant. BT is hereditary and both of the Hashmis are carriers, which means that any child they produce carries a one in four chance of having BT. Zain was diagnosed as suffering from BT at four months. Two months later, Mrs Hashmi conceived naturally in the hope that they might be able to create a match for him. The resulting child, Haris, though free of the disease, was not a tissue match for Zain. His parents then launched a worldwide search for a donor but, when that failed, they began to consider alternative options.⁷

The fertility clinic which was treating the Hashmis applied to the HFEA for permission both to carry out PGD on embryos to ensure that the Hashmis would have a child born free of the disease, but also to conduct tissue typing. This would enable them to identify which, if any, of the embryos created by test tube fertility techniques was a perfect blood match for Zain, so that umbilical cord blood might be used to save his life. Allowing permission to conduct tissue typing Ruth Deech, then chair of the HFEA, said:

⁴ HFEA/Advisory Committee on Genetic Testing Consultation Document, *Pre-Implantation Genetic Diagnosis* (1999) para. 11.

⁵ *Ibid.*

⁶ *Ibid.*

⁷ See S. Boseley, 'Fertility Authority Faces "Designer Child" Decision', *Guardian* (2.10.01); C. Dyer, 'All We Wanted Was to Save our Son', *Guardian* (13.1.03).

We have considered the ethical, medical and technical implications of this treatment very carefully indeed. Where PGD is already being undertaken we can see how the use of tissue typing to save the life of a sibling could be justified. We would see this happening only in very rare circumstances and under strict controls.⁸

The broad parameters of these 'strict controls', were set out in a series of published criteria which the HFEA said would guide its future 'case-by-case' decision-making.

- (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 by which the existing child is affected;
- (c) all other possibilities of treatment and sources of tissue for the affected child should have been explored;
- (d) the techniques should not be available where the intended recipient is a parent;
- (e) the intention should be to take only cord blood for purposes of the treatment, and not other tissues or organs;
- (f) appropriate implications counselling should be a requirement for couples undergoing this type of treatment;
- (g) families should be encouraged to participate in follow-up studies and, as with PGD, clinics should provide detailed information about treatment cycles and their outcomes;
- (h) embryos should not be genetically modified to provide a tissue match.⁹

These criteria largely map those recommended in the report of the HFEA's Ethics Committee, with the notable exception that the Ethics Committee had advised that HLA typing should not be limited to cases where the embryo itself might be at risk of a particular genetic disorder.¹⁰

⁸ HFEA press release, 'HFEA to Allow Tissue Typing in Conjunction with Preimplantation Genetic Diagnosis' (13.12.01): <http://www.hfea.gov.uk/forMedia/archived/13122001.htm>.

⁹ *Ibid.* See also, Ethics Committee of the HFEA, 'Ethical Issues in the Creation and Selection of Preimplantation Embryos to Produce Tissue Donors' (22.11.01) and the minutes of the HFEA's meeting on 29 November 2001, where this issue was discussed, available at: http://www.hfea.gov.uk/aboutHFEA/archived_minutes/00028.htm.

¹⁰ Ethics Committee report, *ibid.* at para. 3.14. This departure from the advice of the Ethics Committee was, however, consistent with the thinking of the Human Genetics Commission and HFEA *Outcome of the Public Consultation on Preimplantation Genetic Diagnosis* (November 2001) which had concluded that 'PGD should only be available where there is a significant risk of a serious genetic condition being present in the embryo' (recommendation 11, at para. 28). This joint working party specifically left open the issue of the selection of saviour siblings as being in need of further discussion (para. 29).

The HFEA noted that it would authorise the use of umbilical cord cells to be taken at the birth of the Hashmis' new child. Any donation of bone marrow coming after birth would fall outwith the remit of the HFEA, being covered by the general principles of health care law.¹¹

Following this decision, the Hashmis produced 14 embryos but none was a match for Zain. Their efforts to select a saviour sibling were then temporarily brought to a halt by a court challenge, which is discussed below. They are now reported to be continuing their attempts to conceive a saviour sibling.¹²

2. The Whitakers

Michelle and Jayson Whitaker have a three-year-old son, Charlie, who suffers from Diamond Blackfan anaemia (DBA), a rare form of anaemia where the bone marrow produces few, or no, red blood cells. Symptoms are similar to other forms of anaemia and include paleness, an irregular heartbeat and heart murmurs because of the increased work the heart needs to do to keep oxygen moving around the body. The disorder can lead to irritability, tiredness and fainting and requires intensive therapy including painful daylong blood transfusions and daily injections. DBA has no cure, although bone marrow transplants can help. If the Whitakers were able to have another child who would be a matching tissue type donor, then cells created by him/her could help Charlie's body to create red blood cells, giving him a 90 per cent chance of recovery. The Whitakers requested that their doctor, Mohammed Tarranissi, be allowed to test embryos taken from Mrs Whitaker using PGD. Their case was urgent: a transplant needed to be carried out in the next 18 months to have a good chance of success. Like the Hashmis, the Whitakers claimed they wanted another baby anyway and would not view a new child purely as a donor infant.¹³

While very similar to the case of Zain Hashmi, Charlie's case differs in one relevant respect: the DBA from which he suffers is 'sporadic' rather than hereditary. This means that the chances of his parents having another baby with the disease are no greater than those of the general population: five to seven per million live births. As such, there is no reason to believe that the Whitakers' embryo would have the same defect and the second of the HFEA's published criteria (that 'the embryos conceived in the course of this treatment should themselves be at risk from the condition by which the existing child is affected') is not met. On

¹¹ The HFEA noted that mere parental consent would not be enough to render such donation lawful. However, it should be noted that such donations are routinely permitted on the basis that it is in the donor child's best interests to preserve the life of a sibling, see n. 58 *infra*.

¹² C. Dyer, 'IVF Donor Attempt to Start Next Week', *Guardian* (17.5.03).

¹³ C. Hall, 'Two Cases Have Similarities and Vital Differences', *Telegraph* (3.8.02).

this basis, the HFEA rejected the Whitakers' application.¹⁴ The justification given was that the tissue typing procedure would be performed solely to find a match for Charlie, and not in order to check whether the embryos themselves carried a genetic disorder. For the HFEA, the Whitakers' case therefore was relevantly different from the Hashmis' since, for the Hashmis, the procedure was in the interests of the new child as well as the interests of Zain.¹⁵ In the case of the Whitakers, only Charlie would directly benefit, and at some point in the future, his new brother or sister might suffer from the knowledge that she or he had been chosen, and other embryos discarded, primarily to save Charlie's life.¹⁶

Following this decision, the Whitakers travelled to the Chicago Reproductive Genetics Institute, where they were able to obtain the treatment which the HFEA had refused to authorise. They selected two embryos which provided a match for Charlie. The resulting child Jamie, who was born in June 2003, is a perfect tissue match for Charlie.¹⁷ It was reported that eight more couples were intending to avoid the need for HFEA authorisation in the same way.¹⁸

II. LEGAL ISSUES

A judicial review of the HFEA's decision to allow HLA tissue typing in the first of these cases was soon to follow, brought by the organisation, 'Comment on Reproductive Ethics' (CORE).¹⁹ The legal dispute between

¹⁴ See in particular, para. 3.14: 'Whilst in the majority of cases there will be indications for PGD to select an embryo free from a heritable genetic condition there are some cases in which an affected sibling requires tissue from a putative child who would not themselves be at risk, as with certain Leukaemias. Considering this the Committee recommends that *the technique should also be available where there is an existing sibling with a life-threatening but non-inherited condition*' (emphasis in original). Ethics Committee of the HFEA, *op.cit.*, n. 9.

¹⁵ *Op.cit.*, n. 13.

¹⁶ *Ibid.*

¹⁷ See R. Dobson, "'Saviour Sibling' is Born after Embryo Selection in the United States' (2003) 326 B.M.J. 1416, J. Laurance, "'Designer Baby' Controversy Ranges after Couple Circumvent British Laws on Embryo Selection to Help Son Beat His Life-Threatening Illness', *Independent* (20.6.03) and BBC News Online, "'Designer Baby' is Perfect Match', <http://news.bbc.co.uk/1/hi/health/3083239.stm>, 21 July 2003.

¹⁸ R. Verkaik, 'Britain's First 'Designer Baby' Prompts Call for Law Change', *Independent* (20.6.03).

¹⁹ In its own words, CORE is a 'public interest group focusing on ethical dilemmas surrounding human reproduction, particularly the new technologies of assisted conception' with 'absolute respect for the human embryo [as its] principal tenet', <http://www.coreethics.org>. For an account of CORE's challenges to the work of the HFEA, see R. Lee and D. Morgan, *Human Fertilisation and Embryology: Regulating the Reproductive Revolution* (Blackstone 2001) at 8-10; and D. Morgan, 'Ethics, Economics and the Exotic: The Early Career of the HFEA' paper presented at the workshop, 'The Human Fertilisation and Embryology Authority', Keele University (19.2.03).

CORE and the HFEA turned not on the large ethical questions which Hashmi raised (though these were clearly the motivation for CORE's challenge) but rather on the correct interpretation of the terms of the Human Fertilisation and Embryology Act 1990 (the '1990 Act'). Specifically, CORE contended that the HFEA had exceeded the limits of the powers accorded to it under this legislation.

The 1990 Act absolutely prohibits certain practices involving the use of embryos,²⁰ and sets up a licensing regime whereby certain others, including the *ex utero* creation, use and storage of embryos, can only be carried out under licence from the HFEA.²¹ Such a licence can only be granted where necessary for one or more of a specified list of purposes. This list includes, most relevantly for our purposes, 'activities in the course of treatment services'²² (defined 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').²³ The 1990 Act also provides a list of the activities which may be licensed in the provision of treatment services including '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'.²⁴

CORE's central contention was that HLA testing was not a practice 'designed to assist women to carry children', and hence could not be licensed under the 1990 Act. The HFEA sought to refute this by way of two claims: firstly that tissue typing did not require a licence because it was performed on a cell extracted from an embryo rather than an embryo itself;²⁵ and secondly, that it was lawfully able to licence tissue typing in that its use was 'desirable for the purpose of rendering treatment services' with the relevant test being one of whether the activity under consideration was 'at least desirable for the overall purpose of providing fertility treatment'.²⁶ We take these two claims in turn.

The first of the HFEA's arguments was swiftly dispatched, convincing neither the High Court nor the Court of Appeal. Mance L.J. summarised it thus:

²⁰ Section 3. All further references to statute are to the Human Fertilisation and Embryology Act 1990, unless otherwise stated.

²¹ Section 3(1)(b): '[n]o person shall keep or use an embryo, except in pursuance of a licence'.

²² Section 11(1).

²³ Section 2(1).

²⁴ Schedule 2, section 1(1)(d).

²⁵ In the Court of Appeal, the HFEA conceded that this point did not go to the heart of the case, preferring to concentrate on the second issue as being the 'vital' one. The argument was, however, raised at that stage by the Secretary of State for Health, who had been allowed to intervene in support of the HFEA.

²⁶ *Op.cit.*, n. 3, paras. 16-18.

A biopsy is necessary in any event for the legitimate purpose of testing embryonic cells to screen out beta thalassaemia. Taking the opportunity to test the same cells to check for tissue compatibility with an affected sibling would not itself constitute an activity requiring a licence and would not affect the legitimacy of the licensed activity of taking a biopsy to screen out beta thalassaemia ... this argument was put on the basis that the HFEA was only prepared to permit tissue typing tests 'where the genetic test (the dominant and necessary purpose of the biopsy) is to take place'.²⁷

This argument was given little attention by Lord Phillips M.R. and Schiemann L.J. in the Court of Appeal. Mance L.J. was not wholly convinced by the submission of either party on this issue but, significantly, he considered that where a biopsy has two basic purposes, a licence cannot be given for it where one of those purposes falls outside what is permitted under the relevant provisions of the Act.²⁸ The alternative understanding would give rise to the strange result that where PGD has been allowed for the purposes of screening for genetic disorders, clinics would be able to screen cells thus obtained for other purposes (including not just tissue typing but also, *inter alia*, sex selection) in a way that would be unregulated. Potential parents at a high risk of conceiving a child with a genetic abnormality would thus be able to avail themselves of a range of tests which were forbidden to others. Given the close regulatory regime established in the 1990 Act, it seems inconceivable that Parliament could have intended such a result.²⁹

²⁷ *Ibid.*, per Mance L.J. at para. 129.

²⁸ Section 2(1) and Schedule 2, section 1(1)(d). See Mance L.J.'s reasoning, *op.cit.*, n. 3 at paras. 110–11 and 131.

²⁹ The finding that embryo biopsy constitutes 'use' of an embryo has since been relied on in another case, see *Evans v. Amicus Healthcare Ltd.* [2003] E.W.H.C. 2161 (Fam.). Here the claimants argued that *Quintavalle*, *op.cit.*, n. 3, established that the meaning of 'use' could not be confined to meaning transfer into a woman. As such, where stored embryos were already likely to have been subject to a selection process, they had already been 'use[d] in providing treatment services' and therefore, under section 4(2) of Schedule 3 of the 1990 Act, consent to their use could not be varied or withdrawn by a gamete donor who no longer wished treatment to go ahead. Rejecting this claim, Wall J. found that what constituted 'use' was to be determined on the basis of the facts of the case in hand. *Evans* was distinguishable from *Quintavalle*, in that creation, selection, freezing and storage of embryos did not constitute 'use', but merely acts which were preparatory to and necessary for use. This leaves open the issue of the legal position if the embryos in *Evans* had been subject to a single cell biopsy before being frozen? Following *Quintavalle*, they would have to be considered 'used'. Yet it was presumably not the intention of Parliament that prior testing should make a difference with regard to the parties' legal ability to vary or to withdraw consent under Schedule 3. The only remaining, rather unsatisfactory, conclusion is to accept that the same embryos can be simultaneously 'used' for some purposes but not 'used' for others.

The second issue of whether HLA typing came within the range of activities forming part of 'treatment services' proved more complex. The HFEA contended that it was within its powers to licence tissue typing in that its use was 'desirable for the purpose of rendering treatment services' with the relevant test being one of whether the activity under consideration was 'at least desirable for the overall purpose of providing fertility treatment'.³⁰ CORE disagreed, relying on a narrower and stricter construction of the phrase. Within this stricter reading, they argued that tissue typing could not be seen as necessary to 'assist women to carry children'.³¹ Rather it was intended to affect the characteristics of the child born to particular woman, by ensuring that it would have tissue that was compatible with the tissue of a sibling.³²

The High Court was persuaded by CORE's argument. Given that the sole purpose of tissue typing was to ensure that a child would have tissue compatible with its older sibling, reasoned Maurice Kay J., it could not be said that it was 'necessary or desirable for the purpose of providing treatment services':

[t]he sole purpose of tissue typing is to ensure that [the conceived] child would have tissue compatibility with its older sibling ... [this cannot] be said to be 'necessary or desirable' for the purpose of assisting a woman to carry a child. The carrying of such a child after implantation would be wholly unaffected by tissue typing.³³

Maurice Kay J. refused to consider the broader implications of this ruling, most notably for screening for genetic disorders, on the basis that this was not raised by the facts in front of him.

The Court of Appeal however preferred the argument of the HFEA. Adopting a purposive construction of the statute and the broader interpretation of 'treatment services' which this would imply, it accepted that PGD assisted a woman to carry a child because it gave her the knowledge that the child would not be born with a genetic disorder.³⁴ Without such knowledge, some women who carried genetic diseases would not be prepared to have children. In the same way, tissue typing would help Mrs Hashmi to carry a child, for her wish to do so was conditional upon

³⁰ *R. (Quintavalle) v. HFEA* [2002] E.W.H.C. 2785 (Admin.) at para. 17.

³¹ As required by section 21(1).

³² *Op.cit.*, n. 30 at para. 18.

³³ *Ibid.* at para. 17.

³⁴ The purposive approach to statutory interpretation here is consistent with that adopted by the House of Lords in rejecting the Quintavalle's earlier attack on the 1990 Act: *R (On the application of Quintavalle) v. Secretary of State for Health* [2003] U.K.H.L. 13, [2003] 2 All E.R. 113 (H.L.).

knowing that the birth of that child would be capable of saving the life and health of Zain. As Mance L.J. put it:

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.³⁵

This broader construction of the meaning of 'treatment services' serves to protect the provision of PGD screening for genetic disorders, which was clearly threatened by Maurice Kay J.'s narrower interpretation. Further, it offers an interpretation which is more easily reconciled with Parliament's clear intention to allow for the licensing of research into screening for genetic disorders.³⁶ Finally, it also accords some recognition to the procreative autonomy of those who make use of treatment services, locating such services firmly within the range of techniques available to help those who wish to control their fertility and make planned decisions about reproduction.

III. ETHICAL ISSUES

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.³⁷

Thus it is now clear that the HFEA was acting within its legal powers in authorising the creation of saviour siblings. However, this leaves open a range of ethical questions including whether the HFEA was right to allow the Hashmis to go ahead and, if so, whether it was right to refuse similar relief to the Whitakers. In what follows we consider each of these questions in turn. We focus first on Hashmi and whether selecting saviour siblings should be allowed where PGD is also necessary to screen out genetic disorders, and second on whether the Whitaker case is morally distinguishable from Hashmi in the way asserted by the HFEA.

³⁵ *Op.cit.*, n. 3, *per* Mance L.J. at para. 128. See also Lord Phillips M.R. at para. 43: 'if the impediment to bearing a child is concern that it may be born with a hereditary defect, treatment which enables women to become pregnant and to bear children in the confidence that they will not be suffering from such defects can properly be described as 'for the purpose of assisting women to carry children'.

³⁶ *Ibid.*, *per* Lord Phillips M.R. at para. 40 and Mance L.J. at para. 120. See Schedule 2, section 3(1)(e).

³⁷ *Per* Lord Phillips M.R., *op.cit.*, n. 3 at para. 50.

A. Hashmi: *Is the Deliberate Creation of Saviour Siblings Ethically Acceptable?*

In this case, hopefully, you're going to end up with two children who are healthy. How can you argue against that? It's difficult.³⁸

Banning the use of PGD and tissue typing to select saviour siblings would lead to the avoidable deaths of existing children. As such, it seems appropriate to assume that the onus of proof rests with the prohibitionists who must demonstrate that these consequences are less terrible than the results of allowing this particular use of PGD. Jonathon Glover puts it succinctly:

You have got to have a very powerful reason to resist the means by which a child's life can be saved.³⁹

The prohibitionists have certainly attempted to present such reasons and our reading of the literature suggests three different kinds of arguments against allowing the deliberate creation of saviour siblings. These reflect concerns about (a) the commodification of babies; (b) a move down a slippery slope towards 'designer babies'; and (c) adversely affecting the welfare of the child to be created. As we have considered these arguments at length elsewhere, here we provide a briefer and more selective consideration of them.⁴⁰

1. Commodification Concerns

The first prohibitionist argument is that a saviour sibling would be 'a commodity rather than a person' and would be wrongfully treated as a means rather than as an end in itself.⁴¹ As Boyle and Savulescu point out, this worry has its philosophical roots in Kant's famous dictum, 'never use people as a means but always treat them as an end'.⁴² However, as these authors also go on to point out, this does not work as an argument against saviour siblings. Firstly it relies on a misreading of Kant who counselled not against treating people as means, but rather against treating them *merely* or *solely* as a means. And so as Professor Hans Ever, chairman of the European Society of Human Reproduction and Embryology, puts it:

³⁸ Dr Paul Veys, a bone marrow transplant specialist at Great Ormond Street, cited in J. Borger and J. Meek, 'Parents Create Baby to Save Sister', *Guardian* (4.10.00).

³⁹ Jonathan Glover, quoted in: BBC News, *Doctor Plans 'Designer Baby' Clinic*, <http://news.bbc.co.uk/1/hi/health/1702854.stm> (11.12.01).

⁴⁰ The arguments in Section III are set out in considerably more detail in S. Sheldon and S. Wilkinson, 'Should Selecting Saviour Siblings be Banned?' (forthcoming J.M.E.).

⁴¹ Vivienne Nathanson quoted in BBC News Online, *Baby Created to Save Older Sister*, <http://news.bbc.co.uk/1/hi/health/1702854.stm> (4.10.00).

⁴² R. Boyle and J. Savulescu, 'Ethics of Using Preimplantation Genetic Diagnosis to Select a Stem Cell Donor for an Existing Person', (2001) 323 B.M.J. 1240 at 1241.

This solution is morally acceptable if the use as a donor is not the only motive for the parents to have a child: i.e. they intend to love and care for this child to the same extent as they love and care for the affected child and if the planned procedure would be acceptable for an existing donor child.⁴³

Secondly, this argument fails to say what is wrong about creating a child as a saviour sibling, when creating a child for a number of other 'instrumental' purposes is widely accepted. Given that (for example) attempting to conceive a child in order to provide a playmate for an existing child is seen as reasonable, how would we distinguish this from the reasons advanced by the Hashmis or Whitakers?⁴⁴ And why should we use the opportunity presented by their need for assistance and an HFEA licence as an excuse to scrutinise their reasoning?⁴⁵ As Yvonne Roberts puts it:

Zain's brother or sister will be born to keep him alive but, one hopes, loved for his or her own sake. Is this really any less complicated than the multiple reasons why children are conceived naturally? Babies are already made to save a broken marriage, to ensnare a man, or because a baby provides an opportunity to buy, buy, buy. The difference between these circumstances and those faced by Zain's parents is that while the Hashmis have had to be open about the terms of engagement, many of the rest of us are, damagingly, less clear about our motives and expectations.⁴⁶

Of course, it might be argued that the kinds of reasons mentioned above are different from the Hashmis' reasons. But whether this is true or not is irrelevant as far as the commodification argument is concerned. For if there is a difference, it clearly is not that the accepted reasons are any less instrumental. In all of these cases, the child is used as a means to some other end, the only difference is the end in question. This suggests that it is not always wrong to have a child as a means to some further end. What matters is whether the child would be *solely* a means and whether

⁴³ Professor Ever was commenting on that body's verdict that the deliberate creation of saviour siblings was acceptable. See M Henderson, 'European Doctors Reject Ban on Saviour Siblings', *The Times* (1.7.03).

⁴⁴ As Charlie Whitaker's mother says: 'There are hundreds of reasons for bringing a child into the world. Some want a child to give a sibling a brother or sister. We always wanted to have four children, so we just combined having more with helping Charlie.' R. Dobson, "'Saviour sibling" is Born after Embryo Selection in the United States' (2003) 326 B.M.J. 1416.

⁴⁵ See Jackson's critique of the 'welfare principle' contained in section 13(5) of the 1990 Act, *inter alia* on the grounds that it discriminates against the infertile whose suitability as parents has to be assessed, when the same is not true of the fertile, E. Jackson, 'Conception and the Irrelevance of the Welfare Principle' (2002) 65 M.L.R. 176.

⁴⁶ Y. Roberts, 'Consumer Conception', *Guardian* (25.2.02).

it would be loved its own right. The possibility that the Hashmis are unlikely to love a saviour sibling is one which they vigorously deny. And, while it is always difficult to predict parenting ability in advance, the fact that they have gone to such lengths to save the life of Zain might provide grounds for believing that they are extremely committed parents. While all of this remains speculative, it is important to recall here our starting point: given the good reasons for allowing the Hashmis to proceed, the onus is on the prohibitionists to say why the Hashmis' desired end (the laudable and understandable desire to save Zain from death) is unacceptable, whilst other desired ends (e.g. so that an existing child will not be an only child) are considered praiseworthy. Such an explanation has not been forthcoming so far.

2. Designer Babies and Slippery Slopes

A second argument against permitting the deliberate creation of saviour siblings is that to do so would be to step onto a slippery slope towards allowing 'designer babies.' As two commentators put it:

... the new technique is a dangerous first step towards allowing parents to use embryo testing to choose other characteristics of the baby, such as eye colour and sex.⁴⁷

You could say it's quickly becoming like buying a new car, when you decide which package of accessories you want ... I suspect that it's only because we don't yet have the tests that we're not having parents asking for embryos without a predisposition to homosexuality or for kids who will grow to more than 6ft tall.⁴⁸

Various objections can be made to this kind of claim.⁴⁹ Here we will consider just one (which we believe to be decisive): that allowing the selection of saviour siblings would not, or need not, cause us to become 'permissive' about fully-fledged 'designer babies' given appropriate regulation. Merely stating that saviour siblings are the first steps toward allowing parents to use embryo testing to choose other characteristics remains nothing more than unsubstantiated assertion. And it is very easy to envisage how, through careful regulation, a 'slide down the slope' might be averted, for there is no reason why selection cannot be allowed for some purposes but not others. Indeed, the role of the HFEA is precisely to draw relevant distinctions, to regulate, and to avert an unthinking slide towards ever greater permissiveness. As the Court of Appeal reasoned:

⁴⁷ Attributed to Josephine Quintavalle by BBC News, 'Pro-Life Challenge to Embryo Testing', <http://news.bbc.co.uk/1/hi/health/2125482.stm> (12.7.02).

⁴⁸ Jeffrey Kahn, Director of Minnesota's Centre for Bioethics, cited in J. Borger and J. Meek, 'Parents Create Baby to Save Sister', *Guardian* (4.10.00).

⁴⁹ But see our consideration of other arguments in *op.cit.*, n. 40.

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. That seems to me to dispose of much of the force of the argument that if what has been sanctioned in principle here and licensed in one case is lawful, then licensing activities for the purpose of social selection is an unavoidable consequence. 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.⁵⁰

The onus is again on the prohibitionists to provide evidence or arguments which show why the system of regulation which Parliament has developed is likely to fail. And again this is something that they have thus far failed to do.

The argument just described is consequence-based and empirical, appealing to the (supposed) danger of society's practices 'sliding down a slippery slope'. However, a second ('logical') version of the slippery slope argument has also been made. In brief, this says that there is no fundamental moral difference between selecting saviour siblings and allowing people to select embryos on the basis of, say, hair-colour. Therefore, given that (it is assumed) everyone would want to ban the latter, everyone ought also to want to ban the former in order to be consistent. However, there do seem to us to be reasons for drawing a distinction between selecting on the basis of 'life or death' characteristics like tissue compatibility and selecting on relatively trivial grounds such as hair colour.⁵¹ Again, this point is well dealt with by the Court of Appeal:

Screening out genetic abnormalities is one thing. Screening out certain normal characteristics is another. The crucial distinction has been put as being between 'screening out abnormalities' and 'screening in preferences'. That distinction raises a spectre of eugenics and 'designer babies'. But it is a crude over-simplification to view this case as being about 'preferences'. The word suggests personal indulgence or predilection and the luxury of real choice. But there is no element of whim in the circumstances that the HFEA had it in mind to licence in December 2001, and Mr and Mrs Hashmi are not seeking to indulge themselves. The case is about a family's reaction, understandable in the light of current scientific possibilities, to a cruel fate which one of its members is suffering and will continue to suffer, without a successful stem cell transplant.⁵²

⁵⁰ *Op.cit.*, n. 3, *per* Schiemann L.J. at para. 98.

⁵¹ See our attempt to formulate such a distinction, *op.cit.*, n. 40.

⁵² *Op.cit.*, n. 3, *per* Mance L.J. at para. 134.

3. The Welfare of the Child

Finally, those who oppose the deliberate creation of saviour siblings, often make claims about the welfare of those children who will be thus created. These are based on a widely shared moral belief (one enshrined in English Law) that, when making decisions about the use of reproductive technologies, we are under an obligation to take very seriously the welfare of any child created.⁵³ Furthermore, some people think it wrong deliberately (or even just knowingly) to create a person who will suffer from a serious disease or genetic disorder, or who will have severe psychological problems.⁵⁴

Given that PGD in general is very widely accepted, we will assume in what follows that the child welfare argument must show not just that saviour siblings will (probably and on average) be worse off than children conceived 'naturally' but also that they will be worse off than other children created using PGD. In other words, merely pointing to risk factors that accompany *all* cases of PGD won't suffice since what we are looking for are risks which could underpin specific objections to saviour sibling selection, not general objections to PGD. Two types of damage resulting from saviour sibling selection are normally suggested: harm to physical health and psychological harm. Each of these will be considered in turn.

In considering the Hashmis' request, the HFEA was asked only to authorise the use of umbilical cord stem cells. Given that no post-natal intervention using the child was envisaged, any physical health problems for the saviour sibling must be caused by the PGD process itself. Is PGD physically harmful to the child thus selected? There is currently no positive evidence of harm, although a recent editorial in *The Lancet* has suggested that whilst 'embryo biopsy for PGD does not seem to produce adverse physical effects in the short term [...] it is too early to exclude the possibility of later effects'.⁵⁵ However what is clear, as far as direct effects on physical health are concerned, is that saviour siblings will not be any worse off than other children created using PGD. The embryo biopsy is the same for both procedures, with HLA typing constituting a

⁵³ Section 13(5). The importance of child welfare is a general principle of family law. Most notably, child welfare must be the paramount concern in all decisions where the upbringing or administration of a child's property is before the court, see section 1(1) of the Children Act 1989. See E. Jackson for a trenchant criticism of the use of child welfare considerations in the context of reproductive decision-making, *op.cit.*, n. 45, and below for more discussion.

⁵⁴ See Jonathon Glover's controversial claim that in some circumstances, the level of disability of a foetus may result in a moral duty to terminate a pregnancy (provided that this termination is followed by 'having another, normal one'): J. Glover, *Causing Death and Saving Lives* (Penguin 1977) at 146.

⁵⁵ Editorial: 'Preimplantation Donor Selection' 358 (2001) *Lancet* 1195.

separate procedure on the same extracted cells. So a straightforward child welfare argument based solely on physical health considerations will either simply fail (because the evidence of harm is inadequate) or will prove too much, counting not only against the creation of saviour siblings but against all uses of PGD.⁵⁶

We turn now to the idea that saviour siblings will be psychologically harmed. There seem to be two linked but analytically separate concerns here: first, that a future child may suffer psychological harm if she finds out that she was wanted not for herself, but as a means to save the life of a sibling; and second, that she may enjoy a less close and loving relationship with her parents who are less likely to value and nurture her given that they want her in order to save the life of her sibling.⁵⁷ Expressing the first of these concerns, Paul Tully of the Society for the Protection of the Unborn Child, claims:

We should be looking at the integrity and autonomy of the child created, not the sick child. How will this child feel knowing that he or she was selected from a group of embryos just to serve as a tissue donor to a sibling?⁵⁸

But even if we concede for the sake of argument that it would be hurtful or upsetting for a selected sibling (A) to discover that she had been conceived for the primary purpose of saving the life of an existing child (B), is it really plausible to suppose that A would be less happy than another, randomly selected sibling (C) who was unable to act as a tissue donor? For it could surely be argued that A would benefit from B's company and may well derive pleasure from knowing that she has saved B's life.⁵⁹ In contrast, imagine the psychological impact on C, born into a

⁵⁶ It is possible to assert a more sophisticated version of this argument whereby the embryo selected via PGD must be a 'net beneficiary' of the procedure. This will be considered later when we come on to look at the possible differences between Hashmi and Whitaker. See nn. 71–6 *infra* and accompanying text.

⁵⁷ A third argument which is sometimes put forward is that the putative 'saviour sibling' would suffer particular psychological harm if the scientists got it wrong and the child selected turned out not to be a tissue match. This argument also fails for the reasons given below, notably that its speculative nature makes it insufficient to overturn the presumption in favour of saving a child's life, and that it does not serve as a basis for believing that this child would have been 'better off not existing' (the only alternative).

⁵⁸ 'The Painful Dilemma over Babies by Design', *Telegraph* (3.8.02).

⁵⁹ These kinds of arguments form the accepted basis for allowing parents to consent to one sibling acting as a donor to another. Such donation is held to be in the donor's best interests, notwithstanding the pain and physical risks associated with the procedure, because of the donor's interest in a continued relationship with his/her sibling, see *Strunk v. Strunk* (1969) 445 S.W. 2d 145 (Ky. C.A.) for a US authority, and *Re Y (Adult Patient) (Transplant: Bone Marrow)* (1996) 35 B.M.L.R. 111 (Fam.) for a UK authority dealing with an incompetent adult donor.

bereaved family, later to discover that she was a huge disappointment to her parents because of her inability to save B's life (or, more emotively, that her tissue incompatibility was the cause of B's death). Similarly, moving onto the second of these concerns, is it not possible that the new child's capacity to save its sibling's life is something which would endear it greatly to its parents? And might not the extent of the Hashmis' efforts to save the life of Zain provide some grounds for believing that they are likely to be devoted parents? Of course, a full consideration of the issue of psychological harm would involve marshalling substantial bodies of empirical evidence (not something that we can do here). But we can at least say that it is far from obvious that child welfare considerations should count against, rather than for, the practice of saviour sibling selection. As such, we find ourselves in agreement with the HFEA Ethics Committee, which concluded on this point that:

... it is certainly possible that it is in the interest of the putative child to be able [to] save the life of its sibling. Certainly this could be argued of an existing child who acted, for example, as a bone marrow donor, thereby saving its family from the turmoil of bereavement, preserving companion siblings, etc.⁶⁰

The existence of a more philosophical response to the child welfare objection should also be noted, namely the fact that:⁶¹

... the alternative for the child who was conceived to provide stem cells is not another life in which he or she was conceived in another way, but non-existence.⁶²

When we choose to implant one embryo rather than another, we are making decisions that are *identity-affecting*. We are not choosing to make one determinate future person better (or worse) off. Rather, we are choosing to create one person rather than a different person. This does not necessarily mean that child welfare considerations should be completely disregarded. But it does make it almost impossible to construct a child welfare argument against creating the child whose welfare is under consideration. For, as John Harris puts it:

To give the 'highest priority to the welfare of the child to be born' is always to let that child come into existence, unless existence overall will be a burden rather than a benefit.⁶³

⁶⁰ Ethics Committee of the HFEA (2001), *op.cit.*, n. 9 at para. 3.7.

⁶¹ See our fuller consideration of this point in *op.cit.*, n. 40.

⁶² *Op.cit.*, n. 42 at 1242.

⁶³ J. Harris, 'The Welfare of the Child' (2000) 8 *Health Care Analysis* 33. See also E. Jackson, *op.cit.*, n. 45.

In other words, except in those very rare and unfortunate cases where life is 'not worth living' to exist rather than not will be a benefit.

Those who declare that the welfare of the saviour sibling is a reason for not allowing the Hashmis to go ahead are then asserting this as an argument against the saviour sibling's very existence. So, given the points made by Harris and by Boyle and Savulescu,⁶⁴ their objection must thus rely on the view that the saviour sibling would have been better off were it never to have existed (this being the only alternative open to those who must select the embryo). But in the absence of other unconnected problems (*e.g.* severe painful illness) the chances of saviour siblings having *negative* quality lives (*i.e.* lives worse than death) are surely remote. Are we really expected to believe that these children will live lives that are worse than not being alive at all?⁶⁵

We would argue then that the ethical arguments against allowing the Hashmis the opportunity to select a saviour sibling are unconvincing and certainly cannot outweigh the powerful countervailing consideration: that Zain's life is likely to be saved by allowing them to go ahead.⁶⁶ The HFEA was right to permit the requested tissue testing and the confirmation of the legality of this decision is to be welcomed. With this conclusion in place, we can now move on to a critical review of the HFEA's decision in Whitaker. Did it make sense for the HFEA to respond differently to the Whitakers' request?

B. Whitaker: Was the HFEA's more Restrictive Approach Justified?

If there are benefits for the child to be created from the [tested] embryo, for instance, to avoid a significant risk of a serious disease, then I think the balance of potential harm and potential good falls in a different place than if you are simply [testing] an embryo for the benefit of another person. We don't know what the social and emotional consequences of being a so-called 'saviour sibling' will

⁶⁴ *Ibid.* and *op.cit.*, n. 42.

⁶⁵ The impossibility of non-life being preferable to life has been judicially expounded in wrongful life actions such as *McKay v. Essex Area Health Authority* [1982] 2 All E.R. 771 and also, increasingly, in wrongful birth actions, most notably *McFarlane v. Tayside Health Board* [1999] 4 All E.R. 961 (H.L.).

⁶⁶ This seems to us to be one important error in the reasoning of Richard Nicholson (editor of the *Bulletin of Medical Ethics*) who notes 'Some glibly say [a saviour sibling] will welcome having helped his sibling, but we have no right to assume that will outweigh the damage to his self-worth'. R. Nicholson, 'We are Some Way Down a Slippery Slope', *Guardian* (20.6.03). Given the countervailing considerations noted above (*i.e.* the avoidable death of a child), it is surely reasonable to place the onus on the prohibitionists to make their case on the basis of empirical evidence. It is noteworthy that Dr Nicholson provides no justification for placing the onus of proof here on those in favour of intervention.

be. It seems to me that in this area of considerable uncertainty, where there is a possibility of theoretical risk, that we should adopt a precautionary approach.⁶⁷

As was noted above, in the course of its deliberations regarding the request made by the Hashmis, the HFEA released a list of criteria which would guide its future decision-making. The second of these was that 'the embryos conceived in the course of this treatment should themselves be at risk from the condition by which the existing child is affected'.⁶⁸ This criterion did provide a clear distinction between the Hashmis and the Whitakers, as Charlie Whitaker's illness was sporadic. Any embryos produced by his parents were at no more risk of developing into a child suffering from Diamond Blackfan Anaemia than would be any other randomly selected embryo, a risk in the order of five to seven per million live births.

What is at issue then is the ethical basis for this second criterion. What motivated the HFEA to introduce it, and to rely on it (against the recommendation of its own ethics committee which had concluded against its inclusion)?⁶⁹ Whilst the HFEA's press release giving its decision in Whitaker is silent on the reasons for drawing this distinction, subsequent interviews and comments reveal three main arguments in support of it.⁷⁰ These reasons mirror the objections put forward by those who opposed the use of this technology by the Hashmis, but the HFEA claimed that each provided a way of distinguishing the Hashmis' request from that made by the Whitakers:

- (i) it is wrong to create a child for a particular purpose (as a 'means to an end');
- (ii) it is wrong to create a child with which to perform this particular procedure, because the child will grow up knowing that it has been created for this particular function and this knowledge will be psychologically damaging;
- (iii) PGD may generate as yet unknown health risks for the child created and so should only be used when there is a known benefit to the particular child (i.e. not merely to third parties such as siblings).

As we saw earlier, the first two arguments were unconvincing when applied to Hashmi. Equally, it seems to us that neither will work as means of distinguishing Hashmi from Whitaker. On the first argument: a saviour sibling born to the Whitakers would not be *merely* a means to

⁶⁷ Suzi Leather, Chair of the HFEA, cited in Laurance, *op.cit.*, n. 17.

⁶⁸ *Op.cit.*, n. 9.

⁶⁹ *Ibid.*

⁷⁰ Personal interview with Ann Furedi, then HFEA Director of Communications.

an end, but like the child sought by the Hashmis, it would also be desired for its own sake; and the Whitakers' reasons for wanting this child are not necessarily any more instrumental than those of other potential parents (including the Hashmis). On the second argument, as was seen above, the claims made about the possibility of psychological harm to the child are speculative and unconvincing with regard to the Hashmis. Surely they must be still more so as a way of distinguishing the Hashmis from the Whitakers. For we would need to believe not just that a child is likely to be adversely affected by the knowledge that she had been selected as a saviour sibling, but that the adverse psychological impact is likely to be greater in the case where she knows that cells taken from the embryo had not first undergone a separate screening process for genetic disorders. This is highly implausible. And in any case, once again it is not supported by the kind of weighty empirical evidence which would be necessary to overturn the presumption in favour of attempting to save a child's life.

The argument which comes closest to an intellectually robust defence of the HFEA's position is the third one. The HFEA's (then) Director of Communications, explains it as follows:

... 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 for that particular child that would be born. But when you get to PGD solely for the purpose of tissue typing ... strictly from the point of view of the physical wellbeing of that child, you cannot say that it is for its benefit, you may even be doing something which is [harmful].⁷¹

This approach also fits with the Authority's earlier decision that PGD should only be available where there is a significant risk of a serious genetic condition being present in the embryo.⁷²

Does this provide a justification for treating the two cases differently? The underlying principle here is that an embryo should be exposed to the risks of PGD only if it (or the person it becomes) is likely to derive enough benefit to outweigh those risks. On this view, the potential child is thought to be like an existing patient and as such doctors should expose it to danger only if, on the balance of probabilities, it will be a net beneficiary. As a different HFEA spokesperson puts it:

We have to look at the benefit for the embryo, not just the sibling [and] HFEA policy states that women are allowed to have treatment only for the benefit of the embryo.⁷³

⁷¹ *Ibid.*

⁷² *Op.cit.*, n. 4, recommendation 11 at para. 28.

⁷³ Unnamed spokeswoman quoted in G. Wright, 'Call for Debate Over "Designer Baby" Laws', *Guardian* (19.6.03).

If this net beneficiary principle is accepted then there seems to be an important difference between selecting a saviour sibling and screening for a serious genetic disorder, since (it is argued) only the latter procedure benefits the child created and so only the latter is acceptable.

However, the net beneficiary principle relies on some confused thinking about what it means to 'benefit an embryo'. It appears to depend on something like the following model. In Hashmi, an embryo (H) is subjected to an intervention (T) which has the following effects:⁷⁴

- (a) T prevents H from having a serious genetic disorder;
- (b) T involves as yet unknown long-term health risks for H.

In Hashmi, subjecting H to T can (on this model) be justified solely by reference to H's interests because the benefit of (a) outweighs the harm or risk involved in (b). In Whitaker however things seem importantly different. For an embryo (W) is subjected to an intervention (T*) with only the following effect:

- (b*) T* involves as yet unknown long-term health risks for W.

In Whitaker, T* cannot be justified by reference to W's interests since there is some risk but no benefit for W. So, if subjecting W to T* is to be justified at all, it must be solely by reference to the interests of a third party (the existing child). Perhaps third party interests are sometimes sufficient to justify subjecting an embryo to harm or risk but, on the HFEA view, third party interests are not a sufficient reason, at least in cases of this type (a position which is entailed by the net beneficiary principle outlined above).

What is wrong with this model? The main difficulty is that in Hashmi it is not the case that T prevents H from having a serious genetic disorder. Rather, H was selected because it did not have the genetic disorder in question (and so had H been 'naturally' implanted, rather than implanted as a result of T, H still would not have had the disorder). So we cannot think of T as benefiting H in any straightforwardly causal way, because T has not cured H or removed a disorder. Rather, T involved choosing H on the grounds that it was *already* a 'healthy' embryo.

Given this, what can it mean to say that H has been benefited by T? The only way to make sense of this claim is to say that H derives benefit because T causes H to be implanted, and being implanted is better for H than not being implanted (assuming that, if implanted, H will go on to have a 'life worth living' and that the alternative to implantation is destruction). So, if there is any benefit at all for H, it is not 'being healthy

⁷⁴ T stands for the process of embryo biopsy, with extracted cells screened for both genetic disorder and tissue compatibility. T* is the same as T except that it does not involve screening for a genetic disorder.

rather than having a genetic disorder'. Rather, the benefit is 'existing rather than not existing'. Hence, the HFEA argument must rest on the view that, for H, the benefit of existence somehow outweighs the as yet unknown long-term health risks.

This style of argument raises a number of very thorny philosophical problems which we cannot explore in any depth here.⁷⁵ But there are also more practical and telling objections to the HFEA view. The most relevant of these for our purposes is that the argument just outlined applies equally to both Hashmi and Whitaker. For if the relevant benefit is being caused to exist (rather than being cured of a genetic disorder), then clearly both H and W stand to gain more or less equally in this respect—since both are caused to exist by the selection process and probably would not have existed without it. And what is more, this will apply (again, more or less equally) to all selected embryos, except in those few cases where the life in question is so bad that it is 'not worth living'. This then is a decisive objection to the HFEA's attempt to justify treating Hashmi and Whitaker differently on the basis of potential physical harm caused by PGD and, more broadly, any child welfare grounds.

A further practical argument against the HFEA position, and in particular the net beneficiary principle, is that it would have far more restrictive implications for infertility treatment services than the HFEA is likely to want allow. The HFEA position relies on the idea that being implanted benefits the embryo and, what is more, this seems to be the only kind of benefit available from the selection process (at least from the perspective of the selected embryo itself) since, as we have seen, PGD does not cure disorders, it merely selects embryos that are already 'healthy'. But what about those embryos which are discarded rather than selected, including those which do have disorders? These embryos stand to gain nothing from the PGD process, which is hardly surprising since the alternative to implantation is use in research and/or destruction. But this does not sit happily with the HFEA position which is supposed to rely on the net beneficiary principle, according to which an embryo should be exposed to the risks of PGD only if it (or the person it becomes) is likely to derive enough benefit to outweigh those risks. Discarded embryos obviously will not derive any benefit and so, if the HFEA is really committed to the net benefit principle, it should ban all forms of PGD—and probably all forms of IVF (since this inevitably involves discarding embryos). It follows that either the HFEA is not really committed to the net beneficiary principle (in which case the attempt to use it to distinguish Hashmi from Whitaker is disingenuous)

⁷⁵ One obvious difficulty, for example, is the question of whether it really makes sense to sense to say of an individual that she was benefited by the events that caused her to exist?

or that the HFEA is inadvertently being inconsistent, not having realised that it cannot endorse the net beneficiary principle, without also ruling out even very mainstream IVF practices. Significantly, and more generally, this means that the HFEA's general position that PGD should only be permitted where the embryo is at significant risk of a serious genetic disorder remains similarly morally unjustified.⁷⁶

It is also worth noting that in relevant respects, the child to be born is *not* in the same position as the adult patient who should only receive treatments which, on balance, are for her benefit. The legal context of the provision of infertility treatment services recognises this, specifically allowing for consideration to be given to the interests of third parties—notably, those who are seeking to make use of infertility treatment services to conceive and, very relevantly for our purposes, the interests of existing children. Indeed, what seems to have escaped many commentators who champion the legal paramountcy of child welfare in this context, is that the 1990 Act actually provides 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 (including the need of that child for a father), *and of any other child who may be affected by the birth.*⁷⁷

So when considering saviour sibling cases, the legislation explicitly requires us to take account of the welfare of the existing sick child. How should the courts seek to balance the unknown effects of PGD on the new addition to the Hashmi family, against the known tremendous health benefits to Zain? It seems hard to resist the conclusion that the tangible short-term benefits to Zain outweigh the risks to the saviour sibling which are (at most) uncertain.

The courts have not been asked to address the issue of how to balance competing welfare demands of more than one (potential or existing)

⁷⁶ *Op.cit.*, n. 10.

⁷⁷ Section 13(5), *our italics*. This did not, however, elude the Court of Appeal: 'Families which cannot, for financial reasons or because of the needs of an existing sibling, accommodate another child, may take steps to avoid having one. Families may equally have another child with the idea in mind that he or she will be company for an existing child. Such considerations may no doubt also play a significant role in the clinical judgment, about the welfare of any child who may be born and of any other child who may be affected by the birth, which is contemplated by section 13(5) of the Act. Whilst that subsection probably had primarily in mind consideration of any adverse effects on the welfare of the future or any existing child, the language does not exclude positive effects. The relevant considerations may indeed point in opposite directions. For example, it might be to the benefit of an existing child to have a companion, but there might be a countervailing risk to the welfare of the new child in the form of some hereditary disability.' *Op.cit.*, n. 3, *per* Mance L.J. at 133.

child in the context of reproductive technologies before and, indeed, have only rarely faced it in the context of existing children.⁷⁸ But some guidance might be found in the Court of Appeal's judgment in a much publicised case dealing with the legality of separating conjoined twins, Mary and Jodie.⁷⁹ Having directed himself that the welfare of the child must be paramount and concluded that separation surgery would be in the best interests of Jodie (for whom the prognosis was good following separation) while continued conjoinment would be in the best interests of Mary (who would inevitably die as a result of surgery rather than survive for a projected few further months of very low quality life), how was Ward L.J. to resolve the resulting dilemma? Noting that his duty was to 'strike a balance between the twins and do what was best for them' he proceeds to suggest a delicate process of weighing benefits and harms:

The analytical problem is to determine what may, and may not be placed in each scale and what weight is then to be given to each of the factors in the scales. (i) The universality of the right to life demands that *the right* to life be treated as equal. The intrinsic value of their human life is equal. So the right of each goes into the scales and the scales remain in balance. (ii) The question which the court has to answer is whether or not the proposed treatment, the operation to separate, is in the best interests of the twins. That enables me to consider and place in the scales of each twin the worthwhileness of the treatment ...⁸⁰

This judgment has been criticised for implicitly pitting Mary against Jodie in an adversarial relationship.⁸¹ However, it does provide one possible model for how lawyers might make a welfare calculation which does not value the life of Zain Hashmi above that of a future sibling but looks to the best interests of the two collectively in order to decide the extent to which a given procedure is worthwhile for each, and hence in their best collective interests.⁸²

What then should we conclude with regard to the HFEA's response to the Whitakers? In authorising the HLA typing in Hashmi, the HFEA had already (rightly in our view) recognised that this was a legitimate form of

⁷⁸ Note the House of Lords' side stepping of this issue in *Birmingham City Council v. H (A Minor)* [1994] 1 All E.R. 12.

⁷⁹ *Re A (Children) (Conjoined Twins)* [2000] 4 All E.R. 961.

⁸⁰ *Ibid.*, per Ward L.J. at 1010.

⁸¹ B. Hewson, 'Killing Off Mary: Was the Court of Appeal Right?' (2001) 9 Med. L. Rev. 281; V. Munro, 'Square Pegs in Round Holes: The Dilemma of Conjoined Twins and Individual Rights' (2001) 10 S.L.S. 459.

⁸² Note also the comments of the HFEA Ethics Committee on this point, *op.cit.*, n. 9 at para. 2.14–2.15.

screening for the selection of embryos. This means that the HFEA had already reached a position on the difficult ethical issue of whether tissue typing should be allowed for the benefit of a third party. As such, it seems to us that their refusal to allow the Whitakers to take advantage of the same procedure rests on a distinction without a difference. It was an irrational decision, reliant on confused thinking, and particularly misguided given that it was liable to result in the death of a child.

IV. CONCLUSION

In this paper we have reviewed two decisions made by the HFEA regarding the deliberate creation of saviour siblings. We have argued that such creation is acceptable and that therefore the Court of Appeal's upholding of the legality of the HFEA's decision in Hashmi is to be welcomed. It is our view however that the HFEA got it badly wrong in Whitaker. While the issue of whether the Whitakers might have succeeded in a judicial review of the HFEA's decision must remain outside of the scope of this paper, it seems clear that there was nothing in the law which prevented the HFEA from deciding their request differently. Further, our review of the ethical issues indicates that there was nothing that *ought* to have prevented the HFEA from approving the Whitakers' request.

Some more general points may be offered by way of conclusion. Firstly, it should be noted that the HFEA is guiding the regulation of reproductive technologies in a direction that does not always fit easily with the general principles of health care law as they have developed elsewhere.⁸³ Paradoxically, it might be noted that the principle of child welfare was intended by the architects of the 1990 Act to enjoy a weaker role in the regulation of human fertilisation and embryology than in other areas of law.⁸⁴ Yet there is little doubt that the courts would sanction the far more invasive procedure of use of bone marrow to save

⁸³ See Margaret Brazier's contention that: 'There is little conceptual depth underpinning British law. The result is that again and again, as new medical developments emerge, we debate the same issues in different disguises ... [the law] displays contradictions, no single, coherent, philosophy underpins the law's response to reproductive medicine.' M. Brazier, 'Regulating the Reproduction Business?' (1999) 7 Med. L. Rev. 166 at 167. It should be noted that Brazier is not wholly convinced that this lack of coherence is a bad thing.

⁸⁴ While section 1(1)(a) of the Children Act 1989 establishes child welfare as the *paramount* factor in any decision involving any aspect of a child's upbringing, section 13(5) of the Human Fertilisation and Embryology Act 1990 directs us merely that it is merely a factor of which 'account must be taken'. See also the guidance of section 13(5) offered in the HFEA's Fifth Code of Practice: '3.3 ... in deciding whether or not to offer treatment, centres should take account both of the wishes and needs of the people seeking treatment and of the needs of any children who may be involved. Neither consideration is paramount over the others, and the subject should be approached with great care and sensitivity.'

Charlie Whitaker, were his saviour sibling already born.⁸⁵ The assertion of child welfare concerns to ground a prohibition of embryo screening to secure a suitable donor for umbilical cord blood might therefore seem puzzling. One question which is thus clearly raised by its decision in Whitaker is whether the HFEA is too focused on considerations of the welfare of the child to be born, to the unfortunate exclusion of other factors.⁸⁶ An alternative and, we would suggest, preferable view is that the child to be born is one party amongst others, each having interests worthy of consideration.⁸⁷ As was seen above, this philosophy is entirely consistent with the wording of the 1990 Act.⁸⁸

Similarly, the HFEA's decision in Whitaker is importantly inconsistent with the law regulating abortion. The HFEA has previously expressed a desire to avoid such a result, at least in terms of an intention that the use of PGD should be consistent with current practices in the use of prenatal diagnosis (PND).⁸⁹ For this reason, in 2001, the HFEA concluded that:

PGD should only be available where there is a significant risk of a serious genetic condition being present in the embryo.⁹⁰

This provision mirrors section 1(1)(d) of the Abortion Act 1967 which foresees the possibility of termination where:

there is substantial risk that if the child were born it would suffer from such physical or mental abnormalities as to be seriously handicapped.

But section 1(1)(d) is not the only basis for lawful termination. If she can find the two willing doctors required by the Abortion Act 1967, it seems to us that there would be nothing to stop Mrs Whitaker from conceiving a series of pregnancies and terminating every one until she is found to be

⁸⁵ *Op.cit.*, n. 59. For another interesting comparison, see a recent study which offered foetal HLA typing to couples at risk of conceiving a child with Beta Thalassaemia. The idea was that if HLA identity could be established between an affected fetus and an existing unaffected child who could then act as a bone-marrow donor, this possibility would offer the parents an alternative to pregnancy termination. See M.G. Orofino, F. Argioli, M.A. Sanna, M.C. Rosatelli, T. Tuveri, M.T. Scalas, M. Badiali, P. Cossu, R. Puddu, M. Eliana Lai and A. Cao, 'Fetal HLA Typing in β Thalassaemia: Implications for Haemopoietic Stem-Cell Transplantation' (2003) 362 *Lancet* 1903.

⁸⁶ See Jackson, n. 45 above for the argument that the welfare provision in the 1990 Act is unjust, meaningless and inconsistent with existing legal principle.

⁸⁷ For this argument made as a criticism of the paramountcy provision of the Children Act 1989, see H. Reece, 'The Paramountcy Principle: Consensus or Construct?' (1996) 49 *C.L.P.* 267.

⁸⁸ Section 13(5). As is shown above, it is also consistent with the HFEA's Code of Practice, *op.cit.*, n. 84.

⁸⁹ *Op. cit.*, n. 10, paras. 25-9.

⁹⁰ *Ibid.*, recommendation 11 at para. 28.

carrying a foetus which would be a compatible tissue donor under the more general permission of section 1(1)(a).⁹¹ This is a solution which is likely not only to cause delay and greater distress to Mrs Whitaker,⁹² but which would be likely to be far less acceptable to the general public.⁹³ And while it may be difficult to find doctors prepared to countenance the repeated use of abortion in this way, it could be argued that the HFEA's decision in Whitaker creates a pressure on doctors to do just that.

Secondly, it seems strange that the HFEA chose to ignore the deliberations of its own Ethics Committee in Whitaker. Having established such a Committee, staffed it with the members of the HFEA with the most relevant expertise, and allowed it the time for reflection necessary to produce a carefully reasoned report, one might have expected the HFEA to have more cognisance to its findings. The HFEA may well be sincere in denying that their refusal of the Whitakers' request had anything to do with criticism of their response to the Hashmis.⁹⁴ However, as we have aimed to demonstrate, it will be more difficult for the HFEA to show that the different treatment meted out to the two couples did not rely on some very confused thinking. The important new issue raised by HLA tissue typing is whether it is justifiable to select an embryo on the basis of its capacity to save another person. The HFEA had already reached a positive view on this issue when it decided to allow the Hashmis to go ahead. Its mistake in Whitaker then was to believe that the fact that tissue typing was combined with another form of screening was morally relevant.⁹⁵

⁹¹ That is to say: '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, or of injury to the physical or mental health of the pregnant woman or any existing children of her family'.

⁹² Z. Miedzybrodzka, A. Templeton, J. Dean, N. Haites, J. Mollison and N. Smith, 'Preimplantation Genetic Diagnosis or Chorionic Villus Biopsy? Women's Attitudes and Preferences, (1993) 8(12) *Human Reproduction* 2192. See also the brief discussion of this study in S. Holm, 'Ethical Issues in Preimplantation Genetic Diagnosis' in S. Holm and J. Harris (eds), *The Future of Human Reproduction* (Oxford University Press 1998) at 179-80.

⁹³ See the HFEA's explicit comparison of PGD and Prenatal Diagnosis in its 1999 Consultation, HFEA and Advisory Committee on Genetic Testing, *Consultation Document on Preimplantation Genetic Diagnosis* (2000) at paras. 24-7, and S. Holm, *ibid.* at 180-2.

⁹⁴ Most notably, the House of Commons Select Committee strongly criticised the HFEA's decision in Hashmi, arguing that it 'went beyond the scope of its own public consultation'. See H.C. Science and Technology Committee, *Developments in Human Genetics and Embryology* (Fourth Report of Session, 2001-2, H.C. 791).

⁹⁵ It is also possible that the HFEA believed that, in refusing the Whitakers, it could claim that tissue typing fitted within its existing rules (which allow embryo biopsy where necessary for screening out genetic disorder) and thus avoid too much adverse public attention. The extent of the Authority's mistake was swiftly demonstrated by the amount of sympathetic media coverage accorded to the Whitakers who quickly emerged as exceptionally articulate, compelling and telegenic opponents.

These cases also raise a final general issue which goes far beyond the scope of this paper: who is the appropriate decision-maker in cases like Hashmi and Whitaker? Are the sorts of issues raised here ones which could rightly be left to the conscience of individual parents and the professional discretion of clinicians? Is it right that these decisions should be located in the hands of a body like the HFEA with its ability to draw on medical, legal and ethical expert and lay members? Or are issues raised by these cases of such fundamental importance that they would be more appropriately determined by a democratically elected body? While views may differ as to who is best qualified to make such decisions, in Hashmi, the Court of Appeal has at least given us a clear answer to who has the legal right to do so.⁹⁶

⁹⁶ See n. 37, *supra*.