



The Wrong Harvest: The Law on Saviour Siblings

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ABSTRACT

The momentous case of *Quintavalle* supported the creation of saviour siblings in English law. The House of Lords confirmed that embryos can be selected for social purposes according to the desires of the mother. This article discusses the implications of that decision for the welfare of saviour siblings and argues that harvesting of young saviour siblings is difficult to justify under the current fragmentary law.

I. INTRODUCTION

This work brings together the legal provisions of the Human Fertilisation and Embryology Act 1990 (as amended) ('the 1990 Act') and the doctrine of *parens patriae* to form a complete picture of the law on 'saviour siblings' in the UK (ie the creation and harvesting of children to benefit others).¹ There are two main provisions relevant to creating a child for harvest – a welfare test under section 13(5) the 1990 Act which 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 supportive parenting), and of any other child who may be affected by the birth', and, when the child is born, a best interests test under the inherent jurisdiction. Neither of these tests nor their connection to each other have been examined in this context by the appeal courts. The common law has also provided subtle guidance on the best interests of incompetent donors in *Re Y (Mental Patient: Bone Marrow Donation)*,² but it is unlikely that the emotional, social, and psychological benefit required under that guidance to validate a bone marrow harvest in law would be evident in a very young child.

The first opportunity to determine the law on saviour siblings was presented to the House of Lords in *Quintavalle v Human Fertilisation and Embryology Authority (and Secretary of State for Health)*,³ where the House of Lords accepted that embryos might be selected in vitro fertilization (IVF) procedures for social purposes.⁴ The crux of this work, therefore, lies in the legal consequences of *Quintavalle*. It will be shown that (i) the welfare provision under section 13(5) of the 1990 Act provides

no protection to children created specifically for harvest, and (ii) the doctrine of *par-ens patriae* has developed to merge the interests of the saviour with those of the sick person to create a subjective best interests test to validate the non-therapeutic harvest in law. It will be concluded that the law in its current fragmentary state does not support the harvesting of a child created solely for this purpose.⁵

II. QUINTAVALLE: STATUTORY INTERPRETATION OR THE FIRST AUTHORITY ON EUGENICS?

Pre-implantation Genetic Diagnosis (PGD) has been used in fertility treatment to screen for genetic disorders in embryos since the first live birth in 1990.⁶ HLA Typing (screening for a Human Leukocyte Antigen tissue match) was added to the procedure and in 2001 in Chicago, USA, Adam Nash became the first ever tissue matched sibling to be born as a result of Pre-implantation Tissue Typing (PTT) when his umbilical cord blood cured his sister of the autosomal recessive disorder fanconi anemia.⁷ Mr and Mrs Hashmi in the UK learnt of this breakthrough and asked the Human Fertilisation and Embryology Authority (HFE Authority) to issue a licence for a course of PTT to create a match for their son Zain, who was suffering from beta thalassaemia major.⁸ The HFE Authority announced their decision in a press release in 2001 to license PTT in the UK as long as any embryo created for the purpose of providing cord blood would itself be *at risk from the same disorder*.⁹ This was to ensure that PTT was used in strictly limited circumstances. The interest group Comment on Reproductive Ethics (CORE) sought permission to apply for a judicial review on the grounds that the HFE Authority had acted *ultra vires* the 1990 Act under which the licence could be granted only for 'authorising activities in the course of providing treatment services', and 'treatment services' were defined as being 'medical, surgical or obstetric services provided to the public or a section of the public for the purpose of assisting women to carry children'.¹⁰ CORE argued that the relevant treatment service sought – PTT – was not acceptable under the 1990 Act because it was not to assist a woman to carry a child but to relieve the suffering of a third party. Mr and Mrs Hashmi temporarily stopped treatment in anticipation of the judgment, handed down in *R (on the application of Josephine Quintavalle) on behalf of CORE v Human Fertilisation and Embryology Authority*.¹¹ CORE were initially successful on the grounds that PTT did not assist women to carry children. The HFE Authority was given leave to appeal to the Court of Appeal on the basis that the case raised 'substantial matters of public importance in the interest of the community. . . [and had] an impact on human life'.¹² The Court of Appeal overturned the decision of the High Court on the grounds that PTT was a 'treatment service' for the 'purpose of assisting women to carry children':

Once it is recognised that the concept of 'services for the purpose of assisting women to carry children' extends beyond purely physical problems affecting the viability of the embryo during pregnancy and birth. . . it becomes clear that such services may have regard to prospective parents' and society's concern for others and for the future.¹³

The decision to read PTT as within the definition of 'treatment services' was rather puzzling. Mance LJ concluded that it was a treatment service because Mr and Mrs

Hashmi were not merely ‘indulging’ in preferences but sought to protect the ‘wellbeing of the whole family’,¹⁴ but PTT was more frequently compared to sex selection throughout the judgment and sex selection is a widely accepted social preference.¹⁵

In light of the Court of Appeal decision, the HFE Authority decided to take another look at their PTT policy and announced two changes in 2004:

1. PTT can be offered in cases where the embryo is not at risk from the condition affecting the existing child;
2. Depending on the needs of the existing child, it can be acceptable to offer PTT with a view to harvesting bone marrow.¹⁶

CORE’s application for leave to appeal to the House of Lords was granted in 2005. It was the final opportunity for the appeal courts to read the provisions of the 1990 Act strictly. This would mean holding that the true meaning of ‘treatment service’ was to exclude the creation of embryos for social purposes. The question to be answered was whether the screening of an embryo for a tissue preference was ‘necessary or desirable’ to ensure that it was ‘in a suitable condition’ to be placed in a woman for it to be considered ‘in the course of’ treatment services’. Lord Hoffmann interpreted the word ‘suitable’ as widely as possible:

‘Suitable’ is one of those adjectives which leaves its content to be determined entirely by context...one is concerned to discover whether the scheme and background throw light on the question of whether the concept of suitability includes taking into account the particular wishes and needs of the mother. [The Authority] may consider that allowing the mother to select an embryo on such grounds is undesirable on ethical or other grounds. But the breadth of the concept of suitability is what determines the breadth of the authority’s discretion.¹⁷

It is likely that when the legislation was constructed, it was intended that ‘healthy’ embryos should be implanted into the mother. However, with no guarantee that every embryo would be free from defect, the word ‘suitable’ was probably considered a more appropriate alternative. Lord Hoffmann however took ‘suitable’ to mean ‘personal preference’ in a much wider interpretation, pointing out that allowing the mother choice had not been specifically prohibited:

There was no proposal to include in the ‘clearly prohibited’ list the testing of embryos to enable the mother to choose to carry a child with *characteristics of her choice*.¹⁸

This short statement endorsed the social selection of embryos in the UK. Lord Hoffmann also added that if an embryo was ‘suitable’ to the mother, it met the statutory requirements of ‘necessary’ and ‘desirable’ too:

Thus, if the concept of suitability is broad enough to include suitability for the purposes of the particular mother, it seems to me clear enough that the activity

of determining the genetic characteristics of the embryo by way of PGD or HLA typing would be 'in the course of' providing the mother with IVF services and that the authority would be entitled to take the view that it was necessary or desirable for the purpose of providing such services.¹⁹

Lord Hoffmann made no reference to the need, when providing treatment services, to take account of the 'welfare of any child who may be born as a result of the treatment' (section 13(5)) but instead referred to the judicial protection offered to the child *after* its birth, saying that he had

no doubt that medical practitioners take very seriously the law that any operation upon a child for which there is no clinical reason relating to the child itself must be justified as being for other reasons in the child's best interests. If the question appears to be doubtful, a ruling from the court may be obtained. The authority is in my opinion entitled to assume that a child conceived pursuant to its licence will, after birth, receive the full protection of the law.²⁰

Lord Brown, in support, confused the issue somewhat when he later admitted that the line between 'serious defects' and 'selective criteria' was not clear:

I was at one time attracted to [the] dividing line between selection aimed purely at eliminating serious genetic or chromosome defects (permissible) and other selective criteria (impermissible). As, however, Lord Hoffmann points out, what amounts to a serious genetic defect will itself often be contentious. Still less can one find in the statutory language any basis for saying that the elimination of serious genetic or chromosome defects contributes to the process of 'assisting women to carry children' whereas other embryo selection does not.²¹

It is agreed that some genetic conditions are not as debilitating as others (eg hereditary hair loss versus severe muscular dystrophy), but there is a very clear line to be drawn between genetic conditions and *preferred characteristics* (eg a tissue match to a sibling). Lord Brown rounded up the appeal judgment with a statement about suitability, stating that it was 'for the woman' to decide what was suitable.²² There is no sign within the relevant provisions of the 1990 Act that suitability is subjective, but if it is (or it became so after this appeal), this is clear confirmation that embryos can be selected for social reasons. Paradoxically, he then finished by stating that genetic selection for 'purely social purposes' would be eradicated by the courts should it ever become an issue:

Whereas, however, suitability is for the woman, the limits of permissible embryo selection are for the authority. In the unlikely event that the authority were to propose licensing genetic selection for purely social purposes, Parliament would surely act at once to remove that possibility. . . failing that, in an extreme case the courts supervisory jurisdiction could be invoked.²³

The only way the courts could now eradicate the genetic selection of embryos for 'purely social purposes' would be to overturn their own judgment.

The influence of *Quintavalle* can be seen in subsequent legal developments. Parliament has now inserted tissue typing for the purposes of saving a sibling into the Human Fertilisation and Embryology Act 1990 in the amending 2008 Act:²⁴

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

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

(d) in a case where a person ('the sibling') who is the child of the persons whose gametes are used to bring about the creation of the embryo (or of either of those persons) suffers from a serious medical condition which could be treated by umbilical cord blood stem cells, bone marrow or other tissue of any resulting child, establishing whether the tissue of any resulting child would be compatible with that of the sibling.

It is highly unlikely that the legitimacy of tissue typing will ever be questioned now that it has been placed on a statutory footing. *Quintavalle* was one of the first legal cases in the developed world to rule on the use of PGD. There have not been many subsequent developments elsewhere. In the USA for example, PGD (like IVF before it) had no research phase and went straight to clinical treatment. The American Society for Reproductive Medicine has stated: 'PGD should be regarded as an established technique with specific and expanding applications for standard clinical practice'.²⁵ The Fertility Clinic Success Rate and Certification Act 1992 only requires fertility clinics to report annual pregnancy rates (excluding PGD) to the Centres for Disease Control and Prevention.²⁶ There has never been federal funding available for any fertility research that involves the destruction of human embryos. The Food and Drug Administration (FDA) does not require premarket approval for PGD.²⁷ The American Society for Reproductive Medicine (ASRM) has published some non-binding recommendations on PGD (eg *Use of Preimplantation Genetic Diagnosis for Serious Adult Onset Conditions: A Committee Opinion*²⁸), but there are no legally binding laws or regulations in place at a national level.

There has been more progress in Canada. The Assisted Human Reproduction Act was passed in 2004, stating that: 'No person shall knowingly for the purpose of creating a human being, perform any procedure or provide, prescribe or administer anything that would ensure or increase the probability that an embryo will be of a particular sex, or that would identify the sex of an in vitro embryo, except to prevent, diagnose or treat a sex-linked disorder or disease.' Unfortunately, in 2012, the Government of Canada decided to wind down the agency created to implement the Act in response to a 2010 ruling of the Supreme Court of Canada that significantly reduced the federal role in assisted human reproduction.²⁹ The regulation of PGD is now delegated to each Canadian province. Finally, an interesting European development occurred recently in Germany. The Federal Court of Justice of Germany ruled in 2010 that PGD could be used in exceptional circumstances, and in July 2011 the Bundestag passed a law that allows PGD when there is a very strong likelihood that the parents will pass on a genetic disease to their child causing a risk of miscarriage or death.³⁰

III. THE WELFARE OF THE SAVIOUR SIBLING UNDER THE HUMAN FERTILISATION AND EMBRYOLOGY ACT 1990 (AS AMENDED)

A saviour sibling is especially deserving of a welfare provision: section 13(5) of the 1990 Act (set out earlier) is designed to identify serious threats to the embryo before it is created, and there are unique threats to saviour siblings.³¹ Firstly, the 1990 Act authorizes the harvest of cord blood, bone marrow and 'other tissue' from a baby.³² The legality of the procedure is highly questionable when performed with a lack of therapeutic benefit, and the risks include multiple birth and prematurity which are inherent to IVF,³³ prolonged efforts to achieve a vaginal birth to increase the amount or quality of cord blood, rapid umbilical cord clamping and raising the new born above the mother to increase placental blood volume.³⁴ The parents, therefore, in creating and selecting embryos, could be jeopardizing the welfare of their child before the pregnancy has even been established.³⁵ Secondly, the most controversial threat to welfare is that of using the tissue-matched child as a commodity for the benefit of the older sibling.³⁶ The parents may take advantage of the saviour sibling if they seek a second harvest, and this has been compared to slavery.³⁷ Thirdly, the saviour sibling faces a risk of abandonment after harvest if it proves to be unsuccessful (or at the very least could face a lifelong sense of worthlessness if the reason for his creation, selection and birth turned out to be unfounded). The IVF/PGD/PTT process is lengthy and costly and the success rates are estimated to be 31.6 per cent, making it a lot of trouble to go to for a fruitless outcome.³⁸ Fourthly, the lifelong debt over the saviour child causes concern. He may know from an early age of his 'specialness' because of the role he played in saving his sibling, but because his creation was underpinned by the intention to harvest, he may feel that his uniqueness is tied up in the worth of his older sibling. He could never venture too far because of the pressure on him to donate for the rest of his life. There is no telling what psychological effect this could have on a person, and it is agreed by the HFEA in their PTT Policy (2004) that not enough research exists to confirm that the welfare of the child is not affected.³⁹

The threats listed above may theoretically need to be taken into account under the welfare provision in section 13(5), but its workability is questionable. The inherent jurisdiction, for example, is better equipped to protect the (saviour) child after birth. However, the HFE Authority has fleshed out section 13(5) in its Code of Practice and it describes the environment of the child – and any risk of harm likely to occur to the child – *after* its birth:

Paragraph 8.10: The centre should consider factors that are likely to cause a risk of significant harm or neglect to any child who may be born or to any existing child of the family. These factors include:

- a. past or current circumstances that may lead to any child mentioned above experiencing serious physical or psychological harm or neglect,
- b. past or current circumstances that are likely to lead to an inability to care throughout childhood for any child who may be born, or that are already seriously impairing the care of any existing child of the family.⁴⁰

The Code of Practice raises a host of red flags as regards embryos selected for harvest after birth. For example, a bone marrow donation on a baby may constitute 'significant harm' when not done for a therapeutic benefit. Paragraph 8.10(b) also refers to 'current circumstances' leading to an 'inability to care' for any child born. A saviour sibling is typically born into a desperate family who are caring for a dying child. The parents may be unable, as a result of their circumstances, to properly care for the saviour child.⁴¹ As supportive as the Code of Practice appears to be to saviour siblings, it probably gives no legal protection to the child. Any action brought by such a sibling against a service provider for failing to safeguard her welfare by refusing to allow the creation of the embryo is likely to fail as it would be like an action for wrongful life in that it compares an existing child to a non-existent child.⁴² *McKay v Essex Area Health Authority*⁴³ confirmed that there is no duty in law to ensure that a person does not exist, which is what section 13(5) is designed to do. Theoretically, if section 13(5) were to be enforced, the action would be brought by the 'designed' child against the HFE Authority or the service provider for damaging his welfare by creating him for harvest. The damages would be nil because the court in *McKay* refused to compensate for existence:

How can a court begin to evaluate non-existence, the undiscovered country from whose bourn no traveller returns? No comparison is possible and therefore no damage can be established which a court could recognise. This goes to the root of the whole cause of action.⁴⁴

The final nail in the coffin for the section 13(5) welfare provision in the context of the creation of saviour siblings is a statement published by the House of Commons Science and Technology Committee (2005) confirming that section 13(5) is unusable:

With assisted reproduction, the child is only theoretical. At a time at which such assessments are made, there is not even an embryo. Moreover, a wealth of expertise is available to assess and evaluate the needs of an existing child, particularly in light of their own individual vulnerabilities. In reality, this provision is more akin to a 'fitness for parenting' requirement, which was historically used to prevent certain 'undesirable' groups from reproducing and is now widely rejected.⁴⁵

It appears that section 13(5) of the 1990 Act offers no legal protection to saviour siblings.

IV. THE BEST INTERESTS OF THE SAVIOUR SIBLING UNDER THE INHERENT JURISDICTION AND AT COMMON LAW

The saviour sibling, once born, moves into a new area of law. Section 1(1)(d) and (f) of the Human Tissue Act 2004 allows for the *storage* and *use* of bone marrow from a living child. Section 2(3)(c) of the Act also states that a person with parental responsibility can consent for the child if he is not competent to do so. The *removal* of bone marrow from a living child is omitted from the statute. It is governed instead by the common law of consent and the inherent jurisdiction. The courts thus

have an opportunity to explore the best interests of the saviour sibling before the procedure can go ahead. It is useful at this juncture to list the risks faced by a child when presented for harvest. A bone marrow donation requires the hipbone to be punctured one hundred times to remove approximately two cups of marrow. This may be required once or repeatedly depending on the circumstances. The physical risks include pre-harvest screening, anaesthesia (allergy, deprivation of oxygen, brain damage, heart attack and stroke), bone fracture, bone infection, rupture of an artery, skin scarring, hypertension, anaemia, broken needles, blood transfusion, and pain. The psychological risks may also include fear of operations, fear of losing a body part, a feeling of worthlessness, spite, resentment, refusal (if harvested repeatedly), force, manipulation, exploitation, guilt, rejection, and being treated as an insurance policy (See Hunter (1991: 535, 550); Griner (1994); Zinner (2004); Ladd (2004); Holm (2004); Ross and Thistlethwaite (2008); Spital (2004)). The legal question at this juncture is: how do the courts justify a non-therapeutic harvesting procedure on a baby designed specifically for that purpose?

1. The Inherent (Wardship) Jurisdiction⁴⁶

The best interests test has its roots in *parens patriae*, an old jurisdiction allowing the state to act for the benefit of those ‘who are incapable to take care of themselves’⁴⁷ and which is now considered as part of the ‘inherent’ jurisdiction of the court. It was applied to incompetent adults in *Falkland v Bertie*⁴⁸ and *ex parte Grimstone*⁴⁹ before the beginnings of a best interests test were formed in *R v Delaval*.⁵⁰ The first application of *parens patriae* in the form of wardship occurred in *Wellesley v Duke of Beaufort*,⁵¹ in which Lord Eldon in a private custody dispute interpreted the law to offer special protection to children:

[Parens patriae] is founded on the obvious necessity that the law should place somewhere the care of individuals who cannot take care of themselves, particularly in cases where it is clear that some care should be thrown round them.

A century later, the best interests test was routinely used to protect children from non-therapeutic procedures. In *Re D (A Minor) (Wardship: Sterilisation)*,⁵² for example, Heilbron J came to the conclusion that a 10-year old girl should not be deprived of her right to have children simply because she was of low intelligence and substantially handicapped:

The type of operation proposed is one which involves the deprivation of a basic human right, and, therefore, it would be, if performed on a woman for non-therapeutic reasons and without her consent, a violation of such a right. I think this is the very type of case where this court should ‘throw some care around this child’...I have come to the conclusion that this operation is neither medically indicated nor necessary, and that it would not be in D’s best interest for it to be performed.

A few years later, *Re B (A Minor) (Wardship: Medical Treatment)*⁵³ confirmed that the court in exercising its *parens patriae* jurisdiction should put the welfare of the child over the desires of its parents:

Although due weight must be given to the decision of the parents which everybody accepts was an entirely responsible one, the fact of the matter is that this court now has to make the decision. It cannot hide behind the decision of the parents or the decision of the doctors; and in making the decision this court's first and paramount consideration is the welfare of this unhappy little baby.

A special development in the context of therapeutic benefit occurred in *re Eve*, a Canadian case in which an incompetent woman faced sterilization. La Forest J drew a distinction between therapeutic and non-therapeutic treatment and held that a correct application of the *parens patriae* jurisdiction would never validate a non-therapeutic procedure:

The grave intrusion on a person's rights and the certain physical damage that ensues from non-therapeutic sterilisation without consent, when compared to the highly questionable advantages that can result from it, have persuaded me that it can never safely be determined that such a procedure is for the benefit of that person. Accordingly, the procedure should never be authorised for non-therapeutic purposes under the *parens patriae* jurisdiction.⁵⁴

The House of Lords had the chance to test this doctrine two years later in *Re B (A Minor) (Wardship: Sterilisation)*, in which a mentally handicapped teenage girl was facing a sterilization operation. Lord Oliver rejected the semantic definition of 'therapeutic' in *re Eve* and replaced it with a general best interests test:

I do not, for my part, find the distinction between 'therapeutic' and 'non-therapeutic' measures helpful...for it seems to me entirely immaterial whether measures undertaken for the protection against future and foreseeable injury are properly described as 'therapeutic'. The primary and paramount question is only whether they are for the welfare and benefit of this particular young woman...it seems to me to contradict what is the sole and paramount criterion for the exercise of the jurisdiction, viz. the welfare and benefit of the ward.⁵⁵

In *Re J (A Minor) (Wardship: Medical Treatment)*,⁵⁶ Balcombe L.J. described the purpose of wardship in objective terms as being to do what a reasonable parent would do:

In deciding in any given case what is in the best interests of the ward, the court adopts the same attitude as a responsible parent would do in the case of his or her own child; the court, exercising the duties of the Sovereign as *parens patriae* is not expected to adopt any higher or different standard than that which, viewed objectively, a reasonable and responsible parent would do.

This objectivity is to be welcomed in the context of saviour siblings where the decision of a desperate mother to harvest her child may not stand up to scrutiny in comparison to a reasonable parent.

The turn of the 21st century saw the best interests of the child confirmed by the European Court of Human Rights in *Scott v UK*, where a mother unsuccessfully argued that her human right to family life had been breached.⁵⁷ At the same time, *Re J (Specific Orders: Child's Religious Upbringing and Circumcision)*⁵⁸ allowed the High Court to carve out a small group of medical decisions that could not be made without judicial guidance:

There is, in my view, a small group of important decisions made on behalf of a child which, in the absence of agreement of those with parental responsibility, ought not to be carried out. . . without the specific approval of the court.

Re J offers less protection than it appears. There must be a disagreement between the parents before the jurisdiction can be invoked, and it is highly unlikely that a couple who created their child specifically for harvest would argue at the point of consent that it was not in her best interests to undergo the procedure. However, the objectivity of the best interests test was preserved by *Re A (Children) (Conjoined Twins: Surgical Separation)*⁵⁹ in which the parents were overruled despite death being a virtual certainty for one of their twins: 'it may seem unduly harsh on these desperate parents to point out that it is the child's best interests which are paramount, not the parents'. In *An NHS Trust v MB*,⁶⁰ Holman J outlined the modern best interests test for children:

- (x) Where the parents spend a great deal of time with their child, their views may have particular value because they know the patient. . . their own wishes, however understandable in human terms, are wholly irrelevant to consideration of the objective best interests of the child.
- (iv) The matter must be decided by the application of an objective approach or test.
- (v) That test is the best interests of the patient.

Thus a saviour sibling can enjoy the protection of the inherent jurisdiction if it is sought. It is also safe to assume that a benefit must be established for the best interests of the saviour sibling to be made out. It does appear, however, that the phrase 'best interests' has expanded to include many factors. Lady Justice Butler-Sloss stated in *Re MB (Medical Treatment)*⁶¹ that 'best interests are not limited to best medical interests', and in *Re A (Male Sterilisation)*⁶² she also stated: 'in my judgment best interests encompasses medical, emotional and all other welfare issues'.⁶³ Thorpe LJ hinted at a wider test in *Re S (Adult Patient: Sterilisation)*:

In deciding what is best. . . the judge must have regard to. . . welfare as the paramount consideration. That embraces issues far wider than the medical. Indeed it would be undesirable and probably impossible to set bounds to what is relevant to a welfare determination.⁶⁴

This idea was supported by Morgan J in the more recent case of *Re G*⁶⁵ in which he stated:

the word “interests” in the phrase “best interests” is not confined to matters of self-interest or, putting it another way, a court could conclude in an appropriate case that it is in the interests of P for P to act altruistically.

Re G can be distinguished on the grounds that it concerned incompetent adults and the power to make gifts and settlements under the Mental Capacity Act 2005. However, there is academic support for a very wide best interests test. Foster and Herring (2012), for example, believe that determinations of best interests are ‘holistic assessments’ that should include the good life, wellbeing, happiness, virtue, altruism, life goals, interconnectedness, and thriving. It is a workable suggestion, but only if the wider determinations relate to the child at the *centre* of the legal action. It would not be acceptable to consider these characteristics for another person (e.g. a sibling). The law has been settled for decades that the child at the heart of the action takes precedence over other parties, as stated by Lord Morris in *S v M*:⁶⁶

D is a separate party in the issue which is to be tried. Her position and her future are at stake. The interests of the other parties must not be advanced by those other parties so as to prejudice or to dominate over the interests of D.

In practice, therefore, a wider best interests test would probably not make any real difference to the outcome for a child facing a non-therapeutic procedure. It could not absorb the needs of other people into the best interests test. It would simply give the child at the centre of the legal action a wider selection of her *own* needs to be considered (and these should not be speculative).

2. The Common Law on Donations from Incompetent Siblings

In the UK, saviour siblings have not yet been harvested for their *organs* and PTT for this purpose is explicitly outlawed by section 1ZA(4) (schedule 2) of the 1990 Act. However, once the child is born and harvested for its bone marrow (which is allowed under section 1ZA(1)(d) (schedule 2) of the 1990 Act), there is nothing to stop a parent from trying to harvest a kidney or liver lobe should the sick sibling suddenly take an unexpected turn for the worse. It would be up to the court to justify the non-therapeutic procedure and there is plenty of US case law to offer support.⁶⁷ The legality of bone marrow procedures on incompetent patients in the UK was developed in *Re Y (Mental Patient: Bone Marrow Donation)*⁶⁸ in which an adult patient was harvested to save her older sister from pre-leukemic bone marrow disorder myelodysplastic syndrome. Connell J stated the legal problem clearly:

The taking of blood tests and the harvesting of bone marrow from the [patient], who is incapable of giving informed consent, would amount to assaults upon the [patient] and would therefore be illegal unless shown to be in the best interests of the [patient] and therefore lawful.

Legal support for a positive outcome was sparse because *parens patriae* over incompetent adults had seen some surprising developments. Part VII of the Mental Health Act 1959 was originally passed to give courts the necessary powers to deal with the ‘affairs of patients’, and as a result the *parens patriae* jurisdiction in respect of persons of unsound mind was withdrawn. It turned out, however, that the powers under the 1959 Act were limited to legal transactions and other business matters and it was realised in *Re F (Mental Patient: Sterilisation)*⁶⁹ that there was no modern statutory mechanism – or *parens patriae* jurisdiction – to approve a sterilization procedure on an incompetent adult. Nevertheless the House of Lords decided that a defence derived from the common law doctrine of necessity could be invoked for carrying out medical procedures on such persons provided they were performed in the best interests of the patient. Lord Brandon added that ‘the operation or other treatment will be in their best interests if, but only if, it is carried out in order either to save their lives, or to ensure improvement or prevent deterioration in their physical or mental health’.⁷⁰ Lord Goff expressed the test in terms of the patient’s ‘health, welfare and well-being’.

In *Re Y Connell J* broadened this test, approving a non-therapeutic bone marrow transplant on the incompetent patient because it would be for the person’s ‘emotional, psychological and social benefit’.⁷¹ In doing so he turned to the USA for an authority that was similar only in material to be harvested, not in facts or in relationship. In *Curran v Bosze*, a 12-year old boy, Jean Pierre, suffered from mixed lineage leukaemia and his father, Tamas Bosze, sought court permission for his twins with Nancy Curran to be tested for compatibility for a bone marrow transplant. The courts found for Nancy Curran, and Jean Pierre eventually died. However the Supreme Court of Illinois handed down an insightful three-part test for child bone marrow donation: (i) the consenting parent must understand the risks and benefits of the procedure, (ii) there must be emotional support from the person with parental responsibility, and (iii) there must be an existing close relationship between the donor and the sick child:

The psychological benefit is grounded firmly in the fact that the donor and recipient are known to each other as family. Only where there is an existing relationship between a healthy child and his or her ill sister or brother may a psychological benefit to the child from donating bone marrow to a sibling realistically be found to exist.⁷²

Connell J gave particular weight to the ‘close relationship’ criteria in *Curran v Bosze* and his final decision in *Re Y* was to order the harvest. However, the decision is out of step with *Curran v Bosze* in two ways. Firstly, despite the decision to the contrary, it is open to question whether the patient in *Re Y* could derive a clear psychological benefit from the procedure. She was so physically and mentally handicapped that according to Connell J she barely knew what was going on:

She is severely mentally and physically handicapped. . . it was apparent that [she] did not understand what was being said to her. Likewise, she did not understand what was being said when told that her older sister is very unwell.

The [patient] understands her own basic needs but cannot understand the needs of others.⁷³

It is highly unlikely that an incompetent patient (including a saviour sibling) could experience any kind of benefit from making a bone marrow donation – or form a meaningful relationship with the donee – if they are unaware of the world around them. Secondly, the plight of the mother in *Re Y* should not have underpinned the decision to harvest. Connell J paid excessive regard to the needs of the family rather than the donor:

[The patient's] most regular visitor and the family member with whom she has the closest relationship is undoubtedly her mother. More recently, the mother has had a coronary bypass operation and at the present time she suffers from angina and gets tired very easily. It is clear that her health is precarious and her condition is significantly exacerbated by her anxieties concerning the health of the [sick sister]. If the plaintiff dies, this is bound to have an adverse effect upon her mother who already suffers from significant ill-health. One lay witness took the view that this event would prove fatal to the mother.⁷⁴

It is unusual for the court to prevent, delay or cure a natural death by validating an invasive procedure on an incompetent relative.⁷⁵ The literature, however, has supported Connell J:

The donation can have an instrumental value to the donor: in donating, the donor may save the life of a sibling and will therefore have a sibling to grow up with and to share a life with, each of which brings with it certain identifiable social and emotional benefits to the donor.⁷⁶

This view was also expressed in the PTT Report (2004) by the HFEA:

If a medical procedure, such as a bone marrow transplant, would save the life of a sibling, it is likely to be in the best interests of the child, since to lose a sibling is psychologically damaging.⁷⁷

Re Y is about kidneys and adults, but it is highly vulnerable – as the only saviour sibling authority – to being drawn upon and applied to a child donor when the first wardship case comes along. There has been significant support for an 'interfamilial' approach in the literature, whereby the best interests of the donor are combined with the interests of the donee and the family.⁷⁸ The HFE Authority referred to an 'intensity' in family relationships after a bone marrow donation in their PTT Report (2004),⁷⁹ although one writer prefers to override the child donor completely:

Although a child who is asked to serve as a donor may dissent because he fears the physical pain, the parents must have the power to override his narrow self-interest for the wellbeing of his sibling and the family as a whole.⁸⁰

These views, however, are not consistent with the doctrine of *parens patriae*. Under the inherent jurisdiction the best interests of the child must take priority – this is

fundamental to the legality of the procedure. The concerns of relatives are sometimes heeded, but their interests should not be merged with those of the child.⁸¹ It is accepted that there should be a balancing act between the benefits and the burdens of the procedure, but the plight of the sick sibling should not be included in the scales, nor should the relevant factors be shared out between the child and her family. The sick sibling will always have an unfair advantage over the donor in that her terminal prognosis will outweigh the discomfort of a bone marrow harvest every time.⁸² Connell J was forced to expand the best interests test in *Re Y* to include family members because he could not find a substantial benefit to the incompetent patient, but by doing this he set the stage for a *subjective* best interests test.

Re Y paved the way for incompetent donors to be harvested for their bone marrow as long as an 'emotional, psychological and social benefit' could be found, but its perhaps inevitable application to engineered saviour siblings (ie embryos selected specifically with a view to harvest) poses two specific problems. Firstly, there cannot possibly be an emotional, psychological, or social benefit in a bone marrow/organ donation if the donor is a baby. The courts would need to find a *future* benefit to the baby to justify the procedure using a unique test of altruistic foresight, but this is not an acceptable way to justify a non-therapeutic procedure in law.⁸³ Secondly, there is no proximity between the relevant parties if the baby is newly born. The harvest in *Re Y* relied on the close relationship between the patient and her mother, but a baby does not have time to form a palpable relationship with anyone.⁸⁴ This was the crux of the refusal in *Curran v Bosze*, in which the Supreme Court of Illinois decided that the 3½-year old twins did not recognize or treat Jean Pierre as 'family' compared to previous cases.⁸⁵ The parents of the saviour baby may have to wait until a relationship developed between the siblings (or at least with the saviour and the mother) for any harvest to go ahead. It is not clear whether the HFE Authority warns parents who are seeking to create a saviour sibling about these delays that the common law might require, but it could lead to disaster for a desperate family.

3. The current regulations by the Human Tissue Authority

The Human Tissue Authority (HTA) has published a Code of Practice on bone marrow donations from children. The court is only required to validate the harvest if there is disagreement as to the best interests of the child:

Paragraph 33: In cases where a child is not competent to consent to donation themselves and there is a dispute between those with parental responsibility, or between them and the clinicians looking after the child, or there is a doubt as to best interests of the child, the court should be asked to rule in advance. The court ruling should be in place before referral to the HTA.⁸⁶

Paragraph A10: If the court is asked to consider the matter, the welfare of the prospective donor child will be the court's paramount consideration and not the welfare of the recipient. The 'welfare checklist' which is set out in the Children Act 1989 will be considered by the court in determining the application.⁸⁷

The courts are therefore not required to validate a bone marrow procedure unless wardship is invoked (this has not happened in a high-profile case yet). It will be up to the HTA to decide whether the harvest should go ahead and to offer any protection from harm. A decision can be made on the child's behalf by a person with parental responsibility.⁸⁸ The clinician responsible for the donor must make a written referral to an Accredited Assessor (AA), who then conducts interviews with the donor, the person acting on the donor's behalf, and the recipient. The AA must state whether they are satisfied that the relevant parts of the 2004 Act have been met along with a recommendation to proceed or reject. A report is then submitted to the HTA for a final decision.⁸⁹ HTA statistics show the following:⁹⁰

Year	Child bone marrow/blood stem cell cases approved ⁹¹	Cases rejected
2007–2008	71	0
2008–2009	57	0
2009–2010	78	0
2010–2011	67	0
2011–2012	68	0
2012–2013	69	0
2013 (until December)	57	0

The decision in *Re Y* has appeared to have influenced the Code of Practice in regards to the legality of bone marrow donation:

Paragraph 78: A person with parental responsibility can consent to storage and use of bone marrow for transplantation on behalf of the child, if the donation is assessed as being in the child's overall best interests, taking into account not only the medical but also emotional, psychological and social aspects of the donation, as well as the risks.⁹²

The phrase 'overall best interests' in the HTA Code of Practice is a clear insertion of the decision in *Re Y* and it may allow for a 'future familial benefit' to be added to the scales, but it may not correlate with the paramountcy principle when a court is deliberating the welfare of the saviour child under the inherent jurisdiction. The HTA have no other way to validate a bone marrow procedure on a very young child except to interpret the best interests test in this way.⁹³

V. CONCLUSION

The conclusion, having brought together the decisions in *Quintavalle* and *Re Y* and the relevant provisions of the 1990 Act (as amended), is that the saviour child is afforded only uncertain protection in the current fragmentary law. Section 13(5) of the 1990 Act offers no protection to saviour siblings. The last source of protection for the saviour sibling, therefore, was the best interests test under the inherent jurisdiction. It is disappointing to see the objective root of wardship, as described in *Wellesley v Duke of Beaufort* as 'not to risk the incurring of damage to children which [the court] cannot repair [and] to prevent the damage being done' become eroded

to include speculative matters.⁹⁴ A strict interpretation of *parens patriae* is to do no harm to the child, and the High Court is still free to exercise its jurisdiction to demand that *only* a therapeutic benefit will suffice to validate a medical procedure in law. This would be supportive of siblings created for harvest. *Curran and Bosze* clearly stated that there should be a positive relationship between the saviour and the sibling (this is crucial when no other benefit is in existence) but this idea was strained in *Re Y* to include the interests of third parties in a balancing act of benefits and burdens, meaning that the saviour sibling cannot escape the fate of her sick sibling because their interests are meshed together.⁹⁵

It is concluded that the best interests test as expressed in *Re Y* cannot be applied to saviour siblings. It is questionable whether it can even be applied to donors of any age because of its speculation as to the benefits to be gained and the merging of interests with other parties. Are the HFEA, therefore, in allowing the creation of saviour siblings, unfairly setting parents up for disappointment? Just because a saviour sibling can be created in law does not mean that they can be *harvested* in law. Saviour siblings are particularly vulnerable to bad decisions by distressed parents. They need *more* protection, not less.

NOTES

- 1 The term 'saviour sibling' refers to a child who is harvested to save its brother or sister from a debilitating disease. It saviour sibling may, therefore, be born naturally and found to be a match later, or created specifically for harvest under the Human Fertilisation and Embryology Act 1990 (as amended).
- 2 [1997] Fam. 110.
- 3 [2005] 2 A.C. 561.
- 4 'Social purposes' is a reference to the HLA Tissue Typing of embryos for non-medical purposes, such as a tissue match to an existing sibling.
- 5 This piece intends to focus specifically on the law, but for an Australian-based perspective on the welfare of the saviour sibling, including feminist and communist ethics, see [Taylor-Sands \(2013\)](#).
- 6 The sex of the embryo was used to determine a predisposition to certain genetic diseases. The first successful project was published in [Handyside et al \(1992\)](#).
- 7 Cord blood transplantation was first introduced as a treatment to help this disorder, and bone marrow transplantation is the only treatment that definitively restores haematopoiesis. The successful project was headed by Yury Verlinsky at the Reproductive Genetics Institute in Chicago. The successful project was published in [Verlinsky et al \(2001\)](#).
- 8 Zain was the fourth of five children. He required a daily cocktail of drugs and regular blood transfusions with no clear life expectancy, and a stem cell transplant from an umbilical cord or bone marrow was his only chance of a cure.
- 9 The 2001 policy can be found in [Human Fertilisation and Embryology Authority \(2004\)](#).
- 10 Human Fertilisation and Embryology Act 1990, ss 2(1) and 11(1).
- 11 [2002] EWHC 2785, per Maurice Kay J.
- 12 At paras 7 and 20.
- 13 *R (on the application of Quintavalle) v Secretary of State for Health* [2003] EWCA Civ 667, per Mance LJ, at para 142.
- 14 At paras 134 and 135.
- 15 PTT was likened to sex selection at paras 27, 124, 135, 140, and 143.
- 16 Human Fertilisation and Embryology Authority (2004: para 37).
- 17 *R (Quintavalle) v Human Fertilisation Embryology Authority (and Secretary of State for Health)* [2005] 2 A.C. 561, at para 14.
- 18 Emphasis added, at para 22.
- 19 At para 24.
- 20 At para 38.
- 21 At para 61.

- 22 At para 62.
- 23 At para 62.
- 24 Human Fertilisation and Embryology Act 2008.
- 25 See Genetics and Public Policy Centre at Johns Hopkins University, Reproductive Genetic Testing: A Regulatory Patchwork, at: http://www.dnapolicy.org/policy.international.php?action=detail&laws_id=63&print=1 (accessed 28 October 2014).
- 26 See the official website: www.cdc.gov (accessed 28 October 2014).
- 27 Congress has imposed a ban on federal funding for research on human embryos since 1996: H.R. 3610, 104th Cong. (1996).
- 28 This recommendation was posted by the Ethics Committee of the American Society for Reproductive Medicine on the 7 March 2013 and suggested that PGD to eliminate serious and 'lesser severity' conditions was ethically acceptable: <http://www.asrm.org/EthicsReports/> (accessed 28 October 2014).
- 29 *Re Assisted Human Reproduction Act 2010* [2010] 3 SCR 457.
- 30 See http://www.bionews.org.uk/page_101402.asp (accessed 12 November 2014).
- 31 The general law of welfare is too broad to be discussed in this article – it will be examined in the strictly narrow context of section 13 of the 1990 Act and how it might apply to a saviour sibling.
- 32 Under schedule 2, para 1ZA(1)(d) of the HFEA 1990.
- 33 One in five IVF pregnancies lead to multiple births compared to one in 80 natural pregnancies (see: <http://www.hfea.gov.uk/Multiple-births-after-IVF.html>, current as of 28 October 2014). This particular risk led the HFEA to introduce the Elective Single Embryo Transfer policy (eSET) in 2009, where only one embryo is transferred into a woman. However, the policy is only applied to women who have a high chance of conceiving, and many women who seek fertility treatment may be struggling to conceive.
- 34 See Wolf et al (2003).
- 35 A view shared by McDougall (2005) and Baruch (2008) *Policy*. Susan Wolf goes further and suggests that, on evidence that the prospective parents would exploit the donor child, the parents should be disqualified from PGD: Wolf et al (2003).
- 36 The 'commodity' argument is denied in the bulk of the literature on various grounds, but none focus on the welfare of the donor child (they prefer instead to look at family welfare as a whole). See Robertson et al (2002); Sheldon and Wilkinson (2004); Bellamy (2005).
- 37 For a slavery and spare parts reference see Devolder (2005) and for a unique reference to cloning, see King (1999).
- 38 Statistics updated frequently on the HFEA website: <http://www.hfea.gov.uk/preimplantation-genetic-diagnosis.html#7> (accessed 28 October 2014).
- 39 Human Fertilisation and Embryology Authority (2004: paras 5, 8, 9, 14, 16, and 17). See also: Jecker (1990).
- 40 Human Fertilisation and Embryology Act, Code of Practice, HFEA, 8th Edition, October 2013, www.hfea.gov.uk (accessed 28 October 2014).
- 41 Especially if he turns out not to be a tissue match after all.
- 42 This problem was first discussed by Parfit (1984) and developed in the context of the HFEA 1990 by Harris (2000); Gavaghan (2000) and Boyle and Savulescu (2001).
- 43 [1982] Q.B. 1166.
- 44 Per Ackner LJ at 1189. See also Stephenson LJ at 1181 and Griffiths LJ at 1192: 'to my mind, the most compelling reason to reject this cause of action is the intolerable and insoluble problem it would create in the assessment of damage'.
- 45 House of Commons, Science and Technology Committee, Human Reproductive Technologies and the Law, Fifth Report of Session 2004-05. Volume 1, 14 March 2005, para 93: <http://www.publications.parliament.uk/pa/cm200405/cmselect/cmsctech/cmsctech.htm> (accessed 28 October 2014).
- 46 Wardship is not used very often but it has been hugely valuable in medical cases where the parents have substituted the best interests of their child for their own. The following trail of cases demonstrates very clearly how the courts have calculated the best interests of the child in these kinds of cases.
- 47 *Eyre v Shaftesbury* 2 P. Wms. 102 24 Eng. Rep. 659 (1722), at page 664. *Parens patriae* (translating to 'parent of the State') has its origins in *De Praerogativa Regis* 17 Edw. 2, cs 9, 10 (1324), in which the Crown delegated its duty to guard infants, idiots and lunatics and their property to the Chancellor.
- 48 (1696) 23 Eng. Rep. 814.
- 49 (1722) 27 Eng. Rep. 458. *Grimstone* contained one of the first references to benefit where the court said: 'in the management of the lunatics estate, the ruling principle is, do what is for the benefit of the lunatic'.

- 50 (1763) 97 Eng. Rep. 913. Lord Mansfield stated: '[the courts are] to judge upon the circumstances of the particular case and to give their directions accordingly' (at 914). This was approved in the subsequent *Blissets Case*, (1774) 98 Eng. Rep. 899 and later in *ex parte Skinner* (1824) 9 Moore C.P. 278.
- 51 (1827) 2 Russ. 1, at 20.
- 52 [1976] 2 W.L.R. 279, at 193, 194, and 196.
- 53 [1981] 1 W.L.R. 1421, per Dunn L.J., at 1424. This decision to override the parents was echoed in *Re J (A Minor) (Wardship: Medical Treatment)* [1991] Fam. 33 in which Lord Donaldson M.R. stated: 'the court when exercising the *parens patriae* jurisdiction takes over the rights and duties of the parents, although this is not to say that the parents will be excluded from the decision-making process. Nevertheless in the end the responsibility for the decision whether to give or to withhold consent is that of the court alone' (at 41).
- 54 (1986) 31 D.L.R. (4th) 1, Supreme Court of Canada, per La Forest J, at 32.
- 55 [1988] A.C. 199, at 211-2. See also Lord Bridge at 205.
- 56 [1991] Fam. 33, per Balcombe L.J., at 50. This was confirmed as the correct approach in *Re Z (Identification: Restrictions on Publication)* [1997] Fam. 1 by Sir Thomas Bingham MR: 'I would for my part accept without reservation that the decision of a devoted and responsible parent should be treated with respect. It should certainly not be disregarded or lightly set aside. But the role of the court is to exercise an independent and objective judgment' (at 32).
- 57 [2000] 1 F.R. 958, per President Mr J P Costa: 'consideration of what is in the best interests of the child is always of crucial importance' (at para 94).
- 58 [2000] 1 F.L.R. 571, per Dame Elizabeth Butler-Sloss, at paras 31-32.
- 59 [2001] Fam. 147, per Ward L.J. at 195. This case turned on its facts: if the wishes of the parents had been respected, both twins would have died.
- 60 [2006] EWHC 507 (Fam.), at para 16.
- 61 [1997] 2 F.L.R. 426.
- 62 [2000] 1 F.L.R. 549.
- 63 At 439 and 555 respectively.
- 64 [2001] Fam. 15, at 30.
- 65 [2010] EWHC 3005, at para 35.
- 66 [1972] A.C. 24 at 53.
- 67 The most prolific kidney donation cases involving child siblings and incompetent patients include: *Masden v Harrison* Eq. no. 68651, Mass. (1957 June 12), *Strunk v Strunk* 445 S. W. 2d 145, Ky (1969), *Hart v Brown* 289 A. 2d 386, Conn. (1972) and *Little v Little* 576 S. W. 2d 493, Tex. (1979).
- 68 [1997] Fam. 110, at 113. He also confirmed that bone marrow donation was inside the 'special category of cases' (at 117), meaning that court approval would have to be sought for incompetent adult donors.
- 69 [1990] 2 A.C. 1.
- 70 At 55. Lord Griffiths derived support from *Bolam v Friern Hospital Management Committee* [1957] 1 W.L.R. 582 to establish an acceptable standard for the test (at 69).
- 71 [1997] Fam 110 at 116.
- 72 (1990) 566 N.E.2d 1319, per Calvo J at 1343-4.
- 73 Per Connell J at 112.
- 74 At 112, 113 and 115.
- 75 The conjoined twins case of Mary and Jodie did so, but it turned on its facts by using the defence of necessity to justify harm to one for the benefit of the other: *Re A (Children) (Conjoined Twins)* [2000] 4 All ER 961.
- 76 Crouch and Elliott (1999: 282).
- 77 Human Fertilisation and Embryology Authority (2004: para 25).
- 78 The 'interfamilial principle' and the 'intimate attachment principle' are discussed in detail in Jansen (2004).
- 79 Human Fertilisation and Embryology Authority (2004: para 15).
- 80 Ross (1993: 254).
- 81 The Mental Capacity Act 2005 confirms that relatives can be consulted about the patient's past and present wishes, feelings, beliefs, and values under section 4(6), and the relatives can also forward their own views as carers or attorney's under section 4(7), but this is merely to help the doctor to make his own decision about the best interests of the patient (and this is only in relation to adults).

- 82 This inequality was evidenced in the US kidney donation case of *Strunk v Strunk* 445 S. W. 2d 145 Ky. (1969) where the court concluded: '[the incompetent donor's] wellbeing would be jeopardised more severely by the loss of his brother than by the removal of a kidney' (at 146).
- 83 Even in *Re Y* the benefit to the incompetent patient was immediate in the form of continued visits from her mother.
- 84 It is highly unlikely that the connection to the mother through birth or breastfeeding would justify a harvesting procedure for the benefit of a third party.
- 85 *Little v Little* 576 S. W. 2d 493 Tex. (1979) at 498: 'existence of a close relationship between Anne and Stephen, a genuine concern by each for the welfare of the other' and 'awareness by Anne of the nature of Stephen's plight and an awareness of the fact that she is in a position to ameliorate Stephen's burden'; *Hart v Brown* 289 A. 2d 386, Conn. Super Ct. (1972) at 389: 'strong identification with her twin sister' and 'it would be a very great loss to the donor if the donee were to die from her illness'; *Strunk v Strunk* 445 S. W. 2d 145 Ky. (1969) at 147: 'he identifies with his brother'. For further discussion on the influence of the US case law, see: Robbenolt et al (1994: 231).
- 86 Code of Practice 6: Donation of Allogeneic Bone Marrow and Peripheral Blood Stem Cells for Transplantation. (2009). Human Tissue Authority. www.hta.gov.uk (accessed 28 October 2014). This guidance is derived from Lady Justice Elizabeth Butler-Sloss in *Re J (Specific Orders: Child's Religious Upbringing and Circumcision)* [2000] 1 FLR 571, at paras 31–32. It is also confirmed under paragraph 50 of the Code that court approval must be sought for incompetent adults before the case is referred to the HTA. It is not explained why children do not need mandatory court validation for the same procedure – perhaps the parents are trusted to put the best interests of the saviour sibling first?
- 87 Appendix A, see n. 86 above. This is a reference to wardship, although it has not yet been used. A representative from CAFCASS (the Children and Family Court Advisory and Support Service) will be assigned to the ward (para A13), but there is a concern that the representative will relate more to the plight of the parents than to the plight of the child if she is a parent herself.
- 88 At para 61. The consent of only one parent is required, under para 78.
- 89 The process is described in greater detail under paras 51, 56, and 57.
- 90 These statistics were requested from the Human Tissue Authority under the Data Protection Act and were delivered via email in February 2014.
- 91 It is not clear how many of these donations came specifically from HLA matched saviour siblings under the 1990 Act.
- 92 Code of Practice 6, n 86 above.
- 93 When it comes to organ donation the court is the only option, and the only authority they have to draw on is *Re Y*.
- 94 (1827) 2 Russ. 1, per Lord Eldon at page 18. Speculative matters include undefined future harm and the grievances of relatives.
- 95 It is probably even more accurate to say that it is the best interests of the *parents* that are trumping everybody else's.

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