Saviour siblings: the role of the welfare principle within the law of assisted reproductive technology in England and Wales (Part 1)

Madeleine Whelan, *Fourteen*

Madeleine Whelan is a barrister at Fourteen, specialising in all areas of family law with a particularly keen interest in children law. Maddie also acts as a member of the Legal Reference Panel for the Centre for Women's Justice and is a governor at a North London primary school. Maddie is passionate about children's rights and the accessibility of justice.

A saviour sibling is a child who is born to provide an organ or cell transplant to a sibling who is affected by a (usually) life-threatening disease. These children can be conceived naturally, but sometimes parents will choose to use certain forms of reproductive technology in order to conceive a child (known as 'the resulting child') who can help or even cure the ill sibling ('the existing child'). The law and the language surrounding this area are complicated and technical, but the area focussed on here is that of assisted reproductive technology, known as ART. In the case of saviour siblings, the technology used is a process called pre-implantation genetic diagnosis ('PGD'), which allows parents to screen embryos for a match to the existing child's needs; since using donors or tissue typing from a sibling increases the chances of a successful transplantation procedure[1] and therefore a disease-free future for the existing child. The law on this area has a stormy history in the UK and whilst it was clarified somewhat in the 2008 amendments to the Human Fertilisation and Embryology Act 1990[2], the legal and ethical objections to this legislation still exist, particularly those regarding the appropriate welfare considerations for the resulting child, and therefore must be examined with a nuance that the legislation failed to provide.

Before the 2008 amendments contained in para 1ZA of the Human Fertilisation and Embryology Act 1990, parents who wished to access PGD in order to create a saviour sibling for an existing child had to apply, on an individual basis, to the Human Fertilisation and Embryology Authority ('HFEA') for a licence to use PGD to 'determine the suitability of an embryo'[3]. No guidance or principles were given as to what exactly 'suitable' in this context meant, and the arbitrariness of the HFEA deciding every individual claim on its own facts was clear. These concerns were most publicly brought to the fore in the early 2000s with the cases of Zain Hashmi and Charlie Whitaker. Zain was born with the genetic condition beta thalassaemia, which has an impact on the body's ability to produce red blood cells, calling for frequent and life-altering blood transfusions. The Hashmis therefore wished to create a sibling for Zain who would be both (i) free from the genetic disease and (ii) a suitable tissue donor for Zain. The clinic treating the Hashmis applied for a licence from the

---

[1] C Anasetti, 'What are the most important factors donor and recipient factors affecting the outcome of related and unrelated allogeneic transplantations?' *Best Practice and Research Clinical Haematology* 691, 694–5

[2] HFEA 1990 as amended, Sch 2, para 1ZA

[3] HFEA 1990 as amended, Sch 2, para 1

HFEA under the 1990 Act[4] for permission to use PGD to screen their created embryos for these two qualities, and permission was granted by the Authority[5], who claimed:

> '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'[6]

It was against this backdrop that the Whitaker family made a similar application for their son, Charlie, who was suffering from Blackfan Diamond Anaemia, a disease which also required the administration of regular blood transfusions. However, the difference between the Whitakers and the Hashmis was that Charlie's condition was not genetic; the chances of the Whitakers' next child having it were no more than the risk to the general population as the disease occurs sporadically rather than genetically[7]. This meant that the Whitakers intended to use the PGD process solely to identify if the resulting child would be a donor, rather than to screen the child for the presence of the disease and because of this, their application was rejected due to lack of tangible benefit to the resulting child[8]. in other words, only Charlie would benefit, rather than both children. This makes it clear that the HFE Authority were deciding claims based on the welfare of the resulting child and thus, required some benefit to that child in order to allow access to this technology. This approach by the HFEA was heavily criticised, with Sheldon and Wilkinson calling the distinction between the Hashmis and the Whitakers 'deeply implausible' and 'unconvincing'[9]. However, the argument about benefit to the resulting child is linked to several other legal and ethical objections to the creation of saviour siblings and selective reproductive technology ('SRT') more generally. The notion of creating one child to save another can raise complicated questions about the potential commodification of human life and the need to protect those in a vulnerable position who could be exploited via wider application of these laws.

However, there are those who argue that within the context of saviour siblings, the regulations in place mean we are able control these potential issues about commodification and welfare whilst allowing use of this technology for the benefit of others (namely, sick siblings). Taylor-Sands emphasises,

> '. . . whilst saviour sibling selection represents a controversial shift in focus from the health of the child to be born to the health of the existing child, the shift does not take us very far down the slippery slope of 'designer babies'. Parents seeking a saviour sibling for an ill child are simply acting on basic parental instincts to care for their children and preserve life'[10].

This does appear to be the approach the UK was attempting to take with the introduction of para 1ZA to the 1990 Act. This paragraph, introduced by the Human Fertilisation and Embryology Act 2008 as an amendment to the 1990 Act, lists the five scenarios in which embryo testing (PGD) will be permitted, including the creation of saviour siblings in para 1(d):

> 1ZA (1) A licence under paragraph 1 cannot authorise the testing of an embryo, except for one or more of the following purposes—
>
> …

---

[4] ibid

[5] http://news.bbc.co.uk/1/hi/health/1836523.stm

[6] Human Fertilisation and Embryology Authority, HFEA to allow tissue typing in conjunction with preimplantation genetic diagnosis (2001) http://www.hfea.gov.uk/961.html, accessed 29 March 2016.

[7] http://diamondblackfan.org.uk/what-is-dba/

[8] Sheldon and Wilkinson, 'Saviour Siblings': Hashmi and Whitaker. An unjustifiable and misguided decision, *Med. L. Rev.* 2004, 12(2), 137–163, 138

[9] Sheldon and Wilkinson, 'Saviour Siblings': Hashmi and Whitaker. An unjustifiable and misguided decision, *Med. L. Rev.* 2004, 12(2), 137–163

[10] ibid. p 10

> (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.
>
> (4) In sub-paragraph (1)(d) the reference to 'other tissue' of the resulting child does not include a reference to any whole organ of the child.[11]

Therefore, we can see that UK law has now departed from its approach in the Whitaker case and allows the use of PGD to create a saviour when the existing child has a serious medical condition, even where the purpose of the PGD is solely to screen for tissue type, rather than the presence of a genetic disease. The other scenarios where PGD is permitted under para 1ZA all make reference to establishing either (i) the presence of a serious disease, or (ii) the sex where there is a risk of a gender-related serious illness or abnormality. Outside these, the use of embryo testing is strictly prohibited even with an HFEA licence. This shows the English legislation is attempting to prevent potential issues around 'designer babies' and eugenics arising, whilst also allowing the use of the technology in limited, life-threatening situations. Furthermore, it can be seen from para (4) (in the quote above) that the UK does not allow the creation of saviour siblings for use as organ donors, but solely as tissue type or blood donors, in order to prevent concerns about 'organ-farming' amongst families.

This approach is laudable and does appear to address the objections raised about this technology, for example, the Act makes very clear that 'a licence under paragraph 1 cannot authorise any practice designed to secure that any resulting child will be of one sex rather than the other'[12], which categorically disallows the use of PGD to choose non-medically desirable characteristics, thus avoiding the eugenics argument. However, some may argue that this legislation closes the door on the possibility of discretion in the area of assisted reproduction and thus fails to address the more nuanced legal and ethical issues. These include, for example: the welfare of the resulting child and the welfare of the existing child respectively, potential commodification of human life, and state paternalism. It is an established principle in children and family law that children should be protected from harm; but it is clear that in allowing the use of PGD in the way the English legislation does, there is a prioritisation of the interests of the existing child against the welfare of the resulting child. Such an approach is controversial and thus requires an examination of the potential harm involved and whether the approach taken by this legislation is justifiable. England and Wales now operates a harm-based approach to the welfare of the child, so that under English law 'there is a presumption to provide treatment unless there is evidence that any child born to an individual or couple, or any existing child of their family, would face a risk of serious harm'[13]. Clinics providing PGD are to refuse to provide it where a risk of serious harm or neglect exists, and this risk must be strong enough to rebut the presumption in favour of the treatment. It is therefore necessary to examine the potential objections to such an open approach.

Harm and the potential risks of ART

The use of assisted reproductive technology has increased enormously over the last decade. In the field of saviour siblings this mainly involves the use of PGD together with human leucocyte antigen ('HLA') typing in order to identify the donor. The idea of using these technologies to deliberately create a saviour sibling tends to elicit comments such as 'it is totally

---

[11] http://www.legislation.gov.uk/ukpga/2008/22/schedule/2

[12] HFEA 1990, Para 1ZB(1)

[13] HFEA, Tomorrow's Children: Report of the Policy Review of Welfare of the Child Assessments in Licensed Assisted Conception Clinics (Jan 2005), 1

unethical. You are not creating a child for itself'[14] and 'the trouble really is that this child as it grows up has been brought into the world because it is a commodity'[15]. These comments highlight some of the main concerns surrounding the use of PGD to select saviour siblings, namely that it will have a detrimental impact on the resulting child if they become aware of their original 'purpose' in being created and secondly, that it creates some form of reproductive commodification, which devalues human integrity. These concerns surrounding the welfare and possible commodification of children will be discussed later, but perhaps the most pressing question in light of the UK's position is whether there may be any physical or health risks to the children born as a result of this technology. The entire process of creating a saviour sibling means that once the child has been selected using PGD to identify its suitability as a donor, the embryo is then implanted using in vitro fertilisation ('IVF') of the same type used for couples who might be infertile or unable to conceive naturally.

This means that all the usual risks of ART/IVF will be associated with creating saviour siblings and, according to the American College of Obstetricians and Gynaecologists, 'the single most important health effect of ART for the offspring remains iatrogenic multiple foetal pregnancy'[16] which is itself associated with prematurity, low birth weight and a higher perinatal mortality rate[17]. A Danish study published in 2010 also suggested that a pregnancy achieved as a result of IVF is four times more likely to result in a stillborn baby than those who conceive naturally[18]. However, the risks associated with IVF are generally well known and the physical risks associated with conceiving a child this way are minimal. What is missing, as Taylor-Sands points out, is a comprehensive, long-term study of the health of those who have been conceived from biopsied embryos, she even suggests that 'trauma is possible' given that at least one cell is removed from the embryo during biopsy[19]. Taylor-Sands also emphasises the risk of harm associated with specifically selected saviour siblings, for example, the 'physical harm associated with peripheral blood and bone marrow donations if the initial cord blood donation is unsuccessful' together with the potential psychological impact on the sibling's sense of self-worth and identity[20]. Therefore, we can see that whilst the risk to the resulting child in terms of physical health is low, it is nonetheless increased as a result of the use of this technology; risks exist that would not exist had the child been conceived naturally. The English position in terms of a presumption in *favour* of treatment is a clear indication that English law views these usual risks to be outweighed by the benefit to the existing child.

Welfare of the resulting child

The welfare of the child is an important principle that runs central to family law and is enshrined in s 1(1) of the Children Act 1989. This requires the child's welfare to be paramount when it comes to any decision concerning a child's upbringing. With regard to PGD and the creation of saviour siblings, that duty is somewhat altered and according to the 1990 Act there is only a general duty to consider the welfare of the child that is going to be born:

> '. . . a woman shall not be provided with treatment unless account has been taken of the welfare of the child who may be born as a result of the treatment (including the need for supportive

---

[14] Quintavalle J. Quoted in: BBC News. Doctor plans 'designer baby' clinic. 11 December 2001, http://news.bbc.co.uk/1/hi/health/1702854.stm

[15] Winston R. Quoted in: BBC News. Go-ahead for 'designer babies'. 13 December 2001, http://news.bbc.co.uk/1/hi/health/1706926.stm

[16] ACOG Committee Opinion, Perinatal Risks associated with Assisted Reproductive Technology, Number 324 (2005)

[17] ibid

[18] K Wisborg, HJ Ingerslev and TB Henrikson, 'IVF and Stillbirth: a Prospective Follow-Up Study' (2010) 25 *Human Reproduction* 1312

[19] M Taylor Sands, *Saviour Siblings: A relational approach to the welfare of the child in selective reproduction*, (2013) Routledge, p 15

[20] ibid p 16

> parenting), and of any other child who may be affected by the birth.'[21]

However, there is no clear guideline as to what would constitute 'account taken' of the welfare of the children involved, meaning the welfare principle in this sense is intrinsically discretionary, as we can see from the pre-2008 decisions involving the Hashmis and the Whitakers. These decisions were highly criticised at the time for being based on a misinterpretation of the welfare principle. This is because the PGD process itself does not *confer* any benefit on the selected embryos, it does not 'cure' them of any genetic disorder, it simply selects the embryos that were *already* healthy, thus conferring no more benefit on an embryo with a potential genetic disorder, than one without one[22]. Therefore, whilst a discretionary approach is not necessarily desirable, it may allow for weightier considerations of welfare than the current approach.

There may be an argument that the English presumption in favour of treatment is eroding the welfare principle as it is intended in other areas of family law, that is, as a paramount consideration. To consider this, it is important to examine the idea that creation in these circumstances will have an impact on the child's psychological or emotional welfare once it discovers its 'purpose' in being created to save its sibling.

The argument put forward is that for various psychological or social reasons it would be harmful to the saviour sibling to be created as a result of using PGD. This is based on the idea that when the saviour sibling becomes aware of its place within the relational family unit, that it was created as a tool to save a prior sibling, the psychological or emotional trauma would be so damaging as to justify restricting these situations wherever possible. Furthermore, there are concerns about the wider social impact, that the child will become a commodity or a 'marrow-farm' for its sibling, without experiencing a proper, bona fide place within the family, which in turn sets a precedent for the commodification of babies and, more generally, human life. These two welfare points: (i) psychological harm, and (ii) commodification, do have some weight and tend to be the most poignant criticisms against the creation of saviour siblings using these processes. The psychological argument seems to be split into two: first, that when the child finds out they were born not for themselves, but for the benefit of a previous child, they will suffer psychological harm; and secondly, the danger that parents may value the child less, especially if the donation to the first child does not work.

There are very few studies done on the psychological impact of being genetically selected saviour siblings, however one famous study was conducted by Packman et al. This concerned the donation from adolescent siblings rather than functionally created siblings but it may nonetheless be possible to analogise the results of this study and draw similar conclusions to those who are created specifically for donation. Packman et al's study focused on the psychological effects of HSCT (hematopoietic stem cell donation) on siblings of paediatric HSCT patients. Their study concluded that donor siblings reported significantly more anxiety and lower self-esteem than non-donors, and one third of donors reported mild to significant post-traumatic stress[23]. Furthermore, they indicated that:

> '(a) sibling donors felt they had 'no choice' and wanted to be more involved in the donation decision-making process, (b) donors experienced considerable loneliness following donation, (c) siblings felt there was minimal explanation of the HSCT process, and (d) donors reacted to the stresses of HSCT and parental inattention by

---

[21] HFEA 1990, s 13(5)

[22] Sheldon and Wilkinson, 'Saviour Siblings': Hashmi and Whitaker. An unjustifiable and misguided decision, *Med. L. Rev.* 2004, 12(2), 137–163

[23] Packman et al, Psychological adjustment of adolescent siblings of HSCT patients, (2004) *Journal of Paediatric Oncology Nursing*, Vol 21, 4

> withdrawing and keeping their feelings to themselves, whereas non-donors reacted with externalizing behaviours (attention-seeking acts in school, sharing feelings with others)'[24].

Whilst, as mentioned, this study does not relate to siblings created solely for the purpose of donating, in the vast majority of cases which come under the 1990 Act, the resulting child would be required to continue donating throughout their childhood, if not well into adolescence, e.g. in the case of bone marrow transplants. Therefore, the potential threat to their physical and psychological well-being may be significant, and it would be difficult to say whether the fact that they are created for this purpose would exacerbate those feelings; although, it seems possible.

Drawing on the points raised by Packman et al's study then – point (a) would definitely be contentious in the arguments for/against saviour siblings – if an adolescent child who has had the procedure explained to him and already has a role within the family unit feels he lacked choice over the decision to donate, then a child whose whole purpose in being brought into the world was to undergo these complicated and often painful procedures would almost certainly feel a lack of physical and familial autonomy. Unfortunately, this area of the psychological impact of selection to saviour siblings is under-researched, thus Packman et al's study should not be considered binding. However, the conclusions drawn are concerning when it comes to the welfare of the resulting child and should be emphasised when evaluating the English position which already erodes the paramountcy principle in selective reproduction.

Others argue that these psychological traumas are over-emphasised by the regulators and in fact, the relational benefits to the resulting child are significant enough to counteract these difficulties. An advocate of the relational approach to welfare is Michelle Taylor-Sands, who argues that whilst the autonomy of the child and respect for its familial role are important to bringing up a child, children are more highly dependent on their intimate relationships in order to flourish, therefore 'the welfare of the child needs to be viewed more broadly within the social context of the family into which the child is born'[25]. As Taylor-Sands points out, the saviour sibling's welfare will be dictated by the way that it is treated once it is born and this will, inevitably, be linked with its role within the family and the strength of relationships formed. Such is the nature of the family, that the individual will be defined and identified by the relationships in their lives, which will shape their experience of the family unit and their interaction with family law. In the context of saviour siblings, opinions will always be swayed by the potential benefit to the existing child. Therefore, when the harms and benefits of using PGD for the creation of saviour siblings are considered together, we identify the benefit to the existing child and the harm to the resulting child rather than concurrent harm and benefit to both children individually. This, Taylor-Sands would argue, is because of the inherent relational approach between donor and saviour sibling, thus, focussing on the harm caused solely to the individual will warp an analysis of the objective benefits. It is important to consider a practice such as this in the context of the benefit to the family unit rather than one individual – using ART to create saviour siblings will always have little to no benefit to the saviour, but untold benefit to the existing child. A strict application of the welfare principle will, therefore, always result in conflicting 'best interests' of the children in question.

Taylor-Sands points out that one way of overcoming this is to look at it from a utilitarian point of view, rather than focusing on each individual interest at stake. She suggests 'a utilitarian approach can take

---

[24] ibid. pg.241

[25] M Taylor Sands, *Saviour Siblings: A relational approach to the welfare of the child in selective reproduction*, (2013) Routledge, p 26

into account other family interests and balance them against those of the child to be born'[26].

As much as this approach is attractive, and incorporates a holistic approach to the family unit, it also runs a coach and horses through all established principles of family law, and the whole concept of individual rights. In the leading judgment of *J v C* [1970] AC 668, the court held that operation of the paramountcy principle is:

> '. . . a process whereby when all the relevant facts, relationships, claims and wishes of parents, risks, choices and other circumstances are taken into account and weighed, the course to be followed will be that which is most in the interests of the child's welfare . . . That is the first consideration because it is of first importance and the paramount consideration because it rules upon or determines the course to be followed' (p710–711)

It could be argued that this approach specifically rejects utilitarianism. Even if an approach is in the best interests of the parents and the sibling, but has no tangible benefit to the child, then it cannot be followed, whereas utilitarianism would demand that that approach should be favoured. It was also ruled in *J v C* that parental rights were not to affect or restrict the application of the welfare test to the child in question (p 727), which specifically rejects the relational approach in the way Taylor-Sands proposes it.

However, what makes the English legislation on saviour siblings unique is that it shifts the welfare approach to the more relational view. This is not seen in any other area of child law, where welfare usually operates as the paramount consideration. This begs the question as to whether the welfare principle we use in other areas for existing children is even appropriate when it comes to legislation and practices governing the creation of children. Whilst the relational approach may be contravening traditional rules when it comes to regulating existing children, there may be a role for it in reproductive regulation and indeed, this is clearly the preferred approach in England and Wales. However, that is not to say that it is appropriate to abandon welfare in this context altogether and merely attempt to minimise harm. The welfare requirement in s.13 indicates that the law demands that welfare plays some kind of role in the decisions regarding the creation of saviour siblings, thus we must examine the strengths of welfare reasoning as a potential justification for more regulation and how it aligns with the more holistic approach apparently advocated by para 1ZA.

In part 2 of this article, I explore the compatibility of the paramountcy principle with the current law.

---

[26] ibid p 27